Examining perspectives of adults with epilepsy and their primary support persons on living with epilepsy and support for self-management: A mixed-methods approach

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An abstract of
A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Behavioral Sciences and Health Education
2013

Abstract

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Epilepsy, a common neurological disorder characterized by recurrent seizures, has a profound effect on the lives of individuals with the condition and their families and friends. However, little is known about a person with epilepsy's (PWE) support person and the support provided. For this dissertation, a mixed-methods study was undertaken to examine the interpersonal relationship between PWE and their primary support persons (PSP), the support provided to PWE, and how support is associated with self-management and quality of life. The quantitative phase of this study included surveys with 101 individuals (53 adults with epilepsy and 48 PSP) and the qualitative phase involved in-depth interviews with 22 PWE and 16 PSP. The results of these studies are reported in two qualitative papers and one mixed-methods paper.

The aim of the first paper was to gain insight into how epilepsy affects the lives of PWE and PSP, as well as the types and influences of support provided to PWE. Illness intrusiveness, the disruptions to valued activities and interests, was significant for both PWE and PSP and negatively affected quality of life. Experiences were shaped by seizure control, the interpersonal relationship, and perceptions about support. In the second paper, the types of self-management support provided to PWE and its effect on self-management was qualitatively examined. PSP's involvement spanned a continuum from PWE-led management, to joint management, to PSP-led management. Where the pairs fell on the continuum depended on develop, and relationship type and dynamics. The purpose of the third paper was to use mixed methods to evaluate which types of self-management support were easier or more difficult to receive and provide. The results suggest that support for seizures and PSP driving PWE to the doctor were types of support that were easier to receive and provide, whereas reminders were more difficult.

This dissertation provides a deeper understanding of the how support for PWE influences self-management of epilepsy and quality of life, and how PWE and PSP's experiences intertwine. The findings can inform efforts to bolster epilepsy self-management and lessen the impact of epilepsy on the lives of both PWE and PSP.

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Acknowledgements

I would like to acknowledge and extend many thanks to the following people who were instrumental to the development and completion of my dissertation.

Many thanks to my chair, Nancy J. Thompson, PhD, MPH, and to my committee, Colleen DiIorio, PhD, George Engelhard, PhD, and Claire E. Sterk, PhD. I am grateful for your insight and guidance as I shaped my ideas, conducted my research, and wrote my dissertation. I am particularly thankful for the opportunities to work on WebEASE and UPLIFT, beginning while I was an MPH student; my work on those projects sparked my interest in epilepsy, in addition to providing me with invaluable experiences with the research process.

I am grateful for the support from the Emory Epilepsy Center. I would like to acknowledge Dr. Kimford Meador, the director of the center, who did not hesitate to allow me to recruit at the clinic. I could not have completed my recruitment without Diane Teagarden, NP, and Karen Kress, NP. To my participants, thank you for sharing your time, stories, and experiences with me.

I want to acknowledge my fabulous colleagues. Thanks to Christina Barmon and Robin McGee for being my second coders, reading my chapters, and helping me untangle my thoughts. Thanks to Sara Head, Emily Russell, and Lisa Oakley for your support, encouragement, suggestions, and answers to my various questions. I am appreciative of all of the BSHE doctoral students over the years; I may have been a “cohort of one” but I always felt supported and surrounded with surrogate cohorts.

I am extremely grateful for the various funding, fellowships, and awards that enabled me to complete a dissertation of my own design. Many thanks to the Laney Graduate School, the Department of Behavioral Sciences and Health Education, the Livingston Foundation, C. Randolph Jones, the Center for Community Partnerships, and Dr. Benjamin Druss. Additional thanks to Dr. Druss for his unwavering support and mentorship as I prepare for the next steps.

Finally, unlimited thanks to my family, with a special shout out to my primary support person, Matt Walker. Matt and Ethan kept me grounded and laughing throughout this process.

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Chapter 1: Introductory Literature Review

Introduction

Epilepsy, a common neurological disorder characterized by recurrent seizures, has a profound effect on the lives of individuals with the condition and their families and friends. People with epilepsy (PWE) consistently report lower quality of life, higher levels of depressive symptoms, and greater impairment of physical and social functioning compared to people without the condition (Strine et al., 2005; Wiebe, Bellhouse, Fallahay, & Eliasziw, 1999). As a result of the Living Well with Epilepsy conferences in 1997 and 2003 and an Institute of Medicine report released in 2012, more attention is being focused on improving quality of life, enhancing self-management behaviors, and addressing the mental health needs of PWE (Austin, Carr, & Hermann, 2006; Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012). Social support is a known determinant of PWE's depressive symptoms, self-management, and quality of life (e.g. Charyton, Elliott, Lu, & Moore, 2009; DiIorio et al., 2004; Mahrer-Imhof et al., 2013; Reisinger & DiIorio, 2009). Relatively little research, however, has focused on PWE's support providers, the types of support provided, and how the PWE's and primary support provider's interpersonal relationship is associated with depressive symptoms and self-management.

The support of a close family member or friend may be important to PWE for several reasons. First, PWE commonly report being worried or embarrassed about having a seizure, having memory and cognitive effects from seizures or as a medication side-effect, and being limited in employment, school, and driving (Choi et al., 2011; Fisher et al., 2000a). The emotional and instrumental support from support persons offers PWE additional resources to help them cope with seizures, medication side-effects, and the limitations that stem from having epilepsy. Second, PWE experience high rates of depression, which negatively affects their quality of life and ability to function and manage their condition (Boylan et al., 2004; Canuet et al., 2009). Social support may help to relieve depressive symptoms by buffering the impact of stress on an individual (Turner, 1999). Third, PWE must adhere to a complex regimen of self-management behaviors, such as proper medication adherence and avoiding seizure triggers, in order to control and manage the effects of seizures (DiIorio, 1997). Complying with self-management regimens may be especially important for the 30% of people with epilepsy whose seizures are not well controlled with medication (Centers for Disease Control and Prevention, 2007). Support persons may be instrumental in helping PWE to adopt and maintain self-management behaviors, such as reminding and monitoring medication taking, supporting strategies for reducing stress and getting enough sleep, and taking PWE to the doctor (Walker, Bamps, Burdett, Rothkopf, & DiIorio, 2012).

Despite the important role of support persons, little is known about how epilepsy affects the lives of the spouses, family, and friends who care for adult PWE. Epilepsy can cause psychosocial distress and difficulties in family members and restrict family activities (Ellis, Upton, & Thompson, 2000; Thompson & Upton, 1992). Support providers of PWE also report low quality of life, particularly for emotional functioning and mental health (van Andel, Zijlmans, Fischer, & Leijten, 2009; Westphal-Guitti et al., 2007).

Current research on social support and epilepsy is sparse and has generally involved quantitative methods (e.g. DiIorio et al., 2004; Hermann & Whitman, 1989; Reisinger & DiIorio, 2009). Further research is warranted to address several key gaps in the literature. First, the voices of PWE's primary support persons (PSP) are needed to elucidate their experiences in living with epilepsy and providing support. Second, the study of the relationship between PWE and PSP, as well as the types and amount of support provided to the PWE, has implications for the health and quality of life of both people. Finally, more work needs to be done to determine the types of support associated with self-management and explore potential negative effects of conflict and strain.

The purpose of this dissertation was to use mixed-methods to explore the interpersonal relationships between PWE and their primary support providers and the effect of that relationship on the PWE's mental health and self-management of their condition. The theoretical framework guiding this research was based on the social ecological model, Social Cognitive Theory (SCT), theories of social support, and Grounded Theory. Both the social ecological model and SCT acknowledge the influence of factors outside of the individual on health and behaviors. 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). Theories of social support posit that social support directly and indirectly affects health (Heaney & Israel, 2008). 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, on health (Cohen, Underwood, & Gottlieb, 2000; Heaney & Israel, 2008; Turner, 1999). These three theories formed the basis of a conceptual model that served as a framework for this research. However, Grounded Theory was also used in order to allow for important concepts related to social support, depression, and self-management to emerge from the participants' narratives (Corbin & Strauss, 2008).

This research provides an initial step towards understanding broader social factors that affect the health of PWE and their support persons. The findings from this dissertation project can be used to inform studies that empirically test the relationships between social support, depression, and self-management. These results may eventually aid in the development of interventions that involve both the PWE and support person in order to improve or maintain the PWE's self-management and maximize quality of life for both individuals.

Epilepsy

Epilepsy is a common neurological disorder, characterized by recurrent seizures, that affects approximately 2.7 million people in the United States. Epilepsy can occur as a result of genetic factors or damage to the brain caused by such conditions as stroke, complications during childbirth, infections, or traumatic brain injury. In the majority of cases, however, the cause of epilepsy is unknown (Banerjee, Filippi, & Allen Hauser, 2009; Centers for Disease Control and Prevention, 2007). Approximately 150,000 new cases of epilepsy are diagnosed in the United States each year, most commonly among children and older adults (Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012).

Epilepsy is a complex condition because it encompasses a spectrum of seizure disorders that range in severity and impact (Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012). Seizures are caused by abnormal electrical activity in the brain, which results in changes in sensation, behavior, and/or movement. There are several different types of seizures that manifest as staring spells, muscle twitches, loss of consciousness, or convulsions (Centers for Disease Control and Prevention, 2007). Individuals who experience minor seizures can recover quickly; however, PWE with more severe seizures can experience a variety of negative symptoms, inducing headache, fatigue, difficulties with memory or concentration, and/or injury, which may last from a few minutes to several hours or days (Baker et al., 1991; Fisher et al., 2000a).

Treatment. The most common form of treatment for epilepsy is anti-epileptic drugs (AEDs). Most PWE can achieve seizure freedom on AEDs; however, up to 30% of PWE are unable to control their seizures with medication. Seizure control becomes less likely every time a PWE has an inadequate response to an AED and need to switch medications (Kwan & Brodie, 2000). AEDs can cause various side-effects, some of which can be intolerable to PWE. Common side-effects include dizziness, drowsiness, weight gain, and impairment of cognition, coordination, or balance (Fisher et al., 2000b; Walia, Khan, Ko, Raza, & Khan, 2004).

Other treatment options for people with uncontrolled seizures include brain surgery and the Vagus Nerve Stimulator. Brain surgery is only an option for PWE whose seizures originate in a specific part of the brain. For these individuals, however, brain surgery can be very effective in eliminating seizures. The Vagus Nerve Stimulator is a medical device that is implanted in the neck; it provides an electrical pulse to the vagus nerve and can be effective in reducing or eliminating seizures in some PWE (Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012). All epilepsy treatment must be complemented by self-management behaviors, which are discussed further below.

Economic cost. Epilepsy is a costly disorder in terms of both direct costs (e.g. healthcare expenditures and community services) and indirect costs due to lost productivity and premature mortality. Estimates of annual epilepsy costs range from $9.6 to $15.5 billion in the United States in medical costs (Begley & Beghi, 2002; Begley et al., 2000; Centers for Disease Control and Prevention, 2007; Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012; Yoon, Frick, Carr, & Austin, 2009). The average medical costs per year are significantly greater for PWE compared to controls and peak at time of diagnosis (Begley & Beghi, 2002; Jennum, Gyllenborg, & Kjellberg, 2011).

Living with Epilepsy

Epilepsy can impart a significant psychosocial burden to PWE, with negative effects on their overall health, mental health, and quality of life. PWE experience limitations in everyday and long-term activities, are at high risk for mental disorders and other comorbidities, and have a shorter life-span than individuals without the condition (Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012). The most significant concerns of adults with epilepsy are described below in more detail: Restrictions to "normal" activities, social limitations, depression, and health and quality of life.

Restrictions to "normal" activities. Epilepsy is an intrusive illness that disrupts valued interests and activities of the people with the condition (Devins, 1994; S. Poochikian-Sarkissian, S. Sidani, R. Wennberg, & G. M. Devins, 2008a; S. Poochikian-Sarkissian, S. Sidani, R. A. Wennberg, & G. M. Devins, 2008b). In a community-based survey conducted by Fisher and colleagues (2000a), the top concerns of PWE included employment difficulties, driving restrictions, dependence on others, and failure to achieve life goals. PWE are legally unable to drive if they have active seizures. States vary in how driving is regulated for PWE, but the majority require PWE to be seizure-free for a fixed amount of time, ranging from three to 12 months, before they are able to drive again (Krauss, Ampaw, & Krumholz, 2001).

PWE experience difficulties in obtaining an education and in finding and maintaining a job. Major barriers include seizure frequency and severity, driving restrictions, adverse side-effects from AEDs, and low self-esteem and self-efficacy (Smeets, van Lierop, Vanhoutvin, Aldenkamp, & Nijhuis, 2007). Compared to individuals without epilepsy, PWE have lower rates of employment and less income (Jennum et al., 2011; Kobau et al., 2008). In a series of focus groups, PWE expressed frustration with the challenges they experienced in trying to find jobs and the unhelpful responses they received from employers (Sample, Ferguson, Wagner, Pickelsimer, & Selassie, 2006).

In a qualitative study of people with epilepsy, Raty and Wilde-Larsson (2011) reported that perceptions of living with epilepsy range from acceptance and living a normal life to struggling with a loss of control and giving up hope of recovery. While some PWE are able to accept their epilepsy and strive to live a normal life, others feel very resigned and restricted (Raty, Soderfeldt, & Wilde Larsson, 2007; Raty & Wilde-Larsson, 2011).

Social limitations. Many people with epilepsy report being isolated and lonely because seizures prevent them from taking part in social activities and other people are uncomfortable with their diagnosis (Sample et al., 2006). Additionally, PWE are less likely than people without the condition to get married. Unmarried PWE tend to have lower educational attainment and income compared to married PWE (Elliott, Charyton, McAuley, & Shneker, 2011). They also commonly disclose that they feel dependent on others, experience interpersonal and social difficulties, and are stigmatized due to their condition (Beran, 1999; Collings, 1990; Fisher et al., 2000a). In a survey of PWE across 15 European countries, Baker and colleagues (1999) reported that almost half of respondents felt stigmatized due to having epilepsy. Stigma is perpetuated due to misperceptions and a lack of education about epilepsy, particularly about the different forms of seizures and how to best respond to seizures, in the general population (Jacoby, Gorry, Gamble, & Baker, 2004; Jacoby, Snape, & Baker, 2005; Kilinc & Campbell, 2009). Epilepsy can cause people to feel different and embarrassed, which may lead them to conceal their condition from others (Kilinc & Campbell, 2009). Higher levels of perceived stigma are associated with having active epilepsy, multiple seizure types, greater limitations due to epilepsy, poorer self-management, and higher depressive symptoms (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997; DiIorio et al., 2003; Jacoby et al., 2005).

Epilepsy and depression. Depression is a mental disorder characterized by sadness, loss of interest and pleasure in daily activities, worry, feelings of worthlessness and guilt, and inability to concentrate. People with depression may also experience crying spells, difficulty sleeping, irritability, or thoughts of suicide (American Psychiatric Association, 2000). Depression is common among people with a variety of chronic conditions, including epilepsy (Egede, 2007; Egede, Zheng, & Simpson, 2002; Reisinger & DiIorio, 2009; Strine, Mokdad, et al., 2008). Comorbid major depression and medical conditions contribute to greater odds of functional disability, reduction of everyday activities, and increased days spent in bed due to illness (Egede, 2007; Stein, Cox, Afifi, Belik, & Sareen, 2006). The presence of comorbid major depression, across a range of chronic medical conditions, also contributes to higher health care utilization and increased work absence (Egede, 2007; Stein, Cox, Afifi, Belik, & Sareen, 2006). Substantial empirical evidence supports the association between depression and exacerbation of the symptoms of medical conditions. People with comorbid depression and chronic conditions experience more severe medical symptoms compared to people with only chronic medical conditions, even when the severity of the medical condition is taken into account (Katon, Lin, & Kroenke, 2007). Successful treatment of depression improves physical, mental, and social functioning (Coulehan, Schulberg, Block, Janosky, & Arena, 1990).

PWE are at higher risk for depression compared to individuals without the condition. The lifetime rate of major depression among PWE is around 30% (Hermann, Seidenberg, & Bell, 2000) compared to 17% in the general population (Kessler et al., 2005). Depression is more common among individuals with uncontrolled seizures compared to PWE whose condition is controlled (Dias et al., 2010; Kanner, 2003). The suicide rate among PWE is 11.5%, which is ten time higher than the suicide rate in the general population (Jones et al., 2003).

Depression in people with epilepsy is predicted by individual characteristics, epilepsy-related factors, and psychosocial variables. The main individual factors affecting depression are unemployment status and financial strain (Ettinger, Reed, & Cramer, 2004; Hermann & Whitman, 1989; Reisinger & DiIorio, 2009). Seizure frequency is consistently associated with depression (Dias et al., 2010; Jacoby, Baker, Steen, Potts, & Chadwick, 1996; Mensah, Beavis, Thapar, & Kerr, 2006; Paradiso, Hermann, Blumer, Davies, & Robinson, 2001), while the relationships between depressive symptoms other epilepsy-related factors, such as duration of epilepsy and seizure type, have been equivocal. Interpersonal factors, including social support and stigma, have not been included in research studies as often as individual and seizure characteristics; however, both social support and stigma appear to influence depression among PWE (Reisinger & DiIorio, 2009). Understanding the factors that contribute to depression in PWE is important because depression, in turn, can affect an individual’s confidence and ability to self-manage epilepsy and can negatively impact quality of life (DiIorio et al., 2004; Robinson et al., 2008; Whatley, DiIorio, & Yeager, 2010).

Depression is often under recognized and undertreated in PWE. PWE may not seek out treatment for depression for several reasons including lack of recognition or acceptance of depressive symptoms, feeling that they can manage without treatment, and fear of the additional stigma of a psychiatric diagnosis (Walker & DiIorio, 2011). Depression may go undetected by providers. Despite recommendations that all PWE should be screened for depression and the existence of brief validated measures, most practitioners do not screen for depression in their patients (Shneker, Cios, & Elliott, 2009). Screening is an effective method of identifying PWE who experience elevated depressive symptoms, but does not ensure that PWE are linked with treatment (Friedman et al., 2009; Seminario, Farias, Jorgensen, Bourgeois, & Seyal, 2009).

Timely treatment of depression for PWE is important because it can be very effective in reducing depressive symptoms. Mehndiratta and Sajatovic (2013) conducted a systematic literature review of intervention studies for people with comorbid epilepsy and depression and found that medications and cognitive behavioral therapy were effective. PWE also respond well to innovative treatment formats, such as group therapy delivered by distance technologies. For example, participants in Project UPLIFT, a Cognitive Behavioral Therapy and mindfulness-based program delivered by phone or Web, showed reductions in depressive symptoms and an increase in knowledge and skills (Thompson et al., 2010). Participants also expressed satisfaction with the program and delivery methods, planned to continue using the materials, and felt that the program was beneficial. In particular, they enjoyed interacting with and learning from other PWE in the group sessions because they understood what each other experienced (Walker, Obolensky, Dini, & Thompson, 2010).

Health and quality of life. PWE often experience compromised health and quality of life. They report more activity restrictions and days lost to poor physical and mental health than people without the condition (Centers for Disease Control and Prevention, 2005). PWE are more likely to be obese, physically inactive, and current smokers and report a variety of additional comorbid health conditions, such as migraine, sleep disorders, asthma, pain disorders, and cancer (Ottman et al., 2011; Strine et al., 2005). As a result of the burden of seizures and comorbidities, PWE report increased healthcare services use compared to the general population (Wiebe et al., 1999).

PWE consistently report poorer quality of life compared to people without epilepsy. The main factors consistently linked with reduced quality of life for PWE are seizure severity, seizure frequency, level of depressive symptoms, and level of anxiety (Gulpek, Bolat, Mete, Arici, & Celebisoy, 2011; Johnson, Jones, Seidenberg, & Hermann, 2004; Kwan, Yu, Leung, Leon, & Mychaskiw, 2009; Poochikian-Sarkissian et al., 2008a; Taylor, Sander, Taylor, & Baker, 2011). Other psychosocial factors that influence quality of life include illness intrusiveness due to epilepsy, perceived control over life, social support, and stigma (Charyton et al., 2009; Gulpek et al., 2011; Poochikian-Sarkissian et al., 2008a; Suurmeijer, Reuvekamp, & Aldenkamp, 2001). Some evidence indicates that duration of epilepsy is associated with poorer quality of life (Guekht et al., 2007; Gulpek et al., 2011; Johnson et al., 2004); however, Taylor and colleagues (2011) conducted a systematic review of predictors of quality of life in epilepsy and found that most epilepsy-related factors aside from seizure severity and frequency did not appear to be associated with quality of life. The authors also rated the studies in their review to be of poor to moderate quality and called for more rigorous research on quality of life for adults with epilepsy.

Self-management of Epilepsy

Overview of chronic disease self-management. People with chronic diseases must employ methods and behaviors to manage symptoms, slow disease progression, and maintain quality of life. This process, which is called self-management, encompasses the behaviors and practices undertaken by an individual to control a chronic condition (DiIorio, 1997). Chronic diseases can affect an individual's life beyond physical symptoms; likewise self-management practices include more than taking medication.

Lorig and colleagues (2003) have outlined three key tasks and six core skills that are necessary for effective self-management of a chronic condition. The self-management tasks involve medication, role, and emotional management. Medication management includes taking medication as prescribed, as well as other disease-specific behaviors such as adhering to dietary guidelines or using an inhaler properly. Role management engages individuals in "…maintaining, changing, and creating new meaningful behaviors or life roles" (Lorig & Holman, 2003, p. 1). Emotional management involves identifying and managing emotions that arise from having a chronic disease, such as anger, frustration, or negative mood, that can impact an individual's outlook and ability to complete the other tasks. Several skills are needed in order to successfully manage a chronic condition. The core skills are problem solving, decision making, resource utilization, partnering with health care providers, action planning, and self-tailoring self-management resources to meet one's needs (Lorig & Holman, 2003).

Self-management behaviors, however, are not easy to implement and maintain. DiMatteo and colleagues (2004b) conducted a meta-analysis of adherence rates to medical recommendations for a variety of chronic diseases and found that almost 25% of patients are non-adherent. Their results indicate that higher levels of adherence are reported for specific and narrowly-defined behaviors, such as taking medications, as opposed to pervasive behaviors such as exercise, diet, and other health behaviors (DiMatteo, 2004b). Non-adherence 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 a myriad of 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, Steiner, Fernald, Crane, & Main, 2003; Dunbar-Jacob & Mortimer-Stephens, 2001; Jerant, von Friederichs-Fitzwater, & Moore, 2005). Depression affects individuals' motivation to manage their condition and ability to cope with adverse symptoms (DiMatteo, Lepper, & Croghan, 2000; Jerant et al., 2005; Katon, 2003). Correspondingly, the odds of a depressed individual being non-adherent to medical treatment recommendations is three times higher compared to individuals who are not depressed (DiMatteo et al., 2000).

Social support, which is discussed further below, is consistently associated with better self-management across a variety of chronic conditions (DiMatteo, 2004a; Gallant, 2003; Rosland et al., 2008). Persons with multiple chronic conditions face an increased self-management burden, largely due to the compound effects of the conditions and complex management regimens (Bayliss et al., 2003).

Epilepsy self-management. Improving self-management behaviors is a priority set forth by the Centers for Disease Control and Prevention, the Epilepsy Foundation, and researchers, advocates, and PWE who attended the Living Well with Epilepsy Conference II that was held in 2003 (Austin et al., 2006; Centers for Disease Control and Prevention, 2007). According to DiIorio (1997), "…epilepsy self-management is the sum total of steps a person takes to control seizures and to control the effects of having a seizure disorder" (p. 214). PWE must take medication, minimize exposure to seizure triggers, monitor symptoms and side-effects, communicate with health care providers, and obtain and process information about symptoms, management, and treatment. Common seizure triggers include stress and fatigue (Nakken et al., 2005), so reducing stress and getting quality sleep are important.

Despite the importance of self-management, close to 30% of people with epilepsy are classified as non-adherent to their medication (Ettinger, Manjunath, Candrilli, & Davis, 2009; Faught, Duh, Weiner, Guerin, & Cunnington, 2008; Hovinga et al., 2008). PWE who do not take their medication as prescribed have a threefold risk of mortality compared to individuals who are adherent (Faught et al., 2008). Non-adherence to anti-epileptic drugs (AEDs) is also associated with reduced seizure control, more emergency room visits and hospital admissions, higher healthcare costs, decreased productivity, seizure-related job loss, and seizure-related motor vehicle accidents (Ettinger et al., 2009; Faught et al., 2008; Faught, Weiner, Guerin, Cunnington, & Duh, 2009; Hovinga et al., 2008). PWE report that their main reasons for not taking medication are because they forget or their pills are not readily available; other less reported reasons include adverse side effects and the cost of the AEDs (Hovinga et al., 2008). Side effects of AEDs can be significant and include decreased energy, lethargy, difficulty thinking, memory loss, and impaired coordination and balance (Fisher et al., 2000b; Wheless, 2006). PWE report greater self-efficacy for adherence to medication regimens than to other lifestyle behaviors, which is similar to individuals with other chronic conditions (Kobau & DiIorio, 2003; McAuley, McFadden, Elliott, & Shneker, 2008).

In a series of studies, DiIorio and colleagues have explored theoretically-based factors that predict self-management behaviors. They found that psychosocial factors, such as self-efficacy, outcome expectations, and social support are significantly associated with higher levels of self-management, whereas affective states, including depression and anxiety, are associated with lower levels of self-management (DiIorio, Hennessy, & Manteuffel, 1996; DiIorio et al., 2004; Robinson et al., 2008). As a result of these initial studies, DiIorio and colleagues (2009) created a theory-based online intervention aimed at increasing self-management behaviors among PWE. At the end of the program, participants reported some improvement in epilepsy self-management, medication adherence, sleep quality, self-efficacy, and social support (DiIorio et al., 2009).

Social Support

Social support and social ties have long been recognized to contribute to positive health outcomes. Social support may be an important mechanism in improving self-management, depressive symptoms, and overall quality of life for PWE. The connections between social support and overall health, mental health, and self-management are reviewed below to give context to the research that has been conducted on epilepsy and social support.

Social support and health. In their seminal article, Berkman and Syme (1979) showed that people who lacked ties to others were over two times more likely to die over a nine year period compared to people with more community and social contacts. Since then, social support has been shown to affect the onset and progression of chronic conditions such as coronary heart disease (Cohen, 1988; Lett et al., 2005) and diabetes (van Dam et al., 2005). Additionally, lower social support is linked with greater activity limitation and disability, depressive and anxiety symptoms, poorer self-rated health, and decreased satisfaction with life (Strine, Chapman, Balluz, & Mokdad, 2008). The results of two systematic reviews indicate that social support focused interventions can improve diabetes outcomes (van Dam et al., 2005) and a variety of physical and mental health outcomes (Hogan, Linden, & Najarian, 2002).

There are three pathways that are hypothesized to explain the link between social support and health outcomes: biological and physiological processes, health behaviors, and psychosocial mechanisms (Berkman, Glass, Brissette, & Seeman, 2000; Uchino, 2006). Social support is proposed to induce changes in biological processes, including cardiovascular, neuroendocrine, and immune function, which may lower the risk for disease and slow disease progression (Uchino, 2006; Uchino, Cacioppo, & Kiecolt-Glaser, 1996). Social support can influence health behaviors and self-management through provision of informational, tangible, and emotional resources (DiMatteo, 2004a; Uchino, 2006). Finally, social support bolsters self-efficacy, self-esteem, and perceptions of control and protects against depression and negative affect, which, in turn, reduces the risk for developing chronic conditions (Berkman et al., 2000; Uchino, 2006).

Social support and mental health. The pathways mentioned above are applicable to mental disorders, such as depression, as well as medical illness. Low social support is consistently associated with higher levels of depressive symptoms and non-recovery from depressive episodes among individuals in the general population and those with various chronic diseases, including epilepsy (Leskela et al., 2006; Reisinger & DiIorio, 2009; Turner, 1999; Vilhjalmsson, 1998). Aspects of social support and related constructs that appear to play a role in relieving symptoms of depression include the presence of a partner or spouse (Bisschop, Kriegsman, Beekman, & Deeg, 2004; Ezquiaga, Garcia, Bravo, & Pallares, 1998; Penninx et al., 1998), being satisfied with support received (Ezquiaga, Garcia, Pallares, & Bravo, 1999), and connectedness with support networks (Brugha, Bebbington, Stretch, MacCarthy, & Wykes, 1997). Pfeiffer and colleagues (2010) conducted a meta-analysis on peer support interventions for depression and found that the interventions improve depressive symptoms more than usual care alone. The effect size of 0.59 for peer interventions is comparable to effect sizes for psychotherapy (Pfeiffer et al., 2010).

Social support is hypothesized to either directly influence depressive symptoms or to buffer, or moderate, the effects of stress on depression. Support may affect depression directly by providing a sense of belonging and reducing feelings of loneliness. The buffering hypothesis posits that social support facilitates coping in times of heightened stress and thus reduces the impact of stress on mental health (Turner, 1999). While some researchers have reported evidence in support of the buffering hypothesis (Penninx et al., 1998; Turner, 1999), others have found only direct effects of social support on depression (Bell, Leroy, & Stephenson, 1982; Schroevers, Ranchor, & Sanderman, 2003).

The quality of interpersonal relationships can be negatively affected by depression, which may diminish the availability of support. Compared to individuals who are not depressed, people who are depressed experience more negative interactions with others, including hostility and conflict, and fewer positive interactions (Rehman, Gollan, & Mortimer, 2008; Zlotnick, Kohn, Keitner, & Della Grotta, 2000). In an analysis of the National Comorbidity Study, Zlotnick and colleagues (2000) showed that people with Major Depressive Disorder report more interpersonal difficulties with spouses or partners than with friends or strangers. They posit that compared to friendships or other more distant ties, intimate relationships involve closer ties, more obligations, and more frequent contact, which could lead to greater conflict (Zlotnick et al., 2000). Depressive symptoms and marital satisfaction also are linked in a complex and potentially bidirectional relationship (Fincham, Beach, Harold, & Osbourne, 1997; Pruchno, Wilson-Genderson, & Cartwright, 2009). This indicates that benefits of the presence of a spouse or partner in relieving depressive symptoms may be counterbalanced by the conflict that can arise in an intimate relationship.

Social support and self-management. Family members and close friends are often involved in the management of an individual's chronic condition. In response, several definitions of self-management have been expanded from the focus on the individual with the chronic condition or the patient and their healthcare provider (Clark, 2003) to also include family members and other caregivers (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009). Models of self- and family-management of chronic conditions depict the factors affecting management and the outcomes for both patients and families. These models are based on the assumption that chronic disease management is a dynamic process requiring both individuals and families to incorporate health-related behaviors into their daily lives (Dunbar et al., 2008; Grey et al., 2006; Ryan & Sawin, 2009).

Self-management behaviors, such as medication taking and stress management, naturally involve individuals beyond the patient because these behaviors take place in a shared environment and in the context of relationships (Rosland, 2009). In one survey, 75% of functionally independent adults with diabetes or heart failure reported supportive family involvement in their self-management (Rosland, Heisler, Choi, Silveira, & Piette, 2010). Family members often provide reminders and direct help for taking medication, eating healthy, exercising, and going to doctor appointments, as well as provide emotional support (Gallant, Spitze, & Prohaska, 2007; Rosland, Heisler, & Piette, 2012; Trief, 2003). Support from family and friends is associated with better self-management and health outcomes (Franks et al., 2006; Rosland et al., 2010; Rosland et al., 2012), particularly when it is encouraging, focuses on enhancing patient autonomy, or fosters family cohesion (Rosland et al., 2012). In contrast, when family members are critical, overprotective, nagging, or controlling, their support is perceived of as unhelpful and may lead to poorer self-management (Bressi et al., 2007; Gallant et al., 2007; Rosland et al., 2010; Rosland et al., 2012; Trief, 2003).

Communication patterns between family and friends and the individual with a chronic condition influences self-management. Trief and colleagues (2003), reporting on qualitative results, stated that teamwork and helpful communication were key elements of spouses working together on diabetes self-management. Conversely, poor communication 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 emerged as key themes in qualitative studies; adults with chronic conditions often felt strongly about being in charge of their self-management (Gallant et al., 2007; Trief, 2003).

Social support and epilepsy. 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 (Amir, Roziner, Knoll, & Neufeld, 1999; Gulpek et al., 2011; LaFrance et al., 2011; Mahrer-Imhof et al., 2013; Whatley et al., 2010), improved self-rated health and life satisfaction (Charyton et al., 2009; Elliott, Charyton, McAuley, et al., 2011), and fewer depressive symptoms (Hermann & Whitman, 1989; Reisinger & DiIorio, 2009) for

PWE. Social support seems to have at least a moderate positive association with self-management behaviors (DiIorio et al., 2004; Gallant, 2003).

PWE rely mainly on parents and spouses, other family members, neighbors, and health care providers for support (Hills & Baker, 1992; Walker et al., 2012). Support persons can play an important role by providing PWE with the resources and emotional support needed to deal with and manage epilepsy. For example, the support provided through marriage appears to offset some of the social, functional, and economic challenges faced by PWE (Elliott, Charyton, Sprangers, Lu, & Moore, 2011).

Support may be particularly important for improving PWE'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., 2000a), may impede a PWE's ability to take medication as prescribed or reduce exposure to triggers. Although there is little research on the support PWE receive for self-management, some initial evidence indicates that support persons are involved in medication reminders and monitoring, supporting strategies for reducing stress and improving sleep, and providing instrumental and emotional support (Walker et al., 2012). Support persons can also facilitate communication between PWE and their neurologists. Gilliam and colleagues (2009) analyzed interactions between neurologists and PWE and found that the presence of a companion at appointments, usually a spouse or parent, resulted in longer and more detailed discussions of medication side-effects. Companions were often able to provide the neurologist with information that could aid the neurologist in treating the PWE, such as how the PWE's behavior may have changed over time (Gilliam et al., 2009).

The dynamics between support persons and PWE can also have negative consequences for self-management. Bressi and colleagues (2007) demonstrated that while PWE whose relatives showed warmth had better medication self-management, PWE who received criticism from their relatives had poor medication adherence. DiIorio and colleagues (DiIorio et al., 1996) found that general assistance was positively associated with medication self-efficacy, but support behaviors specific to the PWE's regimen were not. Specific support, however, was positively associated with anxiety. The researchers suggested that specific support could be viewed as nagging, come across negatively, or work to remove agency of care from the PWE (DiIorio et al., 1996).

Providing Support

The lives and health of the people supporting individuals with chronic disorders can be impacted by the support that they provide. There is an extensive literature on caregiving, particularly for people who are elderly and/or have a debilitating condition (e.g. dementia, stroke), but much less research has involved the family and friends of people with epilepsy. In most cases, the support needs of PWE are not expected to equal the needs of individuals with conditions that require assistance with daily living activities (e.g. bathing, feeding, or dressing). For this reason, the term "primary support person" (PSP) will be used to denote a person who cares for epilepsy. However, the experiences of caregivers and supporters of PWE may share some similarities. Baanders and Heijmans (2007) note that chronic conditions may not require overt caregiving, but can still impact and interfere with a partner or family member's life. Therefore, caregiving relationships are reviewed below, followed by an examination of the current research on people who support PWE.

Caregiving relationships. Informal caregivers are usually unpaid spouses or partners, family members, or close friends who routinely help others who are limited by chronic illness or disabling conditions. Caregivers provide a range of support to care recipients, from transportation or shopping to feeding and bathing. These activities can take a few hours a week to most of the day. The National Alliance for Caregiving and AARP (2004) estimated that there were approximately 44 million caregivers in the United States. As the American population ages and prevalence of chronic disease rises, the number of individuals who must care for people with chronic and disabling conditions will increase. Recently, the recognition that caregiving can be viewed as a public health issue has directed more attention to the health outcomes of the caregivers and care recipients (Talley & Crews, 2007).

Caregiving responsibilities negatively impact caregivers' physical health, mental health, and overall quality of life (Rees, O'Boyle, & MacDonagh, 2001; Smerglia, Miller, Sotnak, & Geiss, 2007). According to the results of a meta-analysis, individuals caring for elderly adults are more likely to experience depression, stress, and poor general health compared to noncaregvers (Pinquart & Sorensen, 2003). Caregiver outcomes are influenced by the characteristics of the caregiver, care-recipient, and caregiving situation (Rees et al., 2001). In particular, increased emotional stress is associated with caregivers reporting high caregiving burden, feeling that they did not a choice in taking on caregiving responsibilities, poor health, living with the care recipient, and being female (National Alliance for Caregiving & AARP, 2004). Nieboer and colleagues (1998) 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. Ohman and Soderberg (2004) conducted a qualitative study to examine the meaning attributed to caregivers' experiences of living with a person with a serious chronic illness. They described three main themes that arose: a shrinking and isolated life, being forced to take on caregiving responsibilities, and struggling to keep going in the face of difficulty (Ohman & Soderberg, 2004).

Despite the difficulties of caregiving, caregivers also report positive feelings and rewards that come from providing assistance to a loved one. Positive aspects of caregiving include increased self-esteem, a sense of meaning in life, and joy in being with the care recipient (Ohman & Soderberg, 2004; Rees et al., 2001). Providing care can also have mixed results; the bonds between spouses can contribute to positive commitments to caregiving out of love for their partners or feelings of obligation that cannot be escaped (Boeije, Duijnstee, & Grypdonck, 2003).

Traditionally, the relationship between caregivers and care recipients has been viewed as rather stable, with care and support flowing unidirectionally from the caregiver to the care-recipient. Linger and colleagues (2008) argued that caring roles are often dynamic, reciprocal, and overlapping. They presented different scenarios to highlight three potential care exchange patterns: 1) a reciprocal relationship in which partners care for each other in times of illness; 2) multiple caregivers who divide the responsibilities of care provision; and 3) a “family care chain,” in which an individual may receive care from one family member and also provide care to another (Lingler et al., 2008). Consideration of alternative support relationships is important for fully understanding the effects of caregiving and care receiving on health.

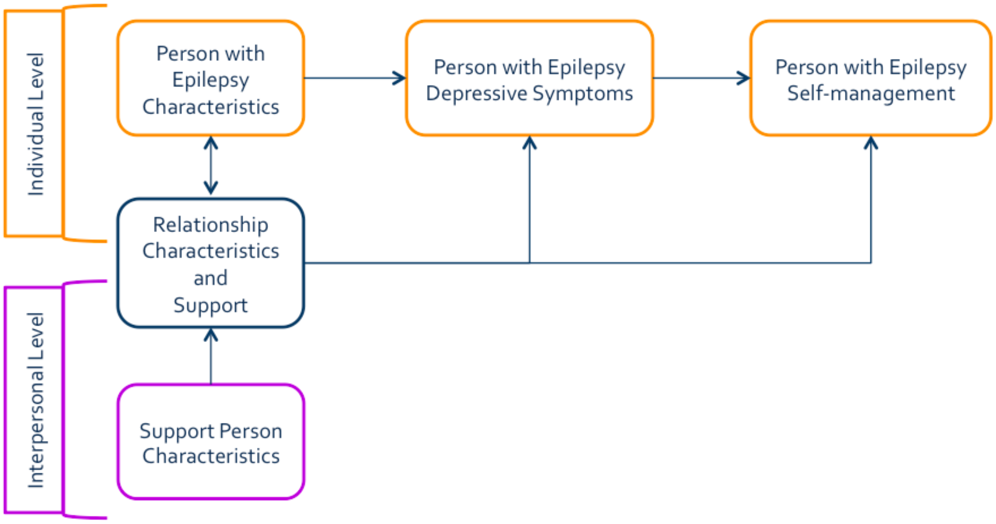
Support persons for people with epilepsy. Relatively little is known about the individuals who care for PWE and their experiences providing support. PSP of PWE tend to be spouses or partners, parents or guardians, or other relatives (Asato et al., 2009; Hills & Baker, 1992; Thompson & Upton, 1992; van Andel et al., 2009; Westphal-Guitti et al., 2007; Wheless, 2006). Epilepsy can cause psychosocial distress and difficulties in all family members and may restrict family activities (Ellis et al., 2000). In a study of 44 families, Thompson and Upton (1992) found that PSP reported problems related to social activities and intimate relationships. The PSP also felt that their own support was limited; they received most support from family members rather than from friends or services outside the home (Thompson & Upton, 1992).

PSP also report low quality of life, particularly for emotional functioning and mental health (van Andel et al., 2009; Westphal-Guitti et al., 2007). The quality of life of PSP is largely explained by coping style, which affects their perceptions of their caregiving burden (van Andel, Westerhuis, Zijlmans, Fischer, & Leijten, 2011), as well as perceived social support within the family, PWE’s knowledge of medication, and size of the support person’s network (Mahrer-Imhof et al., 2013). Seizure-related factors have less effect on supporters’ quality of life (Mahrer-Imhof et al., 2013; van Andel et al., 2011).

Conceptual Framework: Support, Depression, and Self-Management

A conceptual framework based on theory and relevant literature can be helpful in guiding research on social support, depressive symptoms, and self-management behaviors among PWE. A conceptual framework proposes relationships between concepts and a public health problem of interest. It can be informed by more than one theory and conceptualized at multiple levels, from the individual to societal (Earp & Ennett, 1991). The conceptual framework guiding this study is based on the social ecological perspective (Stokols, 1996), models describing the impact of social support on health (Cohen, Gottlieb, & Underwood, 2000; Turner, 1999), and Social Cognitive Theory (Bandura, 2004). These models and theories have been chosen because they seek to explain how individual and interpersonal factors are associated with behaviors and health. Figure 1 depicts a model that may explain how the relationship between PWE and their primary support providers impacts depressive symptoms and self-management.

Figure 1.1: Conceptual framework showing the relationship between support, depressive symptoms, and self-management



The development of this conceptual model was based on the literature and occurred prior to conducting the research for this dissertation project. Because one of the aims of this research was to elicit the experiences of PWE and support persons in their own words, we acknowledged key concepts might emerge that were not part of the conceptual model. Therefore, a Grounded Theory approach was taken to guide analysis and theory development based on the participants' experiences (Corbin & Strauss, 2008; LaRossa, 2005).

Social ecological model. The social ecological perspective states that an individual's health and behaviors are influenced by the environment and social context. Social ecological models include multiple levels of analysis, including factors at the individual, interpersonal, societal, and policy levels (McLeroy et al., 1988; Stokols, 1996). This study is concerned with the first two levels of the model, with the person with epilepsy situated at the individual level and the support person at the interpersonal level. A key facet of this research is examining the interactions between the individuals at the two levels.

Models of social support. Social support is a multifaceted concept that has been variously defined as the "Aid and assistance exchanged through social relationships and interpersonal transactions" (Heaney & Israel, 2002, p. 187) and "…any process through which social relationships might promote health and well-being" (Cohen, Gottlieb, et al., 2000, p. 4). Commonly, four types of social support are described: emotional, instrumental, informational, and appraisal (see Table 1 for definitions). The types are conceptually different, but are often difficult to tease apart because a relationship that provides one type of social support often provides others.

Table 1.1 Types of social support (Heaney & Israel, 2002; Langford, Bowsher, Maloney, & Lillis, 1997)

Types of Support	**Definitions**
Emotional support	Expressions of empathy, love, trust, and caring
Instrumental support	Tangible aid and service
Informational support	Advice, suggestions, and information
Appraisal support	Information that is useful for self-evaluation

Social support is theorized to directly and indirectly affect health. Support directly affects health by providing intimacy, companionship, and feelings of self-worth (Heaney & Israel, 2002). Social support can also work indirectly by moderating or mediating the relationship between a stressor and health or behaviors. Dealing with a chronic condition is an example of a stressor; so for this study, the stressor can be living with epilepsy or caring for someone with epilepsy. The moderating, or buffering, hypothesis indicates that when people are very stressed, social support can reduce the impact of the stressor on health, though when people are less stressed, social support has less of an impact. The mediating hypothesis indicates that social support actually explains some of the relationship between stress and health (Cohen, Gottlieb, et al., 2000; Heaney & Israel, 2002; Turner, 1999). It is this mediating hypothesis that is suggested in Figure 1, where relationship characteristics and support are positioned between the PWE and depressive symptoms.

Social support is a multidimensional concept that is not used in a uniform or consistent manner by investigators. This diversity presents challenges in evaluating the social support literature. Differences in conceptualization of social support involve support versus networks, perceived versus actual support, types of social support, and positive versus negative support.

Social support must be recognized as a separate construct from social networks, though the two are closely related. A social network is defined as the linkages between people or a person-centered web of relationships (Heaney & Israel, 2002). Social networks are the structure through which social support is available and utilized (Lin & Peek, 1999). Langford and colleagues (1997) identify social networks as an antecedent to social support. While social networks are important for the provision of social support, an individual can have a broad network without receiving adequate support (Langford et al., 1997).

There is a conceptual difference in support that is perceived to be available if needed compared to support that is actually available and provided. While it can be argued that perceptions are not necessarily accurate, perceived support is consistently associated with better mental health outcomes and influences satisfaction with the support that is provided (Hupcey, 1998; Turner, 1999). Actual support may be available and given, but the support may not be of adequate quality or of satisfaction to the recipient. One problem with assessing perceptions, however, is that both the support provider and recipient may have different ideas about what type of support is needed or desired and these perceptions do not always match. Additionally, perceptions are rarely measured from the supporter's point of view, thought these perceptions influence the type and amount of support a supporter provides (Hupcey, 1998).

In addition to the four main types of support (emotional, informational, informational, and appraisal), examples of other types of support can be found, including functional, directive, self-efficacy, companionship, and belonging support (Cohen, Underwood, et al., 2000; Dennis, Markey, Johnston, Vander, & Artinian, 2008; Symister & Friend, 2003; Walker, Zona, & Fisher, 2006). Another type of support, disease-specific support, includes actions that are directly related to the support receiver's condition, such as helping a person with diabetes test for sugar levels or reminding a person with epilepsy to avoid seizure triggers. Few investigators have examined the links between disease-specific support and mental health outcomes, perhaps due to a lack of reliable and valid measures. Connell and colleagues (1994) found that perceived support predicted depression, but disease-specific support did not. In a study of PWE, disease-specific support was significantly associated with anxiety, but not with self-efficacy or outcome expectancies for self-management (DiIorio et al., 1996).

The matching hypothesis of social support posits that a particular type of support may be more effective for certain types of stressors. For example, instrumental support may be relevant when someone is experiencing economic difficulties but not when he or she is having relationship problems (Cohen, Underwood, et al., 2000). Additionally, different types of social support may be more or less beneficial at various times in the course of an illness. De Leeuw and colleagues (2000) examined the effects of received and available support before and after treatment for head and neck cancer. They found that, before treatment, received support was positively associated with depressive symptoms and that, after treatment, increased available support was related to lower levels of depressive symptoms.

Social support is generally operationalized as a positive influence, but there are also negative aspects of support that need to be evaluated. Interpersonal relationships and social support may not always benefit the individuals involved due to conflict, strain, and negative perceptions. For example, in a study of people with chronic illnesses and their caregivers, relationship strain was significantly associated with depressive symptoms for both the care recipient and caregiver (Sebern & Whitlatch, 2007). Even support that is provided with good intentions may be perceived by the PWE as nagging, and only serve to increase their stress (DiIorio et al., 1996). Interpersonal relationships can have the dual effects of both providing support and causing stress (Revenson, Schiaffino, Majerovitz, & Gibofsky, 1991).

Social support is a complex construct that is often not consistently operationalized. For this study, the direct effect of social support on depressive symptoms and self-management will be used. Through the exploration of the experiences of PWE and the primary support persons, it will become clearer what types of support are exchanged and the influences of positive and negative interactions.

Social Cognitive Theory. Social Cognitive Theory (SCT) is characterized by reciprocal determinism, which is represented as bidirectional relationships between the person, behavior, and the environment. The environment can include both social support and physical entities (Bandura, 2004). SCT has been used to explain self-management behaviors because of the utility of two key constructs: self-efficacy and social support. Self-efficacy, or the confidence in one's ability to perform a behavior, is consistently associated with a variety of health behaviors (McAlister, Perry, & Parcel, 2008), including self-management. Social support and depression indirectly affect self-management behaviors through self-efficacy; these relationships have been supported for both medication and lifestyle self-management among PWE (DiIorio et al., 2004; Robinson et al., 2008). Social contacts can also influence behaviors of others through modeling, verbal support, and persuasion (Berkman, 1995). For this study, we drew on reciprocal determinism by examining how PWE's interactions with a support person (environment) affect their self-management behaviors and how their self-management behaviors affect their interactions with a support person.

Grounded Theory. Grounded Theory is a set of procedures that guides qualitative study design, data collection, and data analysis for the purpose of generating theory that is "grounded" in the participants' words and experiences. It is based on the assumption that meaning is generated through interactions and experiences; these interactions, in turn, lead to the formation of new meanings, as well as the perpetuation of old ones. Investigators engage in a process of continually reviewing the data, making comparisons and asking questions, and evaluating causes, context, and consequences. The resulting theory provides an explanation of the shared social processes that the participants experience and engage in, and can be a guide to action (Corbin & Strauss, 2008; Jacelon & O'Dell, 2005; LaRossa, 2005).

Rationale for the Research

Epilepsy is a common neurological disorder that imposes significant burden on PWE, their family and friends, and society. A variety of organizations, including the Centers for Disease Control and Prevention, the Epilepsy Foundation, and the Institute of Medicine, have recognized that epilepsy represents a neglected public health problem. Recommendations for addressing this problem and improving the health and quality of life for PWE include supporting their ability to manage their condition. Social support may represent a key mechanism to fulfilling this recommendation. Previous research has demonstrated that social support is associated with depression, self-management, and quality of life for PWE. However, further research is needed to gain a deep and nuanced understanding of these associations.

Gaps in the Literature. Several gaps exist in the research literature around support for PWE. First, current research on social support and PWE's PSP has mainly relied on quantitative methods. While these studies provide important information on the overall associations of support with health outcomes, an in-depth understanding of experiences with and perceptions of support is lacking. Qualitative methods are necessary to provide a rich understanding of people's experiences. Second, little is known about the patterns and influence of support received by PWE, both overall and for self-management, specifically. Some types of support may be easier or harder to receive or provide, likewise some types of support may be more or less necessary, depending on the PWE and PSP. Additionally, the interpersonal relationship between the PWE and PSP could influence the type and amount of support provided, as well as satisfaction with providing and receiving support. Finally, the voices of PSP for PWE are largely absent from the literature. PSP's experiences of living with epilepsy can shed light on the impact of epilepsy on their own lives.

Aims of this Research. The purpose of this dissertation research is to explore the interpersonal relationships between PWE and their PSP, particularly each individual's experiences and the nature of support provided, and the effect of support on the PWE's mental health and self-management of their condition. This study addresses specific gaps in the literature by: 1) providing an in-depth examination of the interpersonal relationship between PWE and their PSP, from the perspectives of both members of the dyad; and 2) developing and refining a model for understanding the interpersonal context in which support is provided to PWE and the associations between support, depressive symptoms, and self-management behaviors.

A sequential mixed-methods research design, including a qualitative phase and a quantitative phase, was employed to achieve the aims of this research. The results are organized into papers in the following three chapters. The first two papers (Chapters 2 and 3) involve qualitative analyses. In Chapter 2 we explored how epilepsy affects the lives of PWE and their primary support persons and the nature of their interpersonal relationships, including the types and influences of support that was provided and received. This analysis culminated in generation of a dyadic model of living with epilepsy and a description of the trajectories that individuals follow through the model. In Chapter 3 we examined self-management support and the support persons' influence on PWE's self-management. This paper contributes to the literature by describing a continuum of self-management support and the factors that contribute to where PWE and their support providers fall on the continuum. In Chapter 4 mixed-methods were used to evaluate the types of self-management support that were easier or harder to receive and provide. We also assessed if the items of an epilepsy self-management support scale functioned the same for PWE and their primary support persons and for individuals with and without depressive symptoms. Additionally, we developed suggestions for expanding and improving the measures of epilepsy self-management support. Overall, the results of this study have implications for future research and practice, which are discussed in the concluding chapter (Chapter 5).

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Chapter 2:

“What affects her affects you”: Perspectives of living with epilepsy from adults with epilepsy and their support persons

Abstract

Introduction: Epilepsy is an example of a chronic condition that significantly affects the lives of individuals with the condition and the people who support them. Few studies have examined the experiences of people with epilepsy together with their support persons. This study qualitatively explored how epilepsy affects the lives and interpersonal relationships between people with epilepsy and their primary support persons, including the types and influences of support.

Methods: This study is based on the qualitative portion of a mixed-methods study. We conducted in-depth interviews with 22 people with epilepsy and 16 support persons, who represented 24 relationships. Data analysis was guided by the constant comparative method commonly used in grounded theory. Main themes were identified and the relationships between themes were explored.

Results: We developed a model that shows how epilepsy impacts the lives of both people with epilepsy and support persons and that the experiences of people with epilepsy and supporters intertwine and influence one another. The core themes in the model 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: “Technically disabled,” “Trying to get back to normal,” “On her own,” “Moving to adulthood,” and “How to be independent with this.” Support providers followed four trajectories based on seizure control, perception of burden, and support for themselves: “Extraordinarily taxing,” “Limiting my time somewhere else,” “Not a burden,” and “Real-world life changes.”

Discussion: People with epilepsy and their primary support providers have varied experiences in how epilepsy affects their lives. Intervention efforts should focus on ways to reduce illness intrusiveness and improve quality of life for people with epilepsy and their supporters.

Introduction

Epilepsy, a common neurological disorder characterized by recurrent seizures, has a profound effect on the lives of individuals with the condition and their families and friends.

Epilepsy is an intrusive illness that disrupts the valued interests and activities of the people with the condition (Devins, 1994; Poochikian-Sarkissian, Sidani, Wennberg, & Devins, 2008a; Poochikian-Sarkissian, Sidani, Wennberg, & Devins, 2008b). People with epilepsy (PWE) can experience memory difficulties, adverse medication side-effects, and functional limitations, such as driving restrictions and difficulties maintaining employment (Clark et al., 2010; Fisher et al., 2000; Unger & Buelow, 2009; Wheless, 2006). As a result, PWE are less likely to get married and be employed, and more likely to have a lower income compared to people without the condition (Elliott, Charyton, Sprangers, Lu, & Moore, 2011; Jennum, Gyllenborg, & Kjellberg, 2011). Additionally, PWE are more likely than people without epilepsy to report frustration and dissatisfaction with their education, work, life goals, family life, friends, and social life, as well as health and energy level (Kobau, Luncheon, Zack, Shegog, & Price, 2012). In a qualitative study of people with epilepsy, Raty and Wilde Larsson (2011) reported that perceptions of living with epilepsy range from acceptance and living a normal life to struggling with a loss of control and giving up hope of recovery. PWE report feeling isolated and dependent on others, experience interpersonal and social difficulties, and are stigmatized due to their condition (Beran, 1999; Collings, 1990; Fisher et al., 2000). 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 the condition (Strine et al., 2005; Wiebe, Bellhouse, Fallahay, & Eliasziw, 1999).

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 (Amir, Roziner, Knoll, & Neufeld, 1999; Gulpek, Bolat, Mete, Arici, & Celebisoy, 2011; LaFrance et al., 2011; Mahrer-Imhof et al., 2013; Whatley, DiIorio, & Yeager, 2010), improved self-rated health and life satisfaction (Charyton, Elliott, Lu, & Moore, 2009; Elliott, Charyton, McAuley, & Shneker, 2011), and fewer depressive symptoms (Hermann & Whitman, 1989; Reisinger & DiIorio, 2009) for PWE. Additionally, social support contributes to increased self-efficacy to perform epilepsy self-management behaviors (DiIorio et al., 2004; Robinson et al., 2008).

PWE rely mainly on parents and spouses, other family members, neighbors, and health care providers for support (Hills & Baker, 1992; Walker, Bamps, Burdett, Rothkopf, & DiIorio, 2012). 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 by helping PWE to minimize stress and improve sleep quality (Walker et al., 2012). The support provided through marriage appears to offset some of the social, functional, and economic challenges faced by PWE (Elliott, Charyton, Sprangers, et al., 2011). However, dynamics between support persons and PWE can also have negative consequences. Bressi and colleagues (2007) 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, little is known about how epilepsy affects the lives of caregivers and family. Epilepsy can cause psychosocial distress and difficulties in all family members and restrict family activities (Ellis, Upton, & Thompson, 2000; Thompson & Upton, 1992). 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 (Thompson & Upton, 1992). Support providers of PWE also report low quality of life, particularly for emotional functioning and mental health (van Andel, Zijlmans, Fischer, & Leijten, 2009; Westphal-Guitti et al., 2007). The quality of life of support providers is largely explained by coping style, which affects their perceptions of their caregiving burden (van Andel, Westerhuis, Zijlmans, Fischer, & Leijten, 2011). 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 (Mahrer-Imhof et al., 2013). Seizure-related factors have less effect on supporters' quality of life (Mahrer-Imhof et al., 2013; van Andel et al., 2011).

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, caregivers' 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 gain insight into the experiences of people with epilepsy and their primary support persons (PSP). The 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 (Bandura, 2004; Heaney & Israel, 2008; McLeroy, Bibeau, Steckler, & Glanz, 1988; Stokols, 1996). 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 types and influences of support.

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. The purpose of the overall mixed-methods study was to examine the interpersonal relationship between PWE and PSP, support provided and received, and the effect of the relationship and support on self-management and mental health. This study focuses on the model developed based on participants' experiences with living with epilepsy and how the experiences of PWE and PSP are intertwined.

Sample and Recruitment

Recruitment occurred at a hospital-based epilepsy clinic from April-November 2011. Healthcare providers referred interested patients to the study team; one researcher (EW) explained the study in detail and screened for eligibility. Eligibility criteria for PWE included: 1) being 18 years of age or older, 2) having a diagnosis of epilepsy for at least 3 months, 3) being able to identify a primary support person, and 4) able to speak and read English. Eligible PWE referred their primary support person, who was defined as a non-paid individual who provided or who would be most likely to provide support to the PWE. Eligibility criteria for support persons included: 1) being 18 years of or older, 2) providing unpaid assistance to a person with epilepsy, and 3) able to speak and read English. Individuals were not eligible if they did not have the cognitive ability to independently provide consent.

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 for self-management, and quality of life, and questions on demographic characteristics. Depressive symptoms were assessed using the Centers for Epidemiologic Studies Depression scale (CES-D; Radloff, 1977). 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 has been shown to be reliable and valid in general populations and in samples of PWE (Jones et al., 2005; Radloff, 1977; Reisinger & DiIorio, 2009).

Purposive sampling among participants who completed the survey was used to recruit participants for the qualitative phase (Patton, 2002). A subset of individuals was invited to complete an in-depth interview. In order to capture information across a diverse and information-rich sample, survey responses were used to identify individuals who represented variation in relationship type, gender, race/ethnicity, self-management, levels of support, and depressive symptoms.

In-depth interviews lasted 45 minutes, on average, and were conducted over the phone in order to accommodate the transportation limitations experienced by PWE. Interviewing by phone yields quality data on par with data gathered from face-to-face interviews (Coderre, Mathieu, & St-Laurent, 2004; Novick, 2008). PWE and PSP were interviewed separately. All participants received a $25 gift card to compensate them for their time.

The semi-structured interview guide covered five domains: experiences with epilepsy, effects of epilepsy on the PWE's and PSP's lives and relationship, characteristics of their interpersonal relationship, support provided to the PWE, and support specifically for self-management. The PWE and PSP were asked similar questions. For example, PWE were asked, "How do seizures affect your life?" whereas support persons were asked, "How do seizures affect [the PWE's] life?" and "How do [the PWE's] seizures affect your life?" Probes were used to prompt the participants to provide additional information, examples, or deeper explanation.

All interviews were audio-recorded, de-identified, labeled with a unique identifier, and transcribed verbatim.

Data Analysis

The constant comparison method commonly used in grounded theory guided the data analysis and model development (Boeije, 2002; Corbin & Strauss, 2008). A codebook was developed deductively, by identifying potential codes from the interview guide, and inductively, through careful reading of the transcripts. First, six transcripts were coded independently by two researchers, who applied the codes identified *a priori* and compiled additional salient codes from the narratives. To ensure intercoder reliability, the researchers met to discuss the coding, address any discrepancies, adjust the codebook, and recode transcripts, as necessary. The resulting codebook was used for coding another set of transcripts. Two researchers coded the remaining transcripts and regularly met to compare and discuss coding, refine the codebook, and recode transcripts as necessary.

The first round of coding was completed by hand; subsequently the transcripts were uploaded into the qualitative software package, MaxQDA, in order to facilitate coding, data management, and analysis. Text retrieval in MaxQDA allowed for the comparison of coded sections to ensure that that each segment fit within the code and to identify dimensions of the code. Main categories and the codes that fell under them were identified. The core categories for this analysis included self-management and support, seizure control, illness intrusiveness, and quality of life. As coding progressed, axial coding was utilized to identify relationships between main categories. Analytic memos were written throughout the coding process to describe these major categories and explore patterns of experiences. Pictorial representations of these relationships were drawn, leading to the development of a model that displayed the interrelationships between themes. Finally, we identified the main trajectories that described the ways in which participants moved through the model. Direct quotes are used to illustrate the main themes. At the end of each quote, participants are identified as being either a PWE or PSP and their relationship in the pair. So, the notation (PWE, daughter) indicates that the speaker was a daughter with epilepsy.

Results

Participant Characteristics

In-depth interviews were conducted with 38 individuals (22 PWE and 16 support persons) who represented 24 relationships (14 complete pairs, 8 additional PWE, and 2 additional support providers). 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 PWE and PSP pairs lived in the same household.

Introduction to the Dyadic Model of Living with Epilepsy

The major categories that emerged in the analysis, and the relationship between these categories, are depicted in Figure 1. The model shows how epilepsy impacts the lives both PWE and PSP and that the experiences of PWE and PSP intertwine and influence one another. A brief definition of each section of the model will be described below, followed by an explanation of the trajectories that PWE and PSP followed through the model.

Treatment Factors. All of the PWE were on medications for the purpose of controlling 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 numerous side effects including weight gain, bone density loss, cognitive impairments, and fatigue. The emergence of side effects caused PWE and PSP to evaluate the benefits of continuing the medication or trying something different.

Several PWE reported having brain surgery or a Vagus Nerve Stimulator (VNS) implanted in an attempt to control seizures that did not respond to medication. One PWE achieved freedom from seizures as a result of surgery; three other PWE continued to have seizures.

Seizure factors. Most PWE began having seizures as children; therefore they had been living with epilepsy for many years (mean = 17.7 years). PWE experienced a variety of seizures from more mild (e.g. absence and simple partial) to more severe (e.g. complex partial and tonic-clonic); several PWE experienced more than one type of seizures (see Table 1). In a few cases, seizure severity increased over time, though participants did not know why this might occur. After a seizure, some PWE recovered easily, while others experienced headache, confusion, fatigue, or injury. As a result of epilepsy, several PWE experienced longer-term memory and cognitive difficulties, which had a negative impact on their life.

Many PWE and PSP expressed fear and anxiety. A woman 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?” (PWE, mother).

Despite the physical and emotional effects of seizures, eventually seizures became normalized into daily life for PWE and PSP, especially for individuals whose epilepsy began in childhood. One mother said, “…the first seizure we saw we didn’t think he’d come back from, you know, and I guess after a while you got used to it.” For some, the seizures never were completely routine, although dealing with them became easier. Another mother said,

> I mean, when a seizure happens, obviously, for the next few days…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 (PSP, mother).

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. PWE and PSP felt close to each other despite also experiencing some "ups and downs" in their relationships. For example, when asked to describe his relationship with his mom, one young man with epilepsy said, "It can be a mixture of supportive and antagonist just because we're relatives, but, I mean, overall I'd say positive."

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

Support Provided. PSP provided a variety of support, including seizure, self-management, emotional, and instrumental support. The amount of seizure support depended on the level of seizure control; PWE with infrequent or uncontrolled seizures received support before, during, and after seizures. PSP were involved to varying degrees in the PWE's self management, ranging from supporting the PWE to performing self-management behaviors for them. PSP aided PWE in all domains of self-management, including monitoring and giving reminders about medication taking, helping the PWE to avoid triggers, driving the PWE to doctor's appointments, communicating with neurologists, tracking seizures, and looking up information about epilepsy. Emotional support, which involved being there for the PWE, was very important to PWE. A man with epilepsy described the emotional support he received from his brother, "I could tell him everything and I will talk to him, sometimes he will help me out. All the time. And he's just there for me all the time." Instrumental support often included driving the PWE, supporting them financially, and, in the case of parents, giving their adult children a place to live.

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. Several of these individuals only had a few seizures in their lives. The other two-thirds of the PWE experienced uncontrolled and unpredictable seizures, despite good self-management and, in several cases, surgery or VNS implantation.

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 originally developed by Devins

(Devins, 1994) and applied to epilepsy by Poochikian-Sarkissian and colleagues (2008a; 2008b). In this model, the concept of illness intrusiveness is described as the disruptions of valued activities and interests that are caused by having an illness. For PWE, the major domain of illness intrusiveness was independence, the ability to live life on their terms without being overly reliant on other people. Some PWE were able to live independently; however others lived with limitations that required them to be dependent on a PSP and others were transitioning to independence. Valued activities and interests that could be disrupted by epilepsy and contributed to a PWE's dependence included driving, jobs, school, and living arrangements. For PSP, illness intrusiveness manifested itself as the perceived burden of caring for the PWE, which ranged from low to high.

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 live ranged from mental and physical well-being to overwhelming stress and high levels of depressive symptoms. Depressive symptoms were the main characteristic of quality of life for PSP; however, PWE with elevated depressive symptoms were dispersed across the three quality of life categories.

PWE Trajectories

PWE's paths through the model resolved into five main trajectories (see Table 2). Seizure control was a major factor in determining which trajectory a PWE followed 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.

Trajectories 1-3: Uncontrolled seizures and high illness intrusiveness. The PWE's epilepsy was uncontrolled in 15 relationships; these PWE had similar experiences with the intrusiveness of epilepsy in their lives, the limitations they faced because of seizures, and the support they received. None of the PWE in this group could drive because they had seizures within the past six months. The inability to drive was closely linked to feelings of dependence and frustration. Seizures left the PWE unable to work or attend school because they could not get to a job or school due to driving restrictions, cognitive processes or memory impairment due to seizures inhibited their ability to complete tasks, or work or school schedules interfered with necessary self-management routines (e.g. getting enough rest). Since PWE could not drive or support themselves by working, they felt dependent on their families. This sense of dependence was associated with the PWE feeling frustration, disappointment, and guilt that they had to rely on others. A man with epilepsy said, "My family helps me, but I mean that's not enough for me, you know. I just can't depend on them the whole time…that's not fair."

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 below under each trajectory.

Trajectory 1: Technically Disabled. The pairs in this group represented a variety of relationship types: five child/parent pairs (4 daughter/mother pairs and 1 son/mother pair), 3 spouse pairs (2 wife/husband pairs and 1 husband/wife pair), 1 mother/daughter pair, and one pair of brothers. The PWE 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. Half of the PWE were very active in managing their epilepsy, two of the spouse pairs managed the PWE's epilepsy jointly, and in three cases the PSP took the primary role in epilepsy management. As with the other PWE with uncontrolled seizures, the PWE in this trajectory stated that driving was the main limitation they faced. Seizures also limited their ability to work or go to school; five of the PWE received Supplemental Security Income and Medicaid benefits and two more PWE were either applying or planning to apply for disability benefits.

> Well I can't drive and I can't go nowhere, so I tell people I'm under house arrest. Just a little joke. And, um because I can't drive, 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. So I can't go out and do anything, so I'm pretty much just stuck in the house (PWE, daughter).

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 described feeling that aspects of their life, such as working or living on their own, had been "taken away."

> Well, for some reason, my body is so sensitive that if I get overexerted, I have the seizures. And then, for some reason, I have constant fatigue. So they really

> handicap me in a lot of ways. Actually, I don't work. I'm technically disabled. And so they hinder me. They actually, like, they rob me of a lot of my life. Just a normal life that other people would have, like, you know, going and working or, you know, going to ball games and sitting in the sun. Things like that that most people take for granted…I'm not exposed to. So I feel robbed (PWE, mother).

For PWE, particularly those who were diagnosed with epilepsy as adults, their disability challenged the role that they wanted to be able to fulfill.

> I'm sure that that's not what [my wife] wanted when we got married to be the breadwinner, if you will, of the family. She would rather, and I would rather, being the husband, be the breadwinner… 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 (PWE, husband).

Conversely, a couple of PWE described acceptance of their condition; this acceptance allowed them to cope with the limitations of their life. One man with epilepsy described that over time his seizures had less emotional impact on him.

> …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 because it was just like, 'Why in the world, how, where am I?' But it's just, like, well, you know what it is (PWE, son).

Another couple stated that their faith helped them to cope with the wife's epilepsy. She describes:

> 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 (PWE, wife).

Trajectory 2: Trying to get back to normal. This group included two wife/husband pairs. Both women had received a diagnosis of epilepsy within the past three years and they and their PSP were still adjusting to the changes that seizures wrought in their lives.

> It's just been so hard on our family. And now, you know, it's like my whole family's had epilepsy with me. It's so hard on my husband because he's had to deal with it. And we still deal with it (PWE, wife).

These women received support for their seizures and self-management. One woman took the lead in managing her epilepsy; her husband took a supporting role by driving her to the doctor, attending her appointments, and keeping track of her seizures in his phone. The other woman had severe seizures with memory loss that necessitated that her husband perform most of the management behaviors. He controlled her medication, monitored her symptoms and seizures, reminded her to go to sleep, made her doctor's appointments, and took her to the doctor.

The onset of epilepsy seriously altered the course of these women's lives. Both women had successful careers at the time the seizures began, and despite attempting to keep working, they eventually had to give up their jobs due to the severity of their seizures.

> And, you know, why I'm not working right now and why, you know, like I said, I'm a strong person. I'm an independent person. I'm, you know, this whole experience has been a really big blow to the way I thought my life was going to be, you know (PWE, wife).

As they and their PSP struggled to come to terms with life with epilepsy, they both looked forward to an uncertain future and back toward what was a "normal" life. Ultimately they hoped that the future would look like the pre-epilepsy past.

> And I guess I'm just, you know, resigned, if that's the right word, to everything, and now more of, 'Okay, what's going to happen next?' You know, we're still waiting to see… I mean, it's affected our lives, my parents' lives, and it'll never be the same. I mean, that's why 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? (PWE, wife)

One couple termed the wife's good days as "JLOT" days – just like old times.

> …my hope is that once this is all behind us and her seizures go from every day to – I don't know, whatever the goal is – once a month, once a year, once every six months – whatever we is, whenever we get there, that things will go back to normal; things will go to JLOT (PSP, husband).

Trajectory 3: Get out on her own. This trajectory included three daughter/parent pairs (two daughter mother pairs and one daughter/father pair). These three women took the lead on managing their epilepsy, with reminders from the PSP. The 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.

> It's frustrating, because…I feel like I have no independence because I cannot drive. So it kind of limits me. As for anything else, because of the type of seizures I have, it doesn't limit me as far as, like, things I can do, per se, because it's not like—it's not something, like, visually, like, that's necessarily going to freak people out, necessarily, because it doesn't last so long and I don't have them frequently. It's more just not being able to get from place to place, having to rely on people, because of the area I do live in currently. And that gets frustrating (PWE, daughter).

These women planned a future that was not governed by disability. 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. One woman described how moving into a city where she would have access to public transportation was a priority.

> And I'll buy a place and live while I'm down there, since I'll be able to get out and do it myself, instead of having someone take me to and from an interview. If I have to go start working in retail or as a waitress while I'm looking for a permanent job, then that's fine. But just to be out and down where I know I can get from place to place without relying on someone. I just need to go and do that (PWE, daughter).

In addition to being a means to living independently, 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. Yeah, I think, you know, she needs to have independence and she needs to have the standing on her own legs, which I still try to have her do here (PSP, father).

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

> Just knowing that, you know, all I ever wanted for her was to, you know, have a normal life and be able to do things that everybody else can do and that type of thing, so I just hope she's -- right now, she's trying to find a job and an apartment and all to get out on her own, and I just want to be there if she, you know, if that's something that she cannot do herself, if she's not able to find a job or if she finds a job and then is not able to keep it, 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 (PSP, mother).

The PSP comments also highlight the importance to them for their daughters to live a "normal" life, in which children are expected to move out of their parents' houses and become self-sufficient.

Trajectory 4: Moving into adulthood. This group was comprised of 4 son/mother pairs; two of the young men had uncontrolled seizures and two of them were seizure free. In all cases, the mothers provided the sons with a significant amount of support. They took the lead in epilepsy management efforts, ensuring that their sons took their epilepsy medication, refilling medication, and making and attending appointments with the neurologist. The mothers also provided emotional support, financial assistance, and housing, even for the two young men who did not live at home. 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 all of the PWE in this group were diagnosed with epilepsy during childhood or early adolescence and three of the young men had additional health conditions (autism, a heart condition, or schizophrenia and diabetes). Therefore, these patterns of support developed over time and perpetuated, even as the young men began transitioning toward adulthood. This transition was a process that involved the young men starting to take on more responsibility for their care and independence in their lives and the mothers letting go of control over their sons' lives. For one pair who was early in this process, the mother hoped:

> 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 (PSP, mother).

This viewpoint that the son needed to demonstrate responsibility before the mother would relinquish control was echoed in other interviews.

The young men were taking steps toward living independently. Two PWE lived on their own in areas with good public transportation, one was in college, and one had recently started a part-time job he could ride his bike to. 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 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."

Trajectory 5: How to be independent with this. The final group included five pairs in which the PWE had infrequent seizures or was seizure free. The pairs included a variety of relationships: 2 spouse pairs (1 wife/husband pair and husband/wife pair), one daughter/father pair, 1 sister/brother pair, and one pair of friends. The PWE all lived independently or with their spouses and were the only PWE in this sample who worked full-time. Overall, epilepsy intruded only minimally into their lives. For the two PWE who had only had a few seizures in their lives, managing epilepsy only entailed taking medication and making sure to get enough rest. The other three PWE had infrequent seizures, which could impact their driving ability and job.

Self-management was a top priority for the PWE in this group in order to prevent any future seizures and keep their driving privileges. Being able to drive was crucial in order to maintain their independence.

> The worst - the actual seizure doesn't bother me, what bothers me is the losing my car, losing the ability to drive. That bothers me far, far more. 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 (PWE, friend).

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.

> And it’s extremely inconvenient, especially now that I don’t live at home. This last time was very frustrating because, you know, 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… (PWE wife)

The PWE with infrequent seizures also faced the challenge of needing to disclose their condition to their employer and potentially needing accommodations when they had a seizure, such as going home early or missing work. In one woman’s experience,

> I don’t want anyone to feel sorry for me. But at the same time, you want them to understand that I’m not going to be able to come back to work tomorrow and be, you know, 100%… I have to kind of find a balance so that they understand what this really does to me so they don’t, you know, have inappropriate expectations (PWE, daughter).

All three experienced situations when coworkers or bosses did not know how to respond or responded inappropriately, such as trying to restrict their duties or offering short-term medical leave when the PWE was going to take “regular time.”

The PWE in this group received mainly emotional support from their PSP, though they also received minimal support for self-management and seizure support, if needed. PSP were a “sounding board” and could be counted on to “have my back.”

> Oh, when I'm having a bad day I can tell him all about it. When I'm having a good day I can tell him all about it. You know. You know, he's there for me. Or if I'm like upset with somebody, you know. He's always there to listen (PWE, sister).

For a couple PWE with infrequent seizures, their PSP’ support was instrumental to allowing them to continue to live independently.

> I think he understood the importance of teaching me how to be independent with this. He went down the path of ‘you need to be responsible’ and that ‘you need to take care of yourself if you are going to do X, Y and Z. If you’re going to live on your own, you have to make sure that you take your medication. You have to make sure that you do this.’ I mean, he’s always taught me that – and I kind of

> have it ingrained in me. Whenever I go and look for a place to live, an apartment and whatnot, I'm always on a bus line. I'm always within a distance to a bus so that I can make sure that I can get to work, or close to a MARTA train or something (PWE, daughter).

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 on their lives. In the majority of cases, 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.

Trajectory 1: Extraordinarily taxing. This group was made up of six pairs that included four child/parent pairs (two son/mother, one daughter/father, one daughter/mother) and two spouse pairs (one husband/wife and one wife/husband). Five of the PWE had uncontrolled seizures and one was seizure free. All of the PSP provided a high level of support to the PWE, including emotional support, support for seizures, and help with self-management tasks. In three of the cases, the PSP took the lead in managing the PWE’s epilepsy, either because the PWE was extremely impaired by her seizures (PWE Trajectory 2) or because, as the mothers of young adult sons, the PSP had been supporting the PWE for a long period of time (PWE Trajectory 4). Other factors added to their caregiving burden, including stress from caring for other sick family members, financial instability, and pressure from work.

All of these PSP experienced high illness intrusiveness due to the PWE’s seizures and the time, energy, and resources devoted to caring for them. In order to meet the PWE’s needs, the PSP described giving up valued activities, such as exercising, travelling, or playing baseball.

> Like I said, I’m limited in what I can do. I mean, I get off from work now, I have to come straight home. Just very limited now. I don’t travel, go places with, you know, hanging out with girlfriends or anything like that, or just going anywhere for long periods of time, I have to be conscious and aware that he’s home (PSP, wife).

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 that 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.

> I guess 95 to 98 percent of the time it’s me, and that’s because we live together. …it’s me or, like I said, her boyfriend, who, if he can and it fits into his work schedule, he will take her to an appointment, or her sister will if I just can’t get

> away or I’m out of town or something like that. But typically if I’m not able to do it, then I reschedule it until I can (PSP, mother).

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.

> I think meeting [the PWE] and thinking that would help with the loss of my mom and then rushing into the marriage and then overwhelmed with all the stuff that’s wrong with him, that it’s all kind of, everything is kind of, the clarity is setting in now and...it’s overwhelming. You know, it’s not that I don’t love him, I do. It’s just that I just didn’t realize what epilepsy entailed (PSP, wife).

Similarly,

> So essentially, I have a kid now, and it’s not what I – 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 (PSP, husband).

Both 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 in this group 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” and took a toll on the PSP’s resources and energy.

> You know, I did really, really well for – for a long time. And I would say in the last couple of months, I’ve just become weary… I’m tired. I’m mentally drained, you know? And it’s – you know, I haven’t taken care of myself. It’s definitely taken my toll, but, you know, I did really well for a really long time (PSP, mother).

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 needed to fulfill their caregiving and other responsibilities, despite their depression.

> I pushed through it. I mean, most people would probably say, ‘You were depressed?’ And I think, even though I knew I was, I also had to have this strong maternal whatever, and I know I have to get up, I have to do these things, I have to put one foot in front of the other. You can’t just lie around in bed and that sort of thing. So I put on a happy face and get going.

Trajectory 2: Limiting my time somewhere else. This group included two pairs, one wife/husband pair and one daughter/mother pair. Both PSP 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 did not experience high levels of stress.

In order to better be able to provide the support needed by their PWE, both PSP limited their employment through retirement or working part-time. Working less increased that amount of time PSP had available to care for the PWE, thus reducing the demands on their time and their stress.

> I will say that over a period of time…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 (PSP, husband).

The PSP also felt that working less and directing their attention to the PWE benefited 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 (PSP, mother).

The PSP did acknowledge 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.

> …we live a good life. She wants to do skydiving and I have encouraged her not to do that, but, you know…we know our limitations, but we do most of what we want to do (PSP, husband).

Trajectory 3: Not a burden. The seven PSP in this group included four child/mother pairs (two son/mother and two daughter/mother) and 3 additional relationship types (one wife/husband, one mother/daughter, and one friend pair). The PWE experienced a range of seizure control from uncontrolled to seizure free. The PSP provided emotional support, seizure support when needed, and assisted with self-management. While over half of the PWE had primary responsibility for managing their epilepsy, one couple managed together and two PSP took the lead in managing their PWE's epilepsy. Overall, however, the amount support PSP provided to the PWE was less compared to the PSP in Trajectories 1 and 2.

The PSP in this group experienced little illness intrusiveness and a low burden of support. Providing support was not a stress, overwhelming, or an inconvenience. Rather, the support was part of normal daily activities.

> So I don't see this as near as overwhelming, I'm sure, as a lot of parents would. Because my experience is, you know, for 30 years, my career has been working with children and parents who have severe disabilities where the whole life revolves around this kid's disability. So I really see our lives as very, very normal, and I see this as just something that you just—you know, you just fold into your life and move on (PSP, mother).

The PSP felt that it was part of their role as a parent, spouse, daughter, or friend to provide support.

> 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. Really, but like I said before, he's a friend, and 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 (PSP, friend).

Three of the 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, and even provided her with some support.

> Well, I've always kind of, you know, I'm kind of religious, and I kind of gave her up to God, you know, for Him to take care of her while I'm at work…because if I start worrying about every little thing about it's going to drive me crazy, and I won’t be able to take care of her, you know. So, I've just got to have faith that God is going to keep her safe… (PSP, mother)

Trajectory 4: Real-world life changes. The experiences of the PSP in this group, a father to a daughter with epilepsy, did not align with the other trajectories. He provided mainly emotional support to his daughter, whose seizures were controlled with medication (PWE Trajectory 5).

> I do get satisfaction that she’s taking care of herself, when she tells me she’s doing things. So I guess it’s satisfaction and I feel good that she’s protecting herself and she’s moving on in life and she’s standing on her own two feet (PSP, father).

However, he described having poor mental health that was due to stress from work and financial difficulties resulting from the poor economy.

> So, hey, there's so much pressure I can't tell you. So I'm not too happy…it's just adjusting to changes, real-world life changes, okay? You have a plan, and there's a linear relationship, but in life it's not linear, okay? It's peak and valley. And currently I'm in a valley…(PSP, father)

Discussion

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

During analysis and model development, the impact of epilepsy on the lives of both the PWE and PSP was evident. The emergent theme of illness intrusiveness figured prominently into our model, which aligned well with and provides support for the Illness Intrusiveness Model (Devins, 1994; Poochikian-Sarkissian et al., 2008a; Poochikian-Sarkissian et al., 2008b). In this model, treatment and illness factors influence illness intrusiveness, which impacts quality of life. Poochikian-Sarkissian and colleagues (2008) 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. Our final model incorporated the main constructs of the Illness Intrusiveness Model, while extending it to include self-management, seizure control, support provided by the PSP, the illness intrusiveness to the PSP's lives, and the PSP's quality of life.

The qualitative findings of our study support and provide insights into the relationships 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 (Johnson, Jones, Seidenberg, & Hermann, 2004; Poochikian-Sarkissian et al., 2008b; Raty, Soderfeldt, & Wilde Larsson, 2007), our results demonstrate how the degree of control and unpredictability of seizures contribute to feelings of anxiety and concern, 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, which have identified driving limitations, difficulties with employment and education, and negative effects on relationships as major concerns (Fisher et al., 2000; Hayden, Penna, & Buchanan, 1992; Kerr, Nixon, & Angalakuditi, 2011; Wheless, 2006).

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 important in shaping the PWE’s outlook and quality of life. PWE trajectories 1 and 5 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, wives and daughters, respectively, 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 (2006) in which the theme of “having to be dependent on others” was particularly chafing for young adults. A gender difference between the young adults in our sample emerged, with daughters in Trajectory 3 taking concrete steps towards independence, while sons in Trajectory 4 were still receiving a high level of support from their mothers, particularly for self-management of epilepsy. The daughters may have been further along in the transition to adulthood for a couple reasons. First, these women were older, on average, than the young adult males. Second, three of the four sons had additional health conditions; their mothers had been very involved in managing their care from an early age and were just now beginning to relinquish control over their sons’ lives. Parents are instrumental in facilitating the development of autonomy in their children, though they may help or hinder young adults take on independence (Hanna, 2012; Sable et al., 2011).

Our study illustrates how PSP also experience illness intrusiveness; their illness intrusiveness is affected by both seizure control and their perceptions of the burden of support that they provide. The support needs of PWE with uncontrolled seizures were significant and included assistance before, during, and after seizures, support for self-management, and emotional and instrumental support. The uncontrolled nature of seizures also caused worry, anxiety, and stress in PSP because they did not feel like they had any control. Other researchers have described lack of control as being stressful to PWE (Kerr et al., 2011; Poochikian-Sarkissian, Wennberg, Sidani, & Devins, 2007; Raty

& Wilde-Larsson, 2011); our results suggest that this holds true for PSP as well. Therefore, it is not surprising that most of the PSP who experienced high burden and stress (PSP Trajectory 1) cared for PWE who had uncontrolled seizures. Similarly, Westphal-Guitti and colleagues (2007) reported that caregivers of older adolescents and adults with epilepsy who reported high levels of burden also experienced role limitations due to emotional problems, reduced vitality, 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 some of the overall burden of support for PSP.

Depressive symptoms also 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 (Westphal-Guitti et al., 2007) and depressive symptoms in a variety of other conditions (Chio, Gauthier, Calvo, Ghiglione, & Mutani, 2005; Nieboer et al., 1998; Phillips, Gallagher, Hunt, Der, & Carroll, 2009). Nieboer and colleagues (1998) 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. In order to meet the needs of their PWE, both PSP reduced the amount of time they worked, thus reducing the demands on their time.

Another important theme across the PSP trajectories was the importance of support for the PSP. Most of the PSP experiencing 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 allowed the caregiving burden for the PWE to be lightened 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 (Mahrer-Imhof et al., 2013; Thompson & Upton, 1992). Our results support the recommendations by Mahrer-Imhof and colleagues (2013) that PSP should be encouraged to share epilepsy management with PWE, share support tasks with other individuals, and cultivate relationships with family and friends.

Limitations

The results of this qualitative study need 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, requiring the care of an epileptologist, 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. Second, we provided a description of a conceptual model drawn from the data, but cannot make claims of causation.

Implications and future research

The model developed in this study identifies pathways for future research on the health and well-being of both PWE and their support persons. 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. In particular, longitudinal studies can shed light on causal relationships between the concepts in the model and explore how individuals proceed along trajectories and what conditions might cause them to change trajectories. 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.

Table 2.1 Demographic background of people with epilepsy and their primary support persons

	People with Epilepsy (n=22)	**Primary Support Persons** (n=16)
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)
Hispanic	1 (4.5)	-
White	16 (72.7)	11 (73.3)
Multiracial	-	1 (6.7)
Employment Status, n (%)		
Full-time	5 (22.7)	9 (56.3)
Part-time	-	2 (12.5)
Student	3 (13.6)	-
Retired	1 (4.5)	4 (25.0)
Unemployed	5 (22.7)	1 (6.3)
On disability	6 (27.3)	-
Other	2 (9.1)	-
Age (years)		
Range	21-59	18-65
Mean (SD)	33.50 (9.78)	50.12 (12.65)
Depressive Symptoms	12 (54.5)	9 (56.3)
No Depression (CES-D score <16)	10 (45.5)	7 (43.8)
Elevated Depressive Symptoms (CES-D score ≥16)		
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		
Tonic-clonic	13 (59.1)	
Complex partial	6 (27.3)	
Simple partial	3 (13.6)	
Absence	3 (13.6)	
Other	3 (13.6)	
Not sure	3 (13.6)	

	Dyad Characteristics (n=24 relationships)
Relationship (PWE/PSP), n (%)	
Child/Parent	13 (54.2)
Spouses	7 (29.2)
Other Family	3 (12.5)
Friends	1 (4.1)
Live in Same Household, n (%)	
Yes	20 (83.3)
No	4 (16.7)

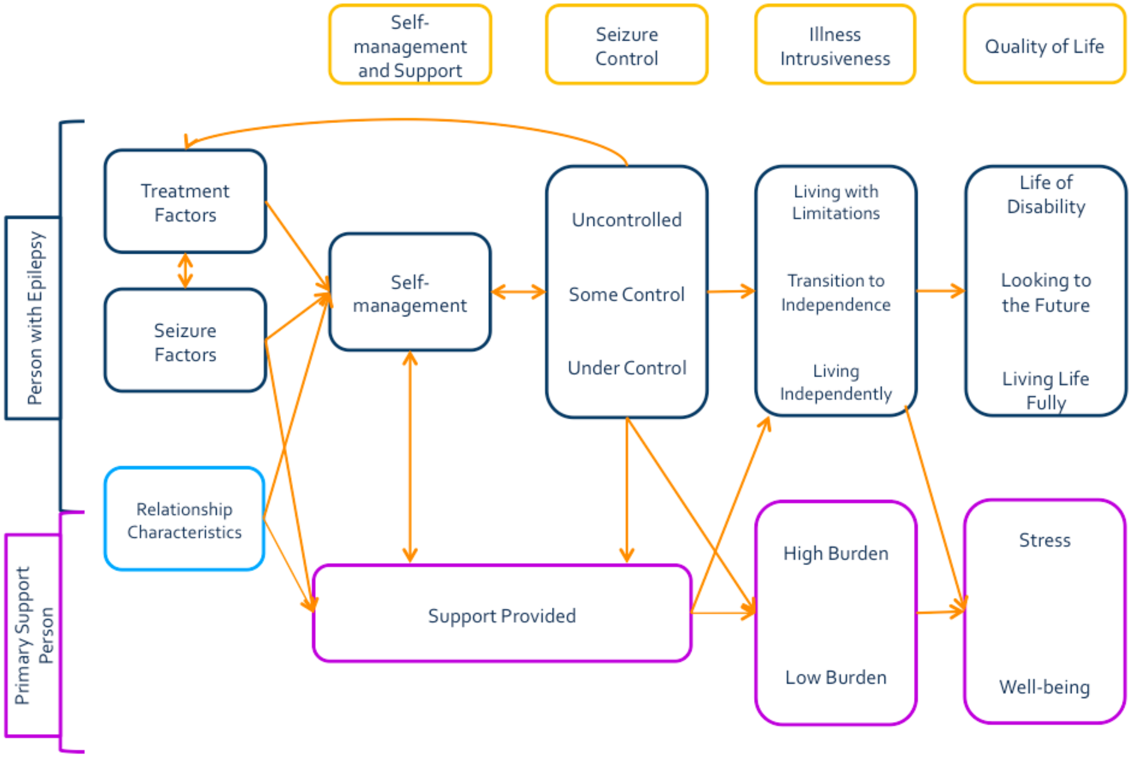
Table 2.2 Trajectories of people with epilepsy

Description	Characteristics
Trajectory 1: Technically disabled	
• Uncontrolled seizures • High illness intrusiveness • Outlook of disability	• 10 pairs • Variety of relationship types
Trajectory 2: Trying to get back to normal	
• Uncontrolled seizures • High illness intrusiveness • Looking to “normal” life in the past • Uncertain future	• 2 wife/husband pairs • Diagnosed with epilepsy within past 3 years
Trajectory 3: On her own	
• Uncontrolled seizures • High illness intrusiveness • Future plans to live independently	• 3 daughter/parent pairs
Trajectory 4: Moving to adulthood	
• Uncontrolled seizures or seizure free • Low to mid illness intrusiveness • Transition to more independence	• 4 son/mother pairs
Trajectory 5: How to be independent with this	
• Infrequent seizures or seizure free • Low illness intrusiveness • Living independently	• 5 pairs • Variety of relationship types

Table 2.3 Trajectories of primary support persons

Description	Characteristics
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	

Figure 2.1 Dyadic model of living with epilepsy



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Chapter 3:

The continuum of support for self-management: Qualitative analysis of perspectives of adults with epilepsy and their support persons

Abstract

Social support is an important mechanism for improving self-management, although little is known about its role in epilepsy self-management. The purpose of this qualitative study was to examine the type of support provided to people with epilepsy and its effect on self-management. In-depth interviews were conducted with 22 people with epilepsy and 16 support persons, representing 14 complete pairs and 10 unpaired individuals. Data analysis was guided by a modified constant comparison approach, commonly part of grounded theory. Salient themes and relationships between these themes were explored. Support persons, 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 development, relationship type, and the dynamics between the person with epilepsy and support provider. Seizure control also 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.

Introduction

People with chronic conditions must manage complex behaviors and practices in order 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 non-adherent to medical recommendations, with higher rates of non-adherence for lifestyle changes, such as exercise and diet, compared to more specific and narrowly-defined behaviors, such as taking medications (DiMatteo, 2004b). Non-adherence 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 a myriad of 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 mechanism of overcoming these barriers and improving self-management. Social support 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 through the provision of 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, such as medication taking and stress management, naturally involve individuals beyond the patient because these behaviors take place in a shared environment and in the context of relationships (Rosland, 2009). In a survey of adults with diabetes or heart failure, 75% of respondents 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 and direct help for taking medication, eating healthy, exercising, and going to doctor appointments (Gallant, Spitze, & Prohaska, 2007; Rosland, Heisler, & Piette, 2012; Trief, 2003). Support from family and friends is associated with better self-management and health outcomes (Franks et al., 2006; Rosland et al., 2010; Rosland et al., 2012), particularly when it is encouraging, focuses on enhancing patient autonomy, or fosters family cohesion (Rosland et al., 2012). Conversely, support is perceived as unhelpful or may lead to poorer self-management when it is critical, overprotective, nagging, or controlling (Bressi et al., 2007; Gallant et al., 2007; Rosland et al., 2010; 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, Trief and colleagues (2003) reported that teamwork and helpful communication were key elements of spouses working together on diabetes self-management. 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 emerged as key themes in qualitative studies; adults with chronic conditions felt strongly about being able to be in charge of their self-management (Gallant et al., 2007; Trief, 2003).

As evidence of the impact of family and friends on an individual’s self-management grows, there are a couple of gaps in the literature that warrant study. First, the experiences of support persons are not often reported in the literature. Quantitative studies usually measure support perceived by individuals with chronic conditions (Rosland et al., 2010; Rosland et al., 2012), though Franks and colleagues (2006) examined how spouses’ reports of health-related support and control influenced cardiac rehabilitation patients’ reports of health behaviors and mental health. Spouses or other support persons are sometimes included in qualitative studies on chronic disease management (e.g. Tapp, 2004; Trief, 2003), though often the focus is on what support is provided and does not offer insight into how they feel about or respond to the support they provide. Second, the literature focuses on a few disease conditions, mainly diabetes, heart disease, and arthritis. Further study of other conditions can contribute to the understanding of similarities and differences of support experiences across chronic conditions. To address these gaps, we sought to explore support for epilepsy self-management from the perspectives of both people with epilepsy and their primary support persons.

Epilepsy, a common neurological condition affecting almost 3 million Americans (Centers for Disease Control and Prevention, 2007), requires significant management in order to prevent seizures. People with epilepsy (PWE) 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). Similar to individuals with other chronic disease, about 30% of PWE are non-adherent to their medication regimens (Hovinga et al., 2008).

Support may be particularly important for improving PWE'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), may impede a PWE's ability to take medication as prescribed or reduce exposure to triggers. Although there is little research on the support PWE receive for self-management, some initial evidence indicates that caregivers 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). PWE whose relatives show warmth reported better medication adherence compared to PWE 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. Both the social ecological model and SCT acknowledge the influence of factors outside of the individual on health and behaviors. 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). Theories of social support posit that social support directly and indirectly affects health (Heaney & Israel, 2008). 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, on health (Cohen, Underwood, & Gottlieb, 2000; Heaney & Israel, 2008; Turner, 1999).

To explore the role of support for epilepsy self-management we used qualitative methods to answer two research questions: 1) What types of support for self-management do PWE receive from their primary support persons (PSP)? 2) How do PSP influence PWE's self-management behaviors?

Methods

Design and Study Procedures

This study draws on the qualitative portion of a mixed methods study that included a quantitative phase followed by a qualitative phase (Creswell & Clark, 2007). The purpose of the overall mixed-methods study was to examine the interpersonal relationship between PWE and PSP and the effect of that relationship on self-management and mental health. This study focused specifically on the types of self-management support provided by PSP and the effects of that support.

People with epilepsy were recruited from a hospital-based epilepsy clinic between April-November 2011. PWE were eligible if they: 1) were 18 years of age or older, 2) had a diagnosis of epilepsy for at least 3 months, 3) could identify a primary support person, and 4) spoke and read English. Eligible PWE referred their primary support person, who was defined as a non-paid individual who provided or who would be most likely to provide support to the PWE. Eligibility criteria for PSP included: 1) being 18 years of or older, 2) provided unpaid assistance to a person with epilepsy, and 3) spoke and read English. Individuals were not eligible if they did not have the cognitive ability to independently provide consent. Healthcare providers at the epilepsy clinic informed patients about the study and referred interested patients to the research team. One researcher (EW) explained the study in detail, determined eligibility, and obtained written informed consent. Emory University's Institutional Review Board approved all study procedures.

Data Collection

Phase 1. All participants completed a short survey over the phone. The survey included scales that measured self-management, support for self-management, depressive symptoms, and quality of life, and questions on demographic characteristics. Results of this phase will be reported elsewhere.

Phase 2. After completing the survey, a subset of participants was invited to take part in an in-depth interview. Because pair members were surveyed separately from their partners, the invitation to do an interview was sometimes offered before the surveys from both members of the dyad were complete. We expected that epilepsy experiences, self-management, and support would vary across dyads due to the heterogeneous nature of the condition. Therefore, we used purposive sampling in order 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 in Phase 1 were used to help identify individuals who could provide a variety of viewpoints.

PWE and support persons independently completed telephone interviews that lasted, on average, 45 minutes. Data collection by telephone was chosen because PWE often experience transportation limitations because they cannot legally drive in the state of Georgia if they have had a seizure within the past 6 months (Epilepsy Foundation, 2012). The benefits of telephone interviewing include ease of access and flexibility in scheduling because participants can take part from their own homes. A potential drawback of telephone interviewing is the absence of visual cues and nonverbal responses; however, attention by the researchers to establishing rapport and to participants' intonation and verbal cues, such as hesitations and sighs, can compensate for not being there in person. Telephone 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.

A semi-structured interview guide was developed, based on the literature, the guiding conceptual model, and research questions, to capture five domains: experiences with epilepsy, effects of epilepsy on the PWE’s and PSP’s lives and relationship, characteristics of their interpersonal relationship, support provided to the PWE, and support specifically for self-management. Parallel questions were asked of PWE and PSP. For example, PWE were asked, “How does [PSP] help you with managing your epilepsy?” whereas PSP were asked, “What do you do to help [PWE] manage his/her epilepsy?” Probes were used to prompt the participants to provide additional information, examples, or deeper explanation.

All interviews were audio-recorded, de-identified and labeled with a unique identification number, and transcribed verbatim by a professional transcriptionist. Upon receipt of the transcripts, the first author reviewed them with the audio to ensure accuracy and become more familiar with the narratives.

Data Analysis

Data analysis was guided by the constant comparison method commonly used in grounded theory (Boeije, 2002; Corbin & Strauss, 2008). A codebook was developed through deductive and inductive approaches. First, a list of potential codes was developed as determined by the interview guide questions. Then the first and second authors independently coded six transcripts (3 PWE/PSP pairs) by applying the codes identified a priori and through open coding, which involved adding new codes that identified additional concepts relevant to the research questions. An initial codebook was developed from these codes. To ensure intercoder reliability, two researchers (ER and CB or RM) independently coded all transcripts. After approximately every 6-10 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 was completed by hand. Subsequently, the qualitative software package, MaxQDA, was used for data management and coding. All transcripts were uploaded into MaxQDA, the codebook was entered, codes were applied to the interviews based on the hand coding, and memos were attached to codes or particular quotes. Retrieval of coded segments across interviews facilitated comparisons in order to ensure that each segment fit within the code and to identify dimensions of the code. As coding progressed, relationships between codes were denoted through axial coding. Analytic memos were written throughout the coding process to explore the relationships between themes. This analysis focused on the categories of self-management, support for self-management, relationships, and seizure control and the five to eight sub-codes specifically related to each of these main themes. Direct quotes from participants are included to illustrate main themes. The speakers of each quote in the results and table are identified as being PWE or PSP and by their relationship in the pair. For example, (PWE, wife) indicates that the quote is from a wife with epilepsy.

Results

A total of 38 individuals completed in-depth interviews (22 PWE and 16 support persons). These participants comprised 14 complete pairs, 8 additional PWE, and 2 additional support providers. Overall, the majority of participants was female, white, lived with family, and completed at least some college (see Table 1). Most PWE were single and not working, whereas most support providers were married and worked full-time. The most common relationships between the PWE and support persons were child/parent and spousal. The majority of PWE had uncontrollable seizures, several achieved some control through medication but experienced infrequent seizures, and 4 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 in PWEs' and PSPs' experiences. 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 PSP were involved in managing the PWEs' epilepsy.

Self-management Behaviors

All of the PWE managed their condition to some degree. The self-management behaviors described fell within the five main categories of epilepsy self-management: medication, trigger, symptom tracking and reporting, treatment, and information (see Table 2). Seizure control was the goal of self-management for both PWE and PSP; they felt that once seizures were under control, the negative effects of epilepsy on their lives would lessen and quality of life would improve.

All of the PWE were taking anti-epileptic medications. Most individuals had a routine for taking daily medication that often included the use of pillboxes, alarms, or reminders from PSP. Non-routine medication management occurred when the PWE was traveling or when deciding to take as-needed medication before or after a seizure.

Almost all of the PWE also tried to reduce their exposure to seizure triggers; thus joint management of medication and triggers was common. PWE who knew what caused their seizures worked to minimize their exposure to these triggers, such as reducing stress, making sure to get enough sleep, and avoiding certain lights or foods. Some PWE who did not know what triggered their seizures were also engaged in trigger management in the hopes that it might have an effect, as evidenced by the quote below.

> We don't know what to do and what not to do. We do know that people tell us that a lack of sleep can bring on seizures, so she's taking one of the things that the doctor there recommended, one of these little herbal type medicines to help her sleep, but, you know, if we knew running up Stone Mountain would cure the seizures we'd be running every day, you know (PSP, husband).

All of the PWE also met regularly with their neurologist to monitor seizures and medications. Less commonly, PWE kept a log of when their seizures occurred in order to inform neurologists about frequency and severity and aid in identifying possible triggers. A few PWE also mentioned that they search for information about seizures and self-management to learn more and keep updated on new treatments.

Self-management Support

Support persons aided PWE across all five categories of epilepsy self-management (see Table 2). Two main categories of support emerged from the participants’ interviews: Helping behaviors and active managing behaviors. Helping behaviors involved reminding PWE about various self-management tasks, such as taking medications, relaxing, remembering upcoming doctor’s appointments, monitoring PWE to make sure they took medication, tracking when seizures occurred, and providing emotional support. PSPs' active managing behaviors involved support persons performing self-management tasks for the PWE. Examples of support persons' active managing behaviors included filling a pillbox for the week, calling in and picking up medication refills, and making doctor's appointment.

Self-management Continuum

PSPs were involved in managing the PWE's epilepsy to differing degrees. The amount of involvement spanned a continuum marked at one end by PWE-led management, the middle by joint management, and the other end by PSP-led management. Figure 1 displays where each pair fell along self-management continuum. Most of the pairs fell on the PWE-led side of the self-management continuum, though almost a third were on the PSP-led side. Three pairs fell under joint management. Influential factors in the placement of pairs along the continuum included gender, relationship type, and relationship dynamics. Degree of seizure control did not determine a pair's location along the continuum; however, seizure control was an important factor in shaping experiences within each group. The patterns of support for self-management, as well as the positive and negative aspects of receiving and providing support, are described below for PWE-led management, joint management, and PSP-led management.

PWE-led Management

In PWE-led management, the PWE was primarily responsible for the management behaviors and strategies and the PSP provided support as needed or wanted by the PWE. Thirteen pairs were classified under PWE-management; these pairs represented a variety of relationship types, including almost all of the daughter/parent and wife/husband pairs. For eleven of these pairs, in which the PWE had infrequent to uncontrolled seizures, the main role of the PSP was “to have your back.” In the remaining two pairs, the PWE did not experience regular seizures and did not live with their PSP. They were almost completely self-reliant in managing their epilepsy.

Have your back. This group was comprised of four daughter/mother pairs, three wife/husband pairs (though only the wives completed interviews), and one each of the following pairs: friends, siblings, mother/daughter, and daughter/father. Women with epilepsy made up the majority of PWE in this group; the two males were the only men to have male PSPs, a brother and a friend. The PWE in this group did not have fully controlled seizures; a few PWE had infrequent seizures, but most had frequent and unpredictable seizures. Despite the lack of total seizure control, all of these PWE took their medication as prescribed and avoided seizure triggers. Several PWE also kept a log of when they had seizures or searched for information about epilepsy.

PWE mainly received helping support that was fairly minimal, but consistent. This helping support involved reminders about trigger management (e.g. going to bed on time) and/or reminders about medication taking, often when the PWE was in non-routine situations such as being away from the house.

> And so she kind of helps me stay on the right path. You know, not stay up too late or forget to take my medication, things like that… So I’m very thankful. Over the years, I’ve pretty much learned to do what I need to do, but if for some reason I would forget, she would handle it for me (PWE, mother).

The PSPs' support was a reinforcement to the PWEs' daily routine of self-management; several PWE mentioned that their PSP "have [their] back" in making sure that they did what was needed to manage their epilepsy. The PSP, including the mother quoted below, described stepping in if they saw the PWE forgetting to take their medication or stay up to late.

> If I see her sometimes at night, and she, sometimes she loses awareness of what time it is, I'll kind of remind her, you know, such and such of time, so she knows she needs to get to bed and that type of thing. That's 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. So, I just try to help her that way… I feel like I'm trying to, you know, to try to help her as much as I can, and 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 (PSP, mother)

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

The PWE described both positive and negative reactions to the support they received. They were grateful for both the self-management support and the emotional support from their PSPs. However, reminders from PSPs could also be frustrating and annoying, particularly when the PWE knew that they needed to do these behaviors and often had already done them or were about to do them when the PSP 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, like, '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. It's like, I'm thirty-two years old, just calm down a little (PWE, daughter).

Some PWE, particularly those who had uncontrolled seizures, felt frustrated that they were not more independent from their PSP. As one woman said,

> Sometimes it makes me feel a little…almost 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 (PWE, daughter).

The PSPs did not express the same frustrations with providing reminders and support; 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 (PSP, father).

For PSPs, the main benefits for providing support were the satisfaction of providing help and showing their love.

Self-reliance. The two pairs in this group, one daughter/father pair and one sister/brother pair, experienced support differently from the other pairs who fell under PWE-led management. The sister experienced only two seizures in her life, and the daughter's seizures were controlled as long as she took her medication as prescribed. Due to the control over their seizures, both women had very self-sufficient lives; they lived on their own and worked full-time. While they were very close to their PSPs and talked to them often on the phone, they did not spend as much time with the PSPs on a daily basis compared to the other PWE 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 PSPs to take their medication, the main type of support they received was emotional. One PWE said of her brother, "I know he's always going to be there." The daughter with epilepsy said, "I don't feel like I'm alone. I think that's probably most important." Her father appreciated her openness with him about when she had seizures.

> I do get satisfaction that she's taking care of herself, when she tells me she's doing things. So I guess it's satisfaction and I feel good that she's protecting herself and she's moving on in life and she's standing on her own two feet (PSP, father).

Joint Management

Three spousal pairs were classified as jointly managing the PWEs' epilepsy: two husband/wife pairs and one wife/husband pair. Joint management was characterized by the spouses working together to manage epilepsy. These pairs often used the pronoun "we" when discussing self-management activities and one wife described her and her husband as a "team." Additionally, all of the PWE stated that communication was an important element of the relationship. As one spouse said,

> Communicate, communicate. Basically just me and the missus here in the house most of the time and I try to communicate with her what would be best for us and listen to her. That's the main thing and hopefully she respects my ideas and thoughts and opinions as I do with her, but, you know, communication has to be a two-way street (PWE, husband).

All of these PSPs engaged in a combination of helping and active managing behaviors – they reminded the PWE to take medication, monitored medication taking, sometimes called in or picked up medication refills, helped PWE avoid triggers, and drove PWE to doctors' appointments.

> 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 thing (PSP, husband).

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

The experiences of providing and receiving support varied depending, not surprisingly, 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 involved taking medication and getting enough sleep. His wife helped him to manage both his epilepsy and diabetes. His description illustrates the enmeshed nature of her support for these two 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 cooking right. And she walk with me too some (PWE, husband).

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.

> It all has blended in with daily life. It don't stress me out. It don't get to me. It don't make me angry to make sure he take his medicine. I just include it as part of my daily life…There's no stress, no nothing. It's good (PSP, wife).

The other two couples dealt with the PWE having uncontrolled epilepsy. The PWE and PSP in both pairs were active in medication and trigger management, even though one couple did not know what caused the wife's seizures. Benefits of support included improved self-management by ensuring that medication was being taken properly and helping to identify seizure triggers, as indicated in the quote below.

> Well, just taking care of and making sure I'm all right and like I 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 (PWE, wife).

Both PWE were “grateful” and “thankful” for the support from their spouses. The husband with epilepsy appreciated his wife’s support, though it bothered him to see the burden that was placed upon her.

> It’s awesome and it’s wonderful and…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, just, just tired. 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 (PWE, husband).

His wife also mentioned that she was tired, “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 a difficulty for the husband of a woman with uncontrolled seizures.

> 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 (PSP, husband).

However, for both of these PSP, providing support was seen as part of their role as “being a good wife” or husband, as suggested in the following quote.

> It wouldn't be fair to complain, not that, you know, that's just one of those things.

> I married her knowing she had seizures…but I loved her and the disease was not going to be a hindrance from us getting married (PSP, husband).

PSP-led management

In PSP-led management, the PSP took on majority of management behaviors for the PWE. The pairs fell into two groups based on two emergent reasons the PSP took primary responsibility for management; one reason was related to seizure control, the other to relationship type and gender. The first group included four pairs in which the PWE were "essentially incapacitated" by uncontrolled seizures. This group included a variety of relationship types: two daughter/mother pairs, one son/mother pair, and one wife and husband. The second group was comprised of four young adult sons with epilepsy and their mothers who were all negotiating the sons' transition to adulthood. This process involved the sons taking on more independence and the mothers "letting go."

Essentially Incapacitated. The four PWE in this group experienced uncontrolled and severe seizures that impeded their ability to perform self-management behaviors on their own. Their epilepsy was caused by brain damage (traumatic brain injury in two cases and infection in two cases), making it unlikely that the PWE would be able to manage completely on their own in the future. These individuals described lingering effects (e.g. tiredness, confusion) and long-term effects (e.g. memory difficulties) from their seizures. While the PWE were involved in managing their epilepsy, the PSPs took the main role. Most commonly, the PSPs managed medication to make sure that PWE took the proper dose and attended doctor's appointments in order to let the neurologist know what was going on. They also provided reminders to the PWE about getting enough rest or not to over-exerting themselves.

> She’s been confused lately, so she used to take her medicine by herself, but it was kind of like you took a pill in the morning and you took one at night. But lately since they’re changing her medicines, it seems like she can’t quite get how that’s supposed to be done. And I didn’t realize that. So it took me a couple times…let me put it in a pill box and then we’ll both try to remember it and take it together where you can check me and I can check you and make sure we’re taking it right, right now (PSP, mother).

Similarly,

> 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.” (PSP, husband)

All of the PWE expressed conflicting emotions regarding the support they received from their PSPs. 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.

> It’s a double-edged sword because in one way, to be selfish, I love it, you know. It’s a validation of how much he loves me and how much he wants me to be better and how strong our relationship is but on the other hand, I have always been an

> extremely independent person. I don't like people managing my life (PWE, wife).

Another woman said,

> I get aggravated because she's [her mother] 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 (PWE, daughter).

Only two of the PSPs 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 their PWE in case of a seizure and then provide support when a seizure did occur. The mother, whose daughter was diagnosed with epilepsy 11 years ago, said that providing support can be "strenuous" and "time-consuming."

> 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... (PSP, mother).

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.

> So essentially, I have a kid now, and it's not what I – 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 (PSP, husband).

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

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 PSP needed to do most of the managing. It became normal and routine for the PSP to continue managing their sons' epilepsy, including such tasks as setting out pills, refilling medication, and making doctor's appointments. In addition, three of the PWE had other conditions (autism, schizophrenia and diabetes, and a heart condition) that required the PSP to be particularly involved in their sons' care. As one mother described it,

> Because this all began at an age when, you know, for the most part, I managed his entire life. So…it feels normal. It's been so long with the heart—he has a heart condition also. Between the heart and the seizures, you know, there's been a lot of doctors and a lot of all that, and a lot of medical tests since he's been 12. So it doesn't—it just feels like what a parent would do. It feels completely normal (PSP, mother).

Similar to other PSP, 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 manage their sons' epilepsy because that is what they had always done and because they felt the sons would not do it themselves.

> 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. And if I felt that he had needed to take his medicine, I sometimes have to browbeat him, you know, or did… 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. You know what I'm saying? (PSP, mother)

As described below, the mothers seemed to be waiting for their sons to take the lead on both 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 (PSP, mother).

Discussion

We examined the perceptions of people with epilepsy and their support persons regarding the types of self-management support received and provided and how that support influenced self-management. The case of epilepsy provides an example of perceptions of and factors that are important to support for self-management of chronic conditions. The experiences of our participants clearly show that the person with a chronic condition rarely undertakes self-management on his or her own; rather, in most cases, the support person is actively involved in management. Self-management behaviors become integrated into the daily lives of both PWE and PSP.

While some definitions of self-management focus on the individual with the chronic condition or the patient and their healthcare provider (Clark, 2003), other definitions also include family members and other caregivers (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009). Our participants' experiences support a definition of self-management that includes support persons. Several models of self- and family-management of chronic conditions depict the factors affecting management and the outcomes for both patients and families. The basis for these models is that chronic disease management is a dynamic process requiring both individuals and families to incorporate health-related behaviors into their daily lives (Dunbar et al., 2008; Grey et al., 2006; Ryan & Sawin, 2009).

Our results further the conversation on self- and family-management by introducing the idea of the self-management continuum. We found that role of PSP in managing PWE's epilepsy ranged from minimal involvement (PWE-led management) to taking the lead (PSP-led management). The location of the PWE/PSP dyads on the management continuum depended mainly on the relationship and dynamics between the PWE and PSP, gender of the PWE, and patterns of support that developed over time.

A clear gender divide emerged along the continuum, where most of the women, particularly daughters, fell under PWE-led management, unless they experienced severe impairment from seizures. Conversely, all of the sons fell under PSP-led management. The apparent gender differences for adult children with epilepsy appear to be influenced by the transition into adulthood. Daughters were farther 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 of the sons' self-management. One possible explanation for this difference is that the daughters were, on average, slightly older than the sons. Alternatively, there may be an expectation for 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 may help or hinder the adolescents or young adults in assuming independence and responsibility for their heath. Parents play a key role in fostering autonomy in their children, which may be necessary for successful self-management (Hanna, 2012; Sable et al., 2011). Further research is needed to understand this process and the long-term implications for self-management and health outcomes for PWE.

There was variation in the location of spouses along the management continuum. Three spouse pairs fell under PWE-led management, three spouse pairs were under joint management and one spouse pair was under PSP-led management. Spouse pairs were the only relationship type represented in joint management, likely because a “team” approach is more common in a spousal relationship in which the partners are on equal footing, compared to the hierarchy of a child/parent relationship, and are living closely together, compared to the siblings or friends. The collaborative nature of joint management is similar to the interactional routines described by Corbin and Strauss’ (1988) study of chronically ill individuals and their spouses; likewise, the supportive and motivational role of spouses in PWE-led management echoes their description of complementary roles. During stable phases of chronic illness, spouses, as well as the other PSP in our study, are engaged in the development and maintenance of routines that balance management activities with everyday tasks (Corbin & Strauss, 1988).

The idea that providing support for epilepsy management was an integral part of the PSP’s role as parents, spouses, and friends emerged in all of the groups across the management continuum. Many PSP felt that support was not a burden because it was a part of their role in the PWE’s life. Some PSP embraced this aspect of their role as a way to express love to their PWE. However, a couple of PSP felt that their role as a husband or child obligated them to care for their PWEs, or at least to stifle any complaints or negative reactions. In a qualitative study of partners facing multiple sclerosis, Boije and colleagues (2003) described how the bonds between spouses can contribute to positive commitments to caregiving out of love for their partner or feelings of obligation that cannot be escaped.

A few individuals struggled with adapting to a role as a supporter. Becoming a caregiver can be overwhelming, especially when the care recipient is debilitated, because responsibilities – to care for the recipient, complete everyday tasks, and take on responsibilities normally completed by the recipient – increase and the relationship between the caregiver and recipient can shift (Plank, Mazzoni, & Cavada, 2012). The strain of caregiving has been widely documented and contributes to depressive symptoms in both the care recipient and caregiver (Dunbar et al., 2008; Rees, O'Boyle, & MacDonagh, 2001; Sebern & Whitlatch, 2007). Westphal-Guitti and colleagues (2007) found that caregivers of PWE who were entirely responsible for medication reported higher burden and poorer mental health and quality of life than other caregivers.

Another cross-cutting theme was the participants' description of both positive and negative aspects of providing and receiving support. There is ample evidence in the literature about the helpful and unhelpful ways in which primary support persons influence chronic disease self-management. Our results align with prior findings indicating that support aids individuals in taking medication and the maintaining the lifestyle changes, such as eating healthy and sleeping well, necessary for managing their condition; however, support is viewed negatively when the people with disease feels like they are being nagged or their autonomy is challenged (Gallant et al., 2007; Rosland et al., 2012; Trief, 2003). Many of the PSPs in this study also identified benefits and drawbacks of providing support. The benefits included being able to express love, being there for the PWE, and fulfilling their role as a spouse, family member, or friend. Negative aspects included the burden of support in time, energy, and resources.

Although the perspectives of family and friends who support individuals managing chronic conditions about their own reactions to support is lacking, the experiences of the PSPs parallels that of caregivers of individuals with more debilitating conditions (Ohman & Soderberg, 2004; Plank et al., 2012; Rees et al., 2001).

The management continuum reflects the diverse management and support needs of PWE. Many of the experiences and perspectives about self-management and support expressed by our participants are not specific to epilepsy. People with a variety of chronic conditions and their caregivers monitor symptoms, communicate with healthcare providers, assist with medication, and provide emotional support (Boutin-Foster, 2005; Gallant et al., 2007; Trief, 2003). However, one way in which experiences with epilepsy may differ from those with other chronic conditions is the fact that faithfully maintaining a self-management regimen does not insure that the PWE will be seizure free. Although the majority of PWE can achieve seizure control by taking medication and avoiding triggers, about a third of individuals continue to experience uncontrolled seizures (Devinsky, 1999). The majority of PWE in our study had uncontrolled seizures, which is common for patients at a hospital-based epilepsy clinic. Both PWE and support providers expressed a desire for PWE to be seizure-free and frustration in not being able to obtain that goal, despite significant efforts. Seizure control, however, did not determine where a pair fell along the management continuum, though it did shape experiences within groups. Individuals with uncontrolled seizures within each group received more support – instrumental, seizure, and self-management support – compared to those with controlled seizures. The support helped these PWE to deal with the debilitating effects of having seizures and the resulting disruptions to their lives, such as not being able to drive.

Several factors could cause the dyads to move along the continuum. First, a worsening of seizure control could cause PWE to rely more heavily on their PSP, whereas improved seizure control, such as through medication change or surgery, could result in PWE taking the lead on their self-management. Second, as young adult children transition further into adulthood, they may assume more responsibility for their management; likewise their parents may relinquish their control and let go of the tasks that the PWE can do for themselves. Finally, a change in relationship or a change in PSP, which could be caused by such events as marriage, divorce, or death, could lead to movement along the continuum, as new self-management routines are negotiated and established. Additional research, particularly longitudinal in nature, is necessary to determine how and when movement along the continuum occurs and the impact on overall self-management.

Limitations

While every effort was made to interview both members of the PWE/PSP 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 PSP; therefore the perspectives of other supportive individuals who also may be instrumental in a PWE’s self-management were not included. Additionally, PWE who did not have a PSP 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, PWE were recruited from a tertiary epilepsy clinic; therefore they may experience more severe or intractable seizures compared to PWE in the general population.

Implications

This study has implications for theory, research, and practice. First, the self-management continuum provides a new aspect that can be integrated into existing models of self- and family-management. We expect that the continuum could also be applied to individuals with other conditions and their support persons. Future research could determine the extent to which the continuum works for other conditions and the 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 patient/supporter dyads along the self-management support continuum 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, healthcare providers and self-management programs should involve support persons and facilitate discussion about desired and optimal support for the patient. These conversations should involved aspects of life beyond the chronic illness that affect self-management, such as a young adult's transition to becoming an autonomous adult.

Table 3.1 Demographic characteristics of interview participants (n=38)

	People with Epilepsy (n=22)	Primary Support Persons (n=16)
Relationship, n (%)		
Adult Child	11 (50.0)	1 (6.3)
Parent	1 (4.5)	10 (62.5)
Spouse	7 (31.8)	4 (25.0)
Sibling	2 (9.1)	-
Friend	1 (4.5)	1 (6.3)
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)
Hispanic	1 (4.5)	-
White	16 (72.7)	11 (73.3)
Multiracial	-	1 (6.7)
Marital Status, n (%)		
Married	6 (27.3)	10 (62.5)
Single	13 (59.1)	3 (18.8)
Separated/Divorced/Widowed	3 (13.5)	3 (18.8)
Living Situation		
Alone	3 (13.6)	1 (6.3)
Immediate family	17 (77.3)	15 (93.8)
Friend, roommate, partner	2 (9.1)	-
Education		
High School or less		
Some college or currently in	5 (22.7)	2 (12.5)
college	7 (31.8)	1 (6.3)
Graduated college or more	8 (33.5)	12 (75.1)
Other program (e.g. technical)	2 (9.1)	1 (6.3)
Employment Status, n (%)		
Full-time	5 (22.7)	9 (56.3)
Part-time	-	2 (12.5)
Student	3 (13.6)	-
Retired	1 (4.5)	4 (25.0)
Unemployed	5 (22.7)	1 (6.3)
On disability	6 (27.3)	-
Other	2 (9.1)	-
Age (years)		
Range	21-59	18-65
Mean (SD)	33.50 (9.78)	50.12 (12.65)

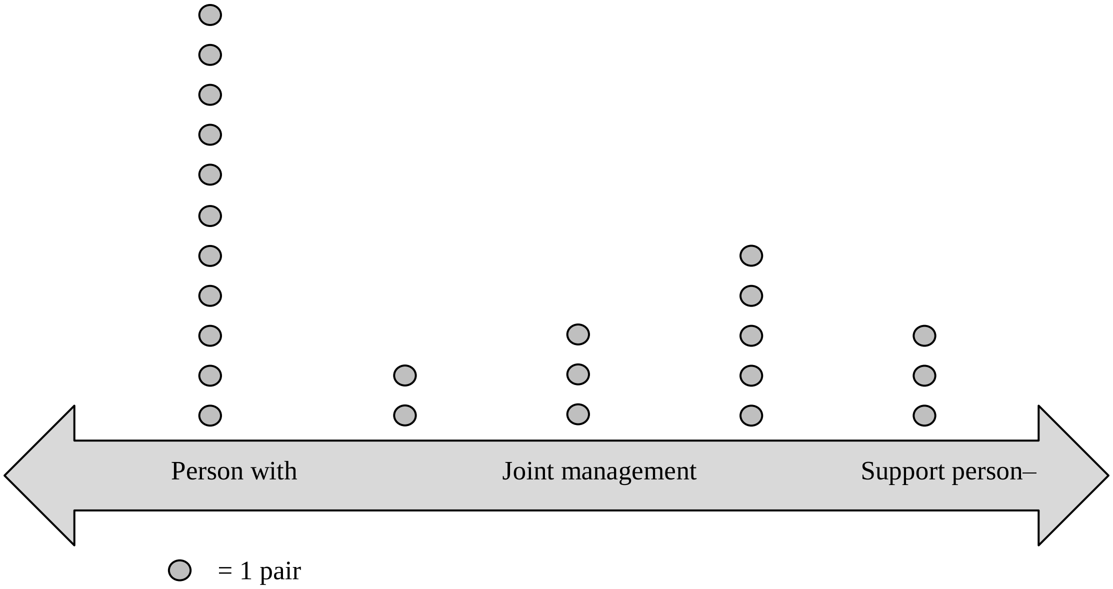
Seizures in the past 4 weeks		
Range	0-6	-
Mean (SD)	1.76 (2.21)	-
Years since Epilepsy Diagnosis		
Range	.3-39	
Mean (SD)	17.7 (9.22)	

Complete pairs: 14 Incomplete: 8 PWE; 2 PSP

Table 3.2 Self-management behaviors and supports

Self-management Categories	Person with Epilepsy – Managing Behaviors	Support Person – Helping Behaviors	Support Person – Active Managing Behaviors	Illustrative Quotes
Medication management	• Reminders (e.g. Alarm) • Pillbox • Refills	• Reminders • Monitoring	• Setting out medication • Pillbox • Refills	• "She does remind me, especially if we're out…So in that case, that is helpful." (PWE, daughter) • "I remind her, you know, to take the right medications. Sometimes she'll like take it and then forget and then like OD…So she'll try to take it again, and I'll be like, no, no, you took it." (PSP, daughter)
Trigger management	• Stress management and relaxation • Sleep routines • Resting, avoiding overexertion • Avoiding foods or stimuli (e.g. flashing lights)	• Reminders (e.g. sleep, stress, avoiding stimuli) • Emotional support • Stress management support		• "Well I try to ensure that she gets proper sleep, proper rest, not to overdo herself, not to worry." (PSP, husband) • "If I see her sometimes at night, and she, sometimes she loses awareness of what time it is, I'll kind of remind her…so she knows she needs to get to bed..." (PSP, mother)
Symptom tracking and reporting	• Seizure log • Symptom and side-effect monitoring	• Symptom and side-effect monitoring	• Seizure log	• "…he has every single seizure I've ever had in his...cell phone…So when we have to answer questions about it, he has that, you know?" (PWE, wife)
Treatment management	• Making and going to appointments • Communication with neurologist • Making medical decisions	• Appointment reminders • Driving PWE to appointments • Going to appointments • Discussing and supporting medical decisions	• Making appointments • Communication with neurologist • Making medical decisions	• "…I don't know I'm having my seizures. She's the one that sees it and is just like, ok, no, this shouldn't be happening. She is the one that will go and call the doctors and see what is going on and what we should do to make it better." (PWE, daughter) • "Well I lived at home for a while so she was taking me to the doctor." (PWE, son)
Information management	• Finding information on symptoms, management, treatment	• Discussing information with PWE	• Finding information on symptoms, management, treatment	• "…she gets from the Epilepsy Foundation the little newsletter and brochure, and we both read that." (PWE, mother)

Figure 3.1 Self-management continuum



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Chapter 4:

A mixed-methods analysis of support for self-management behaviors: Perspectives of people with epilepsy and their support providers

Abstract

Social support is associated with improved self-management for people with chronic conditions, such as epilepsy; however, little is known about the perceived ease or difficulty of receiving and providing support for epilepsy self-management. We examined patterns of self-management support for people with epilepsy from the perspectives of both the people with epilepsy and their support persons. Fifty-three people with epilepsy and 48 support providers completed a survey on epilepsy self-management support. Of these individuals, 22 people with epilepsy and 16 support persons completed an in-depth interview. Rasch measurement models were used to evaluate the degree of difficulty of receiving or providing support for nine self-management tasks. We analyzed model-data fit, person and item location along the support latent variable, and differential person and item functioning. Qualitative methods were used to provide context and insight into the quantitative results. The results demonstrated good model-data fit. Help with seizures was the easiest type of support to receive or provide, followed by rides to doctor's appointments and help avoiding seizure triggers. The most difficult types of support to receive or provide were reminders, particularly for taking and refilling medications. While most participants' responses fit the model, responses of several individuals misfit the model. Person misfit generally

occurred because individuals' experiences were not adequately captured by the scale items. These results could be useful in designing interventions that use support as a means of improving self-management. Additionally, the results provide information to improve or expand current measures of support for epilepsy self-management to better assess the experiences of people with epilepsy and their support persons.

Introduction

People with chronic diseases, such as epilepsy, must employ strategies and behaviors to manage symptoms, slow disease progression, and maintain quality of life. Self-management behaviors for epilepsy include taking medication as prescribed, adjusting one's lifestyle to avoid seizure triggers, tracking seizures and side effects, attending doctor's appointments, and obtaining information on seizures, treatment, and management (DiIorio, 1997). Successful implementation and maintenance of self-management behaviors is difficult. Up to 40% of people with epilepsy (PWE) are considered non-adherent to their medications (Ettinger, Manjunath, Candrilli, & Davis, 2009; Faught, Weiner, Guerin, Cunnington, & Duh, 2009; Hovinga et al., 2008). Non-adherence can have serious consequences, including increased mortality and hospitalizations (Ettinger et al., 2009; Faught, Duh, Weiner, Guerin, & Cunnington, 2008; Faught et al., 2009), reduced seizure control (Hovinga et al., 2008; Manjunath, Davis, Candrilli, & Ettinger, 2009), decreased productivity, job loss, and motor vehicle accidents (Faught et al., 2008; Hovinga et al., 2008). However, PWE report greater self-efficacy for adherence to medication regimens than to other lifestyle behaviors, which is similar to individuals with other chronic conditions (DiMatteo, 2004b; Kobau & DiIorio, 2003; McAuley, McFadden, Elliott, & Shneker, 2008).

Social support is a key mechanism that aids individuals in managing chronic conditions (DiMatteo, 2004a; Gallant, 2003). For PWE, support is associated with greater self-efficacy for performing self-management behaviors (DiIorio et al., 2004; Robinson et al., 2008). Support persons provide reminders and monitor medication taking; assist PWE with strategies to help them take medication, reduce stress, and improve sleep; help before, during, and after seizures; and are key sources of emotional and instrumental support (Walker, Bamps, Burdett, Rothkopf, & DiIorio, 2012).

Social support and social ties have long been recognized to contribute to positive health outcomes (Berkman & Syme, 1979; Hogan, Linden, & Najarian, 2002; van Dam et al., 2005). Low social support in the general population is linked with greater activity limitation and disability, depressive and anxiety symptoms, poorer self-rated health, and decreased satisfaction with life (Strine, Chapman, Balluz, & Mokdad, 2008). However, support is a complex and multifaceted concept. Measures of social support assess a wide variety of support dimensions, including different types of support, perceived or actual support received, satisfaction with support, importance of support, and/or the positive or negative aspects of support. Some types of support may be easier or harder to receive or provide, likewise some types of support may be more or less necessary, depending on the PWE and support person. Additionally, the support relationship may be affected the presence of depressive symptoms in PWE or the people who support them. Depression is associated with diminishing social support over time; people with depression experience a reduction in social network size and perceive less social support (Leskela et al., 2008). For the support person, a higher caregiving burden is associated with poorer mental health (Phillips, Gallagher, Hunt, Der, & Carroll, 2009; Pinquart & Sorensen, 2003; Rees, O'Boyle, & MacDonagh, 2001), which may in turn affect how support is provided. Little is known about these aspects of support for people with epilepsy, particularly from the perspective of the support person.

The purpose of this mixed-methods study was to examine patterns of self-management support for PWE from the perspectives of both PWE and their primary support persons (PSP). Specifically, our main aims were to evaluate: 1) Which types of self-management support are easier or harder to give and receive; 2) If the items functioned in the same way for both PWE and PSP and for individuals with elevated depressive symptoms compared to participants without depression. Secondarily, we evaluated the support for epilepsy self-management instrument to determine if it included a full range of support items.

Methods

Design and Sample

This study was part of a sequential, mixed-methods study that involved a quantitative phase followed by a qualitative phase. The purpose of the overall study was to examine the interpersonal relationship between PWE and PSP, and the effect of the relationship and support provided on epilepsy self-management. This analysis focuses on patterns of self-management support that emerged from the quantitative and qualitative data.

Following Institutional Review Board approval, participants were recruited from a hospital-based epilepsy clinic from April-November 2011. Inclusion criteria for participants with epilepsy included: 1) being 18 years of age or older, 2) having a diagnosis of epilepsy for at least 3 months, 3) being able to identify a primary support person, and 4) speaking and reading English. Eligible PWE were asked to provide the name and contact information of their primary support person, defined as a non-paid individual who provided or who would be most likely to provide support to the PWE. PSP were eligible if they: 1) were 18 years of age or older, 2) provided unpaid assistance to a person with epilepsy, and 3) spoke and read English.

Healthcare providers handed out fliers to interested patients, who could talk to the study staff in person at the clinic or call the number on the flier. The first author described the study to interested individuals and answered any questions. Participants had the option to complete the consent form in the clinic or at home and then return the form by mail. Data collection did not occur until the investigators had the signed consent forms.

Data Collection

Participants completed a 15-minute survey, which was administered over the phone. In addition to marking the participants' answers, the researcher wrote down comments offered by the participants to explain their answers. At the completion of the survey, individuals were recruited through purposive sampling to complete an in-depth interview. Participants were selected to represent a range of self-management levels, support levels, and depressive symptoms. Interviews lasted about 60 minutes and were conducted over the phone. Participants were asked about five main topics: experiences with epilepsy, effects of epilepsy on the PWE's and PSP's lives and relationship, characteristics of their interpersonal relationship, support provided to the PWE, and support specifically for self-management. All interviews were audio-recorded and transcribed verbatim. Participants received a $10 gift card for completing the survey only or a $25 gift card for completing both the survey and interview.

Measures

Self-Management Support. Frequency of perceived available support for assisting with the completion of epilepsy-related self-management tasks was measured using the Epilepsy Regimen-Specific Support Scale (ERSS; DiIorio, Hennessy, & Manteuffel, 1996). The nine items assessed support provided through reminders (reminders to take medication, eat healthy meals, get enough rest, refill medication, and be careful in case PWE has a seizure) and help (bringing PWE to doctor, when PWE has a seizure, and avoiding things that cause seizures). The items were rated on a 5-point Likert scale from *never* (1) to *always* (5). PWE were asked how often the primary support person provides the support, whereas primary support providers were asked how often they provide the support to the PWE. Additionally, the PWE and PSP were asked how often they think the PWE would like the support provider to give the support described in each of the items in the ERSSS.

Depression. The Center for Epidemiological Studies Depression Scale (CES-D) is a 20-item scale that was designed to assess current levels of depressive symptoms in the general population. Each item is rated on a 4-point Likert scale from *rarely occurs* (0) to *occurs most* or *all of the time* (3). Summed scores were dichotomized using the cut-off point of 16, which indicates probable depression (Radloff, 1977).

Demographic Information. Participants were asked to answer questions about their age, gender, race/ethnicity, marital status, living situation, education, employment status, and insurance status. PWE were asked how many seizures they had in the past 4 weeks and what type(s) of seizures they experienced.

Rasch Data Analysis

Descriptive statistics were run using SPSS v.19, and Rasch analyses were conducted using the Facets program v.3.70.1. The Rasch measurement model is an item response theory model that places individuals and items on a common metric so that they can be compared along a unidimensional latent variable. The probability of a person endorsing a particular response is determined by two factors: the person's "ability" and the item difficulty (Bond & Fox, 2007). In this analysis, the latent variable is self-management support; therefore, the person's "ability" refers to the amount of support received (for PWE) or provided (for PSP). The item difficulty indicates the level of difficulty in receiving or providing support more often.

A rating scale model was used because it is appropriate for polytomous data, such as scales with items that have more than two response options (Bond & Fox, 2007). The items from the ERSS, assessing both perceptions of support received and provided and perceptions of support the PWE would like to receive, were entered into the model. A facet was included for each of the following: participants' level of support, difficulty in endorsing an item, an identifier as being a PWE or PSP, and classification of having probable depression or not. The model can be written as follows:

$$\mathrm{Ln}[P_{nik}/P_{nki-1}] = \Theta_n - \delta_i - \alpha_1 - \Delta_1 - \tau_{ik}$$

where:

P_{nik} = the probability of participant n endorsing answer choice k on an item i,

P_{nki-1} = the probability of participant n endorsing answer choice $k-1$ on item i,

Θ_n = the level of social support for participant n,

δ_i = the difficulty of item *i*, and

α_1 = the group effect (PWE or support provider)

Δ_1 = the depression effect

τ_{ik} = the difficulty of responding in category k relative to k-1 on the rating scale

The Facets software provides a variable map, as well as summary and fit statistics for each facet. Location along the latent variable of support is estimated for each component of a facet. The person mean varies along the latent variable, whereas the other facets are anchored at zero to provide a frame of reference. Facet separation reliability indicates the overall separation, or spread, of the components in each facet. The person separation reliability coefficient is considered to be equivalent to Cronbach's alpha, a measure of the internal reliability of the scale, and is viewed as acceptable at values over 0.7 (Bond & Fox, 2007).

The fit of the model to the data is evaluated through Infit and Outfit statistics, which should fall within the range of 0.6 to 1.4. Values above 1.4 indicate that the data include greater variability than expected based on the model, whereas values under 0.6 indicate less variance than expected based on the model (Bond & Fox, 2007).

Person functioning was examined by identifying individuals with Outfit mean square statistics below 0.6 and above 1.4. For these participants, whose responses "misfit" the model, standardized residual plots were created to identify responses that contributed to the misfit with a standardized residual above 2.0 and below -2.0.

Differential Item Functioning (DIF) occurs when item location along the latent variable changes based on person sub-groups; in other words, when there is an interaction between items and sample characteristics (Zumbo, 1999). DIF analyses were conducted to determine if the items were ordered differently based on: 1) whether the individual was a PWE or support provider, and 2) whether or not the participant experienced high levels of depressive symptoms. Evidence of DIF can be found if the overall chi-square test is significant; if so, t-tests comparing the average scores between groups are examined.

Qualitative Data Analysis

Transcripts were uploaded into qualitative software (MaxQDA) for data management and analysis. Data analysis was guided by the constant comparison method commonly used in grounded theory (Boeije, 2002; Corbin & Strauss, 2008). A codebook was developed through two approaches: 1) deductive (identifying initial codes from the interview guide and the literature) and, 2) inductive (identifying salient themes and concepts from the narrative). All transcripts were independently coded by two researchers. The coding was compared for consistency, discrepancies were discussed, and transcripts were recoded as necessary. No major discrepancies in coding were found. Analysis of the transcripts focused on grouping codes into meaningful categories and examining the relationships between concepts and themes (Corbin & Strauss, 2008; Miles & Huberman, 1994). Themes relevant to the quantitative analysis were reviewed for this study.

Results

Sample

One hundred and one individuals (53 PWE and 48 support providers) completed the survey. The sample was comprised of 47 PWE/supporter pairs, 6 additional PWE and

1 additional support provider. Of these participants, 38 individuals (22 PWE and 16 support providers) completed an interview. The interview sample was comprised of 14 complete pairs, 8 additional PWE, and 2 additional support providers. The majority of the participants was female, white, lived with family, and completed at least some college (see Table 1). PWE tended to be single and unemployed or on disability, whereas most PSP were married and working. About 40% of PWE and 30% of PSP had probable depression.

Variable Map and Model-data Fit

Figure 1 displays the variable map, which shows the calibration of facets (persons, items, dyad). The first column is the logit scale, which serves as the common ruler on which persons and items are placed. The next two columns show the location of PWE and persons on the logit scale. For PWE, persons who perceived receiving more support are closer to the top, whereas persons who received less support are at the bottom. Similarly, PSP who reported providing more support are closer to the top. The next two columns show the location of items along the support latent variable. Types of support that were easier to provide or receive more often are at the bottom, whereas types of support that were more difficult to provide or receive more often are toward the top of the column. Help with seizures was the easiest type of support to receive or provide, while reminders about taking and refilling medication were the hardest types of support to receive or provide more often. The final column shows illustrative quotes that align with the items.

The variable map provides information about the spread of persons and items, indicating the degree to which the facets are aligned. PWE are located between about -1.0 and 2.0 logits and PSP are located between about -1.0 and 1.0 logits. The items range from about -1.5 to 0.5 logits. Overall there is good overlap between persons and items, which suggests that the items are calibrated well to the population. However there are no items that overlap with PWE who receive higher levels of support or PSP who provide higher levels of support (above .5 logits).

The Rasch model summary statistics, including mean location on the latent variable and fit statistics for each facet, are shown in Table 2. There is good model-data fit based on the mean Infit and Outfit scores for each facet, which are close to 1. The standard deviations for the person and item fit statistics are above 0.2, which is higher than expected and indicates some misfit. The standard deviations indicate that there is additional variance in the model, which is most likely due to persons not responding as expected. In response to this finding, we looked to the qualitative data to help explain the extra variance; these results are described below.

The reliability of separation is good (above 0.7) for both persons and items. The significant reliability of separation for the dyad facet indicates that the mean location of PWE and PSP on the latent variable is different. PWE reported receiving more support, on average, than the PSP reported providing. There is also a difference in the mean location of individuals who have probable depression compared to those who do not. On average, individuals who were not depressed reported receiving or providing more support compared to people who had elevated depressive symptoms.

The Rasch measures accounted for 43.6% of the variance. Values above 20% indicate an acceptable unidimensional scale for Rasch analysis (Reckase, 1979).

Qualitative Support for Variable Map

Data from the interviews and comments that participants made during the surveys provided context and insight into the ordering of items. Results from the interviews supported the ordering of the items, where seizure support was easier to receive and provide more often and reminders were more difficult.

Seizure Support. PWE and PSP spoke extensively about the support that was provided before, during, and after a seizure. The support person performed a variety of support tasks such as monitoring PWE's symptoms and behavior, making sure PWE remained safe during a seizure, and caring for them during the post-ictal state when the PWE may be experiencing fatigue, confusion, or headache. The amount of support provided depended on the type and severity of seizures, with tonic-clonic seizures requiring more care than other types. This is illustrated by the following quote from a mother of a young woman who experienced two types of seizures that she described as "small" and "big".

> [The "small" seizures are] very concerning, of course, because she kind of loses coordination and her speech is slurred…We'll lay her down, and she kind of pulls out of it… So that's not too bad. When she has the big ones, it is more stressful… I just lay her down and stay with her and, you know, just try to make sure she just doesn't hurt herself or anything. They're usually fairly short, a few minutes long. And we usually get her attention and she starts to come out of it before too long.

Driving to Doctor's Appointments. Driving the PWE to the doctor was another type of support that was easy for PWE to receive and for the PSP to provide. All of the PWE were unable to drive at some point, either currently or in the past, depending on if their seizures were controlled or not. In almost all cases, both the PWE and PSP stated matter-of-factly that the support person drove PWE to the doctor when they could not drive, without positive or negative emotion attached. It appeared that this is a prioritized task that simply must be accomplished.

Avoid Seizure Triggers. The majority of pairs described ways in which the support person helped the PWE to avoid seizure triggers. The most common triggers were lack of sleep and stress; thus, PSP reminded PWE about going to bed at a good time and discussed ways to manage stress. Ways in which PSP aided the PWE in stress management included providing emotional support, talking with the PWE, and completing household tasks or errands. A husband with epilepsy described what his wife did to help him manage stress:

> She tries to make sure that it's a non-stress or stress-free zone here. Explain to me or just stop talking to me when she sees that we're having a conversation and I'm getting frustrated because I got lost somewhere along the way or I'm not getting it. Or she'll say, "We'll just pick this up later."

The participants' experiences demonstrated that support for trigger management encompassed several of the scale items, including help avoiding triggers, reminders to rest, and sometimes reminders to eat healthy.

Reminders. The qualitative data also supported the finding that reminders were more difficult for some PWE and PSP to receive and give. PWE had varied reactions to reminders, which were commonly about taking medication or getting enough sleep, though their reactions did not seem to fall into a pattern based on age, gender, or relationship type. Many PWE felt that the reminders were beneficial, while others expressed annoyance and frustration, especially when they saw the reminders as unnecessary because they were already performing the behavior adequately. For example, a daughter expressed frustration with her mother's reminders about medication:

> It doesn't bother me that she reminds me, it's just like, what she does it's like sometimes like, yes mom I know, leave me alone. Then I'm taking it right now. So just sometimes it's annoying because I know what I need to do and she is just like, hurry up, do it, do it. I take it at seven every night and it will be like 7:06 and it is like mom, six minutes late is not going to affect me.

In several cases, PWE felt ambivalently about reminders. One PWE stated the following about her husband reminding her to take her medication, "I mean, it's good that he's asking me, you know, reminding me. But sometimes he reminding me a bit too much…It gets on my nerves."

Support providers also expressed some frustration when they felt that they needed to make sure that the PWE took their medication but the PWE were not receptive to their efforts. One mother said about her son who has epilepsy:

> But I'm the one that he calls, you know, into the room to help him when he has a seizure. But then at the same time, he wants me there, but he doesn't want me saying anything like, 'Are you sure you took your medicine?' or 'Why didn't you

> take your medicine?'

For some PSP, reminding the PWE to take medication was seen as part of the role of being a wife or mother. According to one mother:

> I nag her. About did you take your medicine. Isn't that a mother's job - did you take your medicine? You know did you clean your room? Did, you know, the usual stuff. Nothing special because I think it's up to her to manage her own gig.

Other Support for Self-management. The types of support provided sometimes went beyond what was captured by the scale items. In addition to reminding PWE about doctor's appointments or driving the PWE to the clinic, several PSP called the doctor or accompanied the PWE to appointments in order to inform the doctor about the PWE's condition. This usually occurred when the PWE was unable to communicate to their doctor what was going on because they were unconscious during seizures or experienced cognitive or memory difficulties. A woman with epilepsy described the need for her mother to provide this support:

> She is the one that always calls the doctors when something is going on, especially with my meds. Because she can be the first hand, because I don't know I'm having my seizures. She's the one that sees it and is just like, ok, no, this shouldn't be happening. She is the one that will go and call the doctors and see what is going on and what we should do to make it better.

Some PSP also kept a record of when the PWE had seizures in order to provide doctors with detailed information.

Person Functioning

Out of 101 participants, 66 had Outfit mean square statistics inside the expected range of 0.6 to 1.4, which indicates good model-data fit. Eighteen individuals had an Outfit mean statistic less than 0.6, indicating less variation than expected, and 17 had an Outfit mean statistic greater than 1.4, indicating more variation than predicted by the model. To identify the reasons for excess variation, we examined the standardized residuals of the 9 participants with the greatest misfit (Infit and/or Outfit >1.8). Each of the 9 individuals had from 1-3 responses where the standardized residual was less than -2.0 or greater than 2.0 (See Table 3).

Qualitative Support for Person Function. Reviewing the qualitative data to explain the excess variation, we found that individuals' circumstances caused them to respond in a way that did not fit the model (See Table 3). For the three cases of misfit for the item on reminders to refill medication, the support person did not remind the PWE because either the support person refilled the medication themselves or the pharmacy automatically refilled the prescription (Table 3: PWE 5, PWE 6, Support Person 2). For the item on support during a seizure, the model predicted that a woman would often provide support to her husband (Table 3: Support Person 3). However, he only had experienced a few seizures and she had never been with him when he had a seizure; therefore she answered "never". For another PWE (Table 3: PWE 3), her support person lives in a different state and provided very little support for her self-management, generating low scores on most items. However, on the survey she responded that he does sometimes remind her to take her medication when they are together, though they only see each other about once a year.

In one misfit case, a female participant's (Table 3: PWE 1) survey responses conflicted with her interview responses. She said that her mother "never" reminded her to take her medication or to eat healthy meals, when the expected response was "most of the time." In the interview, this woman said, "She [mother] reminds me to take my pills. She reminds me not to eat the food that I'm not supposed to eat." This PWE has epilepsy and memory difficulties resulting from traumatic brain injury; thus her condition may have affected her ability to accurately answer the survey questions.

Differential Item Functioning

We tested whether the items functioned differently for: 1) PWE and PSP and 2) people with probable depression compared to those without. The overall chi-square tests were not significant in either case, indicating that there is no evidence of DIF. Therefore, the items were ordered in the same way for PWE and PSP, as well as depressed and non-depressed participants.

Discussion

The purpose of this study was to examine the patterns of support for self-management behaviors, focusing on the support that PWE receive and that support providers give. Results of the Rasch analysis showed good model-data fit and provided us with a unique way to assess support data.

The variable map provides a valuable visual for comparing people and items. Our results showed good overall overlap, or targeting, between the individuals and items. The overlap indicates that, for the most part, the items appropriately measured the level of support that was received or provided. However PWE who received the most support did not overlap with any items. This suggests that additional unmeasured types of support with more “difficulty” could be investigated and incorporated into the scale. Results from the qualitative interviews and the differential person functioning also support the addition of items to the scale. For example, the current ERSS does not capture when the support person performs aspects of self-management for the PWE, such as refilling medications, setting medications out for the PWE, and making doctor’s appointments. Results from the qualitative data also indicated that PSP support PWE in ways that are not assessed by the ERSS, such as keeping a record of the PWE’s seizures and providing information about the PWE’s condition to the doctor.

Although relatively few scales measuring support for self-management of chronic diseases are available in the literature, models can be found for diabetes self-management support (Glasgow & Toobert, 1988; Naderimagham, Niknami, Abolhassani, Hajizadeh, & Montazeri, 2012; Song et al., 2012; Tang, Brown, Funnell, & Anderson, 2008). For example, Naderimgaham and colleagues (2012) developed a scale that includes items assessing how often someone reminds the person with diabetes about specific self-management behaviors, encourages them to complete those behaviors, and completes activities to help the person manage (e.g. buys healthy foods, performs foot care). These scales, however, also illustrate the challenge of measuring social support because they assess different support providers (e.g. someone, family, or family and friends) and different types of self-management support. Some of the measures ask about negatively and positively perceived support, amount of support received, importance of support, and/or satisfaction with support (Glasgow & Toobert, 1988; Song et al., 2012; Tang et al., 2008). Thus, self-management support is not consistently measured across these studies. Additionally, the support person is not included in any of these instances.

Examinations of the relative ease and difficulty of receiving and providing support for self-management behaviors is also lacking in the literature. We found that the easiest type of support to receive or provide most often was support for seizures. People with epilepsy almost always wanted their support person to help them when they had seizures. Depending on the type of seizure, PWE can experience loss of consciousness, loss of control over muscle movements, and convulsions. The after-effects of seizures, which can last from less than an hour to over a day, include memory loss, difficulty concentrating, fatigue, and headaches. Seizures can be major events that disrupt daily life. Additionally, anticipating and experiencing seizures can cause a great deal of fear and anxiety (Ryan & Raisanen, 2012). Therefore, PWE and PSP may prioritize support for seizures as a way to minimize the physical and emotional consequences of seizures.

Reminders, particularly about taking medication, eating healthy, and getting enough rest, were the most difficult types of support to receive and provide more often. However, reminders to take medication were the most common type of support reported by PWE in a self-management program (Walker et al., 2012). The qualitative data suggest that reminders can be frustrating, especially for PWE who successfully manage their epilepsy on their own. These results align with findings by DiIorio and colleagues (1996), who found that self-management support was positively associated with anxiety, but not associated with medication self-efficacy. The researchers suggested that self-management support could be viewed as nagging or come across negatively (DiIorio et al., 1996). As described by Tapp (2004), family members and other PSP may nag out of concern and as a way to help and encourage a person with a chronic condition. Nagging presents a paradox in that it can be helpful in motivating behavior change, or harmful by increasing resentment and irritability between caregivers and care recipients (Tapp, 2004). Additional research is needed to tease out the situations in which nagging is acceptable or harmful for people with epilepsy and their supporters. When designing interventions that include PWE and PSP, these results suggest that intervention approaches, such as Motivational Interviewing (Miller & Rollnick, 2002), may be helpful in facilitating reflection and conversation about self-management behaviors, support, and responses to support.

The results of the DIF analyses provide additional information about the nuances of support that is received and provided. No DIF was found when comparing PWE versus PSP as well as non-depressed participants versus those with elevated depressive symptoms. This means that the items were ordered the same way for the different groups—individuals in both groups had the same perceptions about how difficult it was to receive or provide support across the items. This suggests that PWE and PSP have similar perceptions of the different types of support. Additionally, it appears that the presence of depressive symptoms does not cause the person to perceive certain support behaviors as easier or harder to receive or provide.

Limitations

While the results of this study are strengthened by the mixed methods design, three main limitations of this study should be considered. First, the sample size is small;

therefore the results should be interpreted with caution. While Rasch analyses are often conducted on large samples, the small sample enabled us to examine individual and item characteristics in detail and compare them to the qualitative results. However, replication of the findings in a larger sample would be useful. Second, the sample was drawn from one tertiary epilepsy clinic; therefore the results may not be generalizable to all people with epilepsy and PSP. Finally, these analyses are cross-sectional and exploratory; no conclusions about causation can be drawn from the results.

Implications and Future Research

This research demonstrates how Rasch modeling can provide valuable information on self-management behaviors, beyond its traditional use in psychometrics. Rasch analyses would be useful in future research examining the alignment between the amount of support PWE perceive they receive and the amount of support that PSP feel that they provide. Additionally, a revised scale for self-management support could be developed that includes additional behaviors and captures when the support person performs the self-management behaviors.

The results suggest that not all types of support are equally as easy to receive and provide. Self-management programs for PWE should address these differences and facilitate conversations between PWE and support providers in order to optimally meet PWE’s support needs.

Table 4.1 Demographic characteristics of people with epilepsy and their primary support persons

	People with Epilepsy (n=53)	Primary Support Persons (n=48)
Relationship, n (%)		
Child	27 (50.9)	1 (2.1)
Parent	2 (3.8)	29 (60.4)
Spouse	15 (28.3)	10 (20.8)
Sibling	4 (7.5)	3 (6.3)
Friend	1 (1.9)	1 (2.1)
Significant Other	4 (7.5)	4 (8.3)
Gender, n (%)		
Female	34 (64.2)	34 (70.8)
Male	19 (35.8)	14 (29.2)
Race, n (%)		
Asian/Pacific Islander	1 (1.9)	1 (2.1)
African American	8 (15.1)	7 (14.9)
Hispanic	1 (1.9)	2 (4.3)
White	42 (79.2)	36 (76.6)
Multiracial	1 (1.9)	1 (2.1)
Marital Status, n (%)		
Married	16 (30.2)	32 (66.7)
Single	32 (60.4)	8 (16.7)
Separated/Divorced/Widowed	5 (9.4)	8 (16.7)
Living Situation		
Alone	5 (9.4)	5 (10.4)
Immediate family	42 (79.2)	38 (79.2)
Friend, roommate, partner	5 (9.4)	5 (10.4)
Other	1 (1.9)	-
Education		
< High School	5 (9.4)	1 (2.1)
High School	12 (22.6)	13 (27.1)
Some college or currently in college	17 (32.1)	7 (14.6)
College	15 (28.3)	19 (39.6)
Graduate School	2 (3.8)	5 (10.4)
Other program (e.g. technical)	2 (3.8)	3 (6.3)
Employment Status, n (%)		
Full-time	11 (20.8)	24 (50.0)
Part-time	6 (11.3)	3 (6.3)
Student	9 (17.0)	2 (4.2)
Retired	1 (1.9)	8 (16.3)
Unemployed	10 (18.9)	4 (8.5)
On disability	13 (24.5)	2 (4.2)
Other	3 (5.7)	5 (10.4)
Depression Level, n(%)		
No depression (CES-D score <16)	32 (60.4)	33 (68.8)
Possible depression (CES-D score ≥16)	21 (39.6)	15 (31.3)
Age (years)		
Range	18-59	18-76
Mean (SD)	31.30 (9.80)	48.23 (13.64)
Seizures in the past 4 weeks	0-364	-

Range	13.94 (54.41)	-
Mean (SD)		
Years since Epilepsy Diagnosis		
Range	.3-39	
Mean (SD)	14.9 (9.53)	

Abbreviations: CES-D, Center for Epidemiological Studies Depression Scale; SD, standard deviation

Table 4.2 FACETS summary statistics from the Rasch analysis of the Epilepsy Regimen-Specific Support Scale

	Measures			Infit		Outfit		Reliability of Separation	χ^2 statistic	p-value	df
	Mean	SD	n	Mean	SD	Mean	SD				
Persons[1]	.43	.84	101	1.04	.49	1.11	.87	.80	523.8	<.001	100
Items	0	.53	18	1.05	.35	1.11	.45	.97	399.4	<.001	17
Dyad	0	.18	2	1.00	.06	1.11	.00	.97	37.4	<.001	1
Depression	0	.09	2	.98	.13	1.05	.29	.87	7.5	.01	1

[1] Includes responses of both people with epilepsy and their support persons

Abbreviation: df, degrees of freedom; SD, standard deviation; n, number of participants

Table 4.3 Mixed-methods data to explain misfit in person functioning

Individuals with Misfit	Items with Standard Residuals <-2 or >2	Observed Response[1]	Expected Response	Comments on Survey	Completed an Interview	Information from interview
PWE 1	Reminder to take medication	1	4	None	Y	• PWE has brain injury that affects memory • Mother takes care of medications and refills
	Reminder to eat healthy	1	4.42	None		
	Help avoid things that cause seizures	1	3.69	None		
PWE 2	Help avoid things that cause seizures	1	4.1	None	Y	• Support person mainly helps by taking her to the doctor, tracking seizures, and providing support during seizures
	Reminder to be careful	1	3.87	None		
PWE 3	Reminder to take medication	3	1.41	When she is visiting brother, he will remind her about her medication	Y	• PWE's support provider, her brother, lives out of state • She visits him about once a year • Brother mostly provides emotional support
	How often PWE would like to be reminded to take medication	3	1.26			
	How often PWE would like to be reminded to get enough rest	3	1.32	None		
PWE 4	Bring to doctor's appointment	3	4.83	None	N	
	How often PWE would like to be brought to doctor's appointment	3	4.81	None		
	How often PWE would like to be reminded about doctor's appointments	2	4.59	None		
PWE 5	Reminder to refill medications	1	4.56	Mother refills medications	N	
PWE 6	Reminder to refill medications	1	4.06	Does it online automatically	Y	• Her support person is "in

	How often PWE would like to be reminded to refill medications	1	4.24			charge” of her medication
Support Person 1	How often the PWE would like help with seizures	1	4.89	None	N	
	How often the PWE would like to be reminded to be careful	1	4.14	None		
Support Person 2	Reminder about doctor’s appointment	5	2.14	None	Y	• She refills meds for PWE and takes him to the doctor
	Reminder to refill medications	5	1.69	None		
	How often the PWE would like help with seizures	1	4.36	None		
Support Person 3	Help with seizures	1	4.71	She has never been with PWE when he has had a seizure	N	

[1] Response options: 1 (never), 2 (rarely), 3 (sometimes), 4 (most of the time), 5 (always)

Figure 4.1 Self-management support variable map

Logits	Persons (PWE)	Persons (PSP)	Items: How often support was received/provided	Items: How often PWE would like to have support or how often PSP think PWE would like support	Quotes
	More support received	More support provided	Harder to give/receive more often	Harder for PWE to want to receive more often	
2	•••				
	•				
	•				
	••				
	••				
	•				
	•	◆			
1	••	◆◆◆			
	•	◆◆			"So I won't have to have to hear her nag, so I be sure to take it." (PWE, husband)
	••	◆			
	•••••	◆◆◆		Reminder – take medication	
	•	◆◆◆◆◆		Reminder – eat healthy	
	•••	◆◆	Reminder – refill medications	Reminder – rest	"I make sure he gets to the doctor. I make sure he always has medication refills." (PSP, mother)
	•••	◆◆◆◆◆◆		Reminder – refill medications	
	••••	◆◆◆◆	Reminder – take medication		
	•	◆◆◆	Reminder – clinic visits, Reminder – eat healthy	Reminder – clinic visits, Reminder – be careful	
	•••	◆◆◆◆			
0		◆◆◆			
	••••	◆◆◆◆	Reminder – rest, Reminder – be careful		"Well, I try to ensure that she gets proper sleep, proper rest, not to overdo herself, not to worry." (PSP, husband)
	••••	◆			
	••	◆	Help – avoid triggers	Help – avoid triggers	
	•••			Help – drive to doctor appointments	
	•••	◆	Help – drive to doctor appointments		"She actually takes me to the doctor so she could explain one or two things that may have happened…" (PWE, son)
		◆			
		◆			
		◆	Help – seizure		"Just try to make sure that she's safe and she's, you know, try to get her laying down, that she's not going to get hurt, that type of thing." (PSP, mother)
-1		◆			
	•				
				Help - seizure	
-2					
Logits	Less support received	Less support provided	Easier to give/receive more often	Easier for PWE to want to receive more often	
	•=1 PWE	◆=1 PSP			

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Chapter 5: Summary and Conclusion

Epilepsy has a significant impact on both people with epilepsy (PWE) and their friends and families. PWE, particularly individuals with uncontrolled seizures, experience limitations in daily life, high rates of depression, and poor quality of life (Canuet et al., 2009; Fisher et al., 2000a; Gulpek, Bolat, Mete, Arici, & Celebisoy, 2011; Reisinger & DiIorio, 2009). They must engage in an ongoing and sometimes complex set of behaviors to manage their epilepsy and prevent seizures. Family members and friends are in an optimal position to aid PWE in management of their epilepsy and to help minimize the impact of epilepsy on PWE's lives. Indeed, social support is associated with better self-management, lower depressive symptoms, and better quality of life for PWE (Charyton, Elliott, Lu, & Moore, 2009; Reisinger & DiIorio, 2009; Robinson et al., 2008; Whatley, DiIorio, & Yeager, 2010). However, providing support to PWE can have negative consequences for their primary support persons (PSP; Ellis, Upton, & Thompson, 2000; Thompson & Upton, 1992; van Andel, Zijlmans, Fischer, & Leijten, 2009; Westphal-Guitti et al., 2007). The study of the interplay of factors involved in provision and receipt of social support could have important implications for the health and well-being of PWE and PSP.

For this dissertation, a mixed-methods study was undertaken to examine the interpersonal relationship between PWE and PSP, the support provided to PWE in general and specifically for self-management, and the ways in which support is associated with self-management and quality of life. This dissertation provides a deeper understanding of how PWE and PSP experience and deal with epilepsy, and the impact of epilepsy on their lives. It also sheds light on the factors and characteristics, particularly at the interpersonal level, that shape the participants' experiences.

The aim of the first paper (Chapter 2) was to gain insight into how epilepsy affects the lives of PWE and PSP, the types of support provided to the PWE, and the influences of support on PWE and PSP. We found that illness intrusiveness, the disruptions to valued activities and interests, was significant for both PWE and PSP. Our qualitative results aligned with the quantitative findings of Poochikian-Sarkissian and colleagues (2008a; 2008b) that poor seizure control is associated with increased illness intrusiveness. While seizure control is a major factor that shapes individuals' experiences, other identified influential factors included the interpersonal relationship between the PWE and PSP and perceptions about receiving and providing support. These findings add to the recognition that epilepsy is not conceptualized as only a medical condition, but as a psycho-social phenomenon, as well (Raty, Larsson, Starrin, & Larsson, 2009). This conceptualization and the relationship between support, seizure control, and illness intrusiveness are reflected in the model that was generated from the qualitative data. This dyadic model can serve as a guiding framework for future studies on PWE and PSP.

In the second paper (Chapter 3) we qualitatively examined the types of self-management support provided to PWE and its effect on self-management. PSP provided support across the five main domains of self-management: medication management, trigger identification and avoidance, treatment management, information management, and symptom tracking and reporting. PSP's involvement spanned a continuum from

PWE-led management, to joint management, to PSP-led involvement. Where the pairs fell on the continuum depended on development, relationship type, and the dynamics between the person with epilepsy and support provider. Seizure control shaped individuals' experiences with self-management and support within each group, but did not determine PSP's control over PWE's management. The influence of PSP on the PWE's self-management supports a definition of epilepsy management that includes support persons. Definitions and models of self and family management have been developed and used in nursing research. Such models are based on the assumption that managing a chronic condition is a dynamic process involving interactions between the individual with the condition and his or her family, the utilization of a variety of resources, and collaboration with healthcare professionals. Self and family management is expected to affect a variety of outcomes, including health status, quality of life, family functioning and lifestyle, and healthcare use (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008; Grey, Knafl, & McCorkle, 2006; Rosland & Piette, 2010; Ryan & Sawin, 2009). Multidisciplinary approaches using these models could prove useful for epilepsy management.

The purpose of the third paper (Chapter 4) was to evaluate which types of self-management support were easier or more difficult to receive and provide, and to determine if the items functioned the same way for PWE and PSP, as well as for participants with and without depressive symptoms. The result of the Rasch measurement models and qualitative data suggested that PSP's support for seizures and PSP driving PWE to the doctor were types of support that were easier to receive and provide, whereas reminders to take medication, eat healthy, and get enough rest were more difficult. The results of this paper and Chapter 3 indicate that reminders, which can be seen as nagging, are very common across the self-management continuum. Other research indicates that reminders can be viewed as unhelpful and, in some cases, may negatively affect self-management (Bressi et al., 2007; Gallant, Spitze, & Prohaska, 2007; Rosland, Heisler, Choi, Silveira, & Piette, 2010; Rosland, Heisler, & Piette, 2012; Trief, 2003). However, Tapp (2004) notes that family members and other PSP may nag out of concern and as a way to help and encourage a person with a chronic condition. Skills training on effective methods of communication may be helpful in allowing PWE and PSP to determine the optimal level of support for maintaining self-management behaviors (Rosland, 2009).

The results of the Rasch analysis also have implications for measurement of support for epilepsy self-management. The Epilepsy Regimen-Specific Support Scale (ERSSS) assesses support provided through reminders and helping behaviors (DiIorio, Hennessy, & Manteuffel, 1996). The findings from Chapters 3 and 4 demonstrate that PSP sometimes complete certain self-management tasks, such as refilling medications and communicating with neurologists, for the PWE. Therefore, the results could inform the addition of certain support behaviors to the ERSSS. Examples of scales that measure support for diabetes self-management offer models for a revised scale for epilepsy, but also illustrate the inconsistencies in how support for self-management is assessed (Glasgow & Toobert, 1988; Naderimagham, Niknami, Abolhassani, Hajizadeh, & Montazeri, 2012; Song et al., 2012; Tang, Brown, Funnell, & Anderson, 2008).

There are several overarching themes across Chapters 2-4, namely the positive and negative aspects of support, differences in experiences based on relationship type and interpersonal dynamics, and differences in developmental level. Across all three papers, the benefits and drawbacks of receiving and providing support were a key aspect of participants' experiences. In general, the positives of support outweighed the negatives. PWE recognized that support was beneficial in ensuring completion of self-management tasks and in their lives overall; they expressed gratitude for their PSP. Many PSP, in turn, felt that providing support was not a burden, rather it was part of their role as a parent, spouse, or friend. Similarly, Gallant and colleagues (2007) found that the support network of people with chronic illness provided many more positive than negative influences on chronic illness self-management. However, support does have downsides that should be recognized. PWE who felt nagged expressed frustration and annoyance with their PSP. In this sample, the negative impact of support was perhaps felt more strongly by certain PSP who shouldered a heavy burden of support. Almost all of the PSP who described a heavy caregiving burden experienced elevated depressive symptoms. The link between caregiver burden and depression is strongly supported in the literature (Nieboer et al., 1998; Pinquart & Sorensen, 2003; Rees, O'Boyle, & MacDonagh, 2001).

Differences in experiences by relationship type and gender were unexpected findings from the qualitative analyses. Most notably, the experiences of young adult sons and their mothers differed from other dyads, including young adult women and their parents. These young men relied on their mothers for self-management and instrumental support to a larger degree than young women. The sons and mothers were entering into a process of negotiation in which the sons would take on more responsibility and the mothers would let go of their control over their sons' lives. In contrast, the young women were further along in their development; they already had primary responsibility for their self-management and often were taking concrete steps toward living independently. Very little is known about the transition of PWE, as well as young adults with other chronic conditions, into adulthood, the factors that facilitate or inhibit that process, and the impact on self-management and quality of life. This area warrants further investigation.

Evaluation of the Dissertation Research

Strengths. This study has several strengths and provides new information on the experiences of and interactions between PWE and PSP. We included the experiences and perspectives of the PSP because their voices are not represented in the research literature. To our knowledge, this is the first study that used qualitative methods to ask PSP to describe their experiences providing support to adults with epilepsy. Other research has quantitatively assessed PSP's quality of life (e.g., Mahrer-Imhof et al., 2013; van Andel et al., 2009; Westphal-Guitti et al., 2007) or asked PSP to comment on PWE's experiences rather than their own (e.g., Sample, Ferguson, Wagner, Pickelsimer, & Selassie, 2006; Wheless, 2006). Another strength is the use of mixed-methods, which provides a better understanding of the research aims than could be achieved through qualitative or quantitative methods alone (Creswell & Clark, 2007). The qualitative methodology allowed us to gain an in-depth understanding of the impact of epilepsy on the lives of PWE and PSP, as well as the support that is provided for self-management.

Our use of Rasch measurement models is novel in two respects. First, Rasch analyses have traditionally been used to test the psychometric properties of scales and have only recently been applied in mixed-methods research in order to probe the meanings behind item ordering and differential functioning of items and persons. Second, to our knowledge, this is only the second study to utilize Rasch methods in the study of epilepsy.

Limitations. The results of this dissertation project should be considered in light of several limitations. First, PWE were recruited from a hospital-based, tertiary epilepsy clinic; they may experience more severe or complicated epilepsy, requiring the care of an epileptologist, compared to PWE who receive care from general neurologists or primary care physicians. Therefore, the experiences of participants in this sample may not apply in different contexts. Also, this study focused on PWE and their PSP; therefore the perspectives of other supportive individuals who also may be instrumental in a PWE's self-management were not included. The dyad may be a simplified representation of support that is available. Additionally, PWE who did not have a support person were excluded from the study. Second, while every effort was made to survey and interview both members of the PWE/PSP dyad, it was not always possible to contact, receive informed consent from, or schedule data collection with both people. Surveys and interviews with individuals whose pair-member did not participate still provided valuable information; however, the ability to compare perspectives on shared experiences and relationships was lost. Third, this study was cross-sectional in nature; thus no conclusions about causality can be made. Finally, the sample size was small, particularly for the Rasch measurement model analysis; therefore it is recommended that the findings be validated in a larger sample.

Implications for Research and Practice

Future research based on dissertation data. This study generated much more data than could be incorporated into the three papers comprising this dissertation. Further research will be conducted in order to fully explore and report on the information that our participants provided. At this point, four analyses have been identified to extend the dissertation findings on self-management support and depression, as well as to examine additional themes in the qualitative data.

1. <u>Alignment of self-management support</u>: Rasch measurement models will be used to assess the alignment in the amount of self-management support that PWE receive compared to the amount that PSP provide. Preliminary analyses indicate that PWE report that they receive more support, on average, than what PSP report providing. Alignment between the support that PSP provide and what PWE want and need could have important implications for satisfaction with support.
2. <u>Depressive symptoms in PWE and PSP</u>: Mixed-methods will be used to further explore depressive symptoms in our sample. Rasch measurement models will be used to determine if the items of the Centers for Epidemiologic Studies Depression Scale function the same way for PWE and PSP. It is possible that depression items may function differently between people with and without epilepsy because PWE experience symptoms due to their condition or medication side-effects that overlap with epilepsy. These symptoms include fatigue, memory

problems, difficulties concentrating, or sleep disturbances (Fisher et al., 2000b; Gilliam et al., 2006; Hayden, Penna, & Buchanan, 1992). Qualitative data may be valuable in providing context to the Rasch findings.

3. PWE's support system. Mixed-methods will be used to examine the PWE's support system, specifically who PWE receive support from beyond the PSP and what types of support is provided. Preliminary analysis indicates that PWE fall into one of three categories that describe the size of their support network: only the PSP, the PSP and one or two other key individuals, or the PSP and a larger network of supporters. Additional support persons provide self-management, instrumental, and/or emotional support. Differences in experiences will be examined by category, including any differences in self-management and depressive symptoms.
4. Disclosure of epilepsy. The theme of disclosure of epilepsy emerged in participants' narratives of experiences with seizures, employment, and relationships. Therefore, qualitative methods will be used to explore dimensions of disclosure, including when, where, how, and to whom PWE disclose their condition and the consequences of disclosure. Perspectives of PSP on disclosure will be a new addition to the research literature.

Future research building off of dissertation results. The findings from this study can inform additional research. First, the dyadic model and self-management continuum 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 will be instrumental in determining causal pathways within the model and exploring how individuals move along and between the trajectories in the model and along the self-management continuum. Second, qualitative methods could be used to explore how young adult children with epilepsy and their parents experience the PWE's transition to adulthood, the methods by which PWE take on responsibility for their self-management, and the impact on self-management and quality of life. Additionally, results from the first paper (Chapter 2) suggest that the two women who had recently received a diagnosis of epilepsy shared experiences that were unique from the other participants. Qualitative methods would be useful in examining the processes by which self-management behaviors and support are established after diagnosis. Lastly, the results of the third paper (Chapter 4) can inform efforts to expand and improve current measures of epilepsy self-management support.

Intervention development and practice. Given the central role of PSP in PWE's management of epilepsy, it is important to incorporate PSP into self-management interventions. Rosland and Piette (2010) reviewed three main types of programs for mobilizing family support for management of chronic conditions: 1) Guiding family members in setting goals to support self-management, 2) Skills training in communication techniques to improve coping and support patient autonomy, and 3) Giving family members tools to effectively support patients in clinical settings. These types of interventions show promising results in implementation of family support and patient health outcomes. These types of interventions have not yet been tested for epilepsy, but could serve as a blueprint for developing programs for PWE and PSP.

A focus on PSP may also be warranted in order to improve their own quality of life. As demonstrated in Chapter 2, epilepsy intrudes into the lives of PSP and can negatively affect quality of life, particularly for PSP who perceive a heavy caregiving burden and have few resources to help them cope. Interventions for PSP should focus on how to enhance PWE autonomy in order to efficiently share management tasks, cope with life transitions and changes in their role as a parent or spouse, and maintain supportive relationships with family and friends. These programs could ultimately benefit PWE, as well, because PSP's quality of life is an independent predictor of PWE's quality of life (Mahrer-Imhof et al., 2013).

The PWE and PSP in this study described a range of experiences based on level of seizure control and the type and nature of their relationship. Therefore, it will be important to tailor interventions that aim to improve self-management and quality of life in this population. PWE who have recently received a diagnosis of epilepsy and their families may have different management, support, and coping needs compared to people who have been dealing with the condition for a longer period of time. Tailoring may also be needed based on relationship type (e.g., child/parent versus spouses), with particular attention being given to helping young adults with epilepsy and their parents through the PWE's transition to adulthood.

Finally, efforts to prevent and reduce seizures should be a priority. Poor seizure control is associated with increased illness intrusiveness, higher levels of depressive symptoms, and lower quality of life (Dias et al., 2010; Johnson, Jones, Seidenberg, & Hermann, 2004; Mensah, Beavis, Thapar, & Kerr, 2006; Poochikian-Sarkissian et al., 2008a; Poochikian-Sarkissian et al., 2008b). A main recommendation from the Institute of Medicine in its report entitled *Epilepsy Across the Spectrum* (2012) is to “Develop and evaluate prevention efforts for epilepsy and its consequences” (p.6). These efforts should include preventing new cases of epilepsy, reducing seizures in people with epilepsy, preventing comorbidities, and effectively treating comorbidities (Committee on the Public Health Dimensions of the Epilepsies & Board on Health Sciences, 2012). Improving seizure control will have significant benefits to PWE and PSP.

Conclusion

This dissertation research contributes to our understanding of the interactions between PWE and their PSP and how their interpersonal relationship influences self-management and quality of life. Furthermore, the findings emphasize the degree to which the experiences of PWE and PSP intertwine and affect each other. The findings may serve to inform efforts to bolster epilepsy self-management and lessen the impact of epilepsy on the lives of both PWE and PSP.

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