EPILEPSY SELF-MANAGEMENT IN OLDER ADULTS: A QUALITATIVE STUDY

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DEDICATION

This work is dedicated to my children, Amelia Anne and Rowan Wesley. May you

always seek the truth and attempt to right the wrong. I love you.

ACKNOWLEDGEMENTS

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ABSTRACT

Wendy Renee Miller

EPILEPSY SELF-MANAGEMENT IN OLDER ADULTS: A QUALITATIVE STUDY

Epilepsy is the most common chronic neurological condition in the United States, and it is incurable. Those who suffer from it must engage in both collaborative and independent management of their condition for the remainder of their lives. The treatment and care of those with epilepsy must therefore include not only medical interventions, which alone cannot cure the disorder or prevent the disability associated with it, but must also prepare persons for and facilitate their independent management—self-management—of the disorder. Self-management is a process that affects important outcomes including resource utilization, mortality, and quality of life. In the United States, those age 60 years and older have the highest incidence of new-onset epilepsy. Despite the high incidence of epilepsy in this population, coupled with the knowledge that self-management affects important outcomes, a thorough search of the literature suggests that self-management experiences of older adults diagnosed with epilepsy late in life have not been investigated.

The purpose of the study was to examine, using a qualitative descriptive design, the self-management experiences of older adults diagnosed with epilepsy at or after age 60. Semi-structured interviews were used to generate data. A total of 20 older adults participated. Major findings indicate that older adults in the sample, and particularly the women, experienced a delay in receiving an epilepsy diagnosis. These older adults experienced multiple problems and life changes since diagnosis—some of which are

unique to this population and many of which are amenable to intervention. These older

adults devise and execute a variety of management strategies, within a system, that are

classified as disease/treatment-focused and problem/life changes-focused. These

strategies further are categorized as proactive or reactive, with proactive strategies being

pre-planned and effective, and reactive strategies being unplanned and less effective.

Knowledge generated from this study reveals the problems experienced by older adults

with epilepsy, as well as their management needs. These findings will inform future

studies, the aim of which will be to investigate more thoroughly these problems and

needs and, ultimately, to inform interventions aimed at resolving this population's

problems and concerns while also improving outcomes.

Janice M. Buelow, PhD, RN, FAAN, Chair

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CHAPTER I

INTRODUCTION AND NATURE OF THE STUDY

Background and Description of Problem

Epilepsy, the most common chronic neurological disease in the United States, currently affects over 3 million people in this country, and 200,000 Americans are newly diagnosed with the condition each year. In 2008, epilepsy resulted in 400,000 hospitalizations, 2 million emergency room visits, and 9,000 deaths in the United States (Centers for Disease Control and Prevention, 2009). Epilepsy is "a medical condition characterized by the occurrence of more than one unprovoked seizure" (Epilepsy Foundation, 2009, p. 1). Like all chronic diseases and conditions, epilepsy is incurable. Thus, those who suffer from it are required to engage in both collaborative and independent management of their condition, often for the remainder of their lives. The treatment and care of those with epilepsy therefore must include not only medical interventions, which by themselves cannot cure the disorder or prevent the disability and other negative effects associated with it (Bodenheimer, Lorig, Holman, & Grumbach, 2002), but also must prepare persons for and facilitate their independent management—self-management—of the disorder.

The requisite self-management accompanying an epilepsy diagnosis often is complex, as those with the condition are faced with the constant need to perform behaviors to ensure medication adherence, to manage symptoms and medication side effects, to monitor for exacerbations, to ensure safety, and to lessen the overall effect of the disease and its treatment on daily life (Buelow & Johnson, 2000; Kobau & DiIorio, 2003; Unger & Buelow, 2009). In addition, unique to epilepsy is the potential for a great loss of independence upon diagnosis—those with epilepsy often cannot drive a motor

vehicle and have numerous other lifestyle and activity restrictions that interfere with their ability to fulfill daily roles (Gilliam et al., 1997; Krumholz, 2009).

While epilepsy affects people of all ages, those age 60 years and older have the highest incidence of new onset epilepsy. In fact, in the United States, 27% of new epilepsy diagnoses each year involve those age 60 years and older (Hesdorffer et al., 2011). While limited literature surrounding the epilepsy self-management of younger adults—including of what it is comprised and what affects and influences it, as well as the effectiveness of some interventions to improve it and its associated outcomes—exists, researchers have not yet investigated the epilepsy self-management of older adults—those age 60 years and older (Epilepsy Foundation, 2009; Martin, Vogtle, Gilliam, & Faught, 2003)—who have been diagnosed with epilepsy in older adulthood. Researchers who have published research done with older adults with epilepsy have focused on investigating those older adults' concerns about *having* epilepsy (Martin, Vogtle, Gilliam, & Faught, 2005) and their quality of life (Laccheo et al., 2008), but no published literature pertaining to their actual epilepsy self-management experiences can be found. Further, no studies in which older adults diagnosed with epilepsy *in older adulthood* comprised the sample can be found in the literature.

Researchers' lack of attention to older adults' experiences with epilepsy self-management persists despite knowledge that this portion of the population is profoundly affected by new-onset epilepsy and that epilepsy self-management affects important outcomes such as quality of life, disease severity, mortality, and healthcare resource utilization (Centers for Disease Control and Prevention, 2009). The knowledge that exists regarding the epilepsy self-management of younger adults may not be wholly

applicable to older adults given the uniqueness of this population in terms of age-associated physiologic changes, the existence of multiple comorbidities, polypharmacy, and the common existence of a family member—spouse, adult child, or significant other—who is involved intricately in managing the older adult's epilepsy (Rowan & Ramsay, 1997). Moreover, older adults suffer disproportionately from the negative sequelae of epilepsy (i.e., falls, medication toxicity) than do younger adults with the disorder (Brodie & Kwan, 2005). Therefore, existing interventions that are intended to improve epilepsy self-management and outcomes, which have been based on research findings with younger adults with epilepsy, may not be as effective for older adults given that they are not tailored for this population.

Thousands of older adults begin self-managing epilepsy on a yearly basis (Hesdorffer et al., 2011). Since older adults are the fastest growing portion of the population and the life expectancy in this country continues to rise (Centers for Disease Control and Prevention, 2010a; Rowan & Ramsay, 1997; United States Census Bureau, 2009), a growing number of older adults will be required to begin management of epilepsy in the coming years (Hesdorffer et al., 2011). Thus, in order to generate knowledge that will guide the development of self-management outcome-enhancing interventions for older adults diagnosed with epilepsy later in life, the epilepsy self-management experiences of this population must be explored.

The remainder of this chapter includes a discussion of the purpose of a study aimed at addressing the previously described problems, the specific aims of and research questions that guided the study, definitions of key terms, the significance and

contribution of the study, and the assumptions and philosophical perspective upon which the study was based.

Study Purpose

While researchers have begun investigating the self-management experiences of young and middle-aged adults with epilepsy, no studies examining the self-management experiences of older adults diagnosed with epilepsy at or after age 60 can be found in the literature. Understanding the impact of epilepsy on the lives of older adults and the problems they face in managing this disorder is necessary to develop effective interventions to improve self-management outcomes for the population of older adults diagnosed with epilepsy at or after age 60. Thus, the purpose of this study was, via qualitative inquiry, to explore the epilepsy self-management of older adults diagnosed with epilepsy at or after age 60.

Specific Aim and Research Questions

The specific aim of the study was to describe the epilepsy self-management experiences of older adults diagnosed with epilepsy at or after age 60 from the perspective of those older adults.

Because very little is known about the phenomenon of interest, a qualitative descriptive research design was employed to fulfill the study's purpose (Sandelowski, 2000). Sandelowski (1995a) espouses the use of research questions to guide a qualitative descriptive study as such questions help to ensure that specific aspects of the phenomenon of interest are well explored. The questions that follow in this section guided the study, though it is acknowledged that other aspects of the phenomenon not included in the research questions emerged during the course of data generation and

analysis as important in describing the phenomenon of interest (Sandelowski, 1995a; see Chapter III).

Research Question One: What are older adults' experiences with the process of being diagnosed with epilepsy?

Research Question Two: What problems are experienced by older adults while self-managing epilepsy?

Research Question Three: How do older adults perceive that their lives have changed since being diagnosed with epilepsy?

Research Question Four: What strategies do older adults utilize in self-managing epilepsy?

Research Question Five: What outcomes do older adults hope to achieve in self-managing their epilepsy?

Definitions of Key Terms

Epilepsy: A medical condition characterized by the occurrence of more than one unprovoked seizure.

Older adult: A person age 60 years or older who, in this situation, has been diagnosed with epilepsy at or after age 60 (Epilepsy Foundation, 2009; Hesdorffer et al., 2011).

Self-management: In reference to general chronic disease—a dynamic, self-directed, action-oriented, ever-changing behavioral and cognitive process in which those with chronic diseases engage, within a family or other system, in order to manage various aspects of their disease and its effect on their lives in multiple domains (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Clark, 2003; Holman & Lorig, 2004;

Lorig, Feigenbaum, Regan, Ung, & Holman, 1986; Lorig & Holman, 2003; Ryan & Sawin, 2009).

Epilepsy self-management: An interactive, fluid phenomenon in which persons with epilepsy continually evaluate their perceived health status (comprised of how they feel emotionally/physically and how they are able to function on a daily basis) and implement a variety of behaviors to manage their medications/treatments, seizures, safety, physical and emotional comfort, functional status, and other factors depending on their current perceived health (Unger & Buelow, 2009).

Significance and Contribution

Chronic disease is the central health issue in the United States, accounting for more than 70% of healthcare expenditures each year (Partnership for Solutions, 2002). Self-management has been recognized by many researchers, including nurse researchers (Barlow et al., 2002; Lorig, 2003; Lorig & Holman, 2003; Marks, Allegrante, & Lorig, 2005a, 2005b), as highly influential to outcomes associated with chronic diseases, including epilepsy. Because self-management plays an integral role in influencing important outcomes associated with epilepsy (e.g., quality of life, healthcare resource utilization, and disease/seizure severity), knowledge of what epilepsy self-management is comprised must be generated in order to inform the design of self-management interventions that ultimately could improve outcomes. Unfortunately, there are no published results of investigations pertaining to the epilepsy self-management experiences of the hundreds of thousands of older adults—a unique population in terms of their experiences with chronic diseases—in the United States who have been diagnosed with epilepsy at or after age 60. Such research is necessary to ensure that older

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adults who have been diagnosed with epilepsy later in life are able to receive tailored self-management interventions that ultimately will lead to improvement in their outcomes. Moreover, investigation into older adults' epilepsy self-management experiences is important given that the incidence of epilepsy in the older adult population is expected to increase in the United States in the coming years as the life expectancy in this country continues to rise (United States Census Bureau, 2009). This study addressed the afore-mentioned gaps in the literature by generating knowledge, in the form of rich description, regarding older adults' experiences with epilepsy self-management. The results of this study will serve as a base upon which more explanatory and interpretive qualitative research—which can ultimately inform quantitative inquiry and intervention development for this population—can be designed. Results rendered from this study also will directly and immediately inform intervention development for the population of older adults diagnosed with epilepsy at or after age 60.

Assumptions and Philosophical Perspective

The study was based on the following assumptions:

1.   Epilepsy self-management is a process that is experienced subjectively.

2.   Epilepsy self-management can be investigated systematically.

3.   Narratives of individuals' experiences of epilepsy self-management are

        sufficient sources of data to explore and describe the components of

        epilepsy self-management, which was the primary purpose of the study.

The study was executed via a qualitative descriptive design. Qualitative description shares the core philosophical underpinning—the use of a realist perspective—that underlies all qualitative methods. A realist perspective is characterized

by the belief that reality is context-dependent and individually constructed. Such a perspective denies the existence of a single, true reality. The goal of qualitative research, then, is not to discover the one true depiction of reality but to produce idiographic knowledge in the pursuit of ascertaining how the social world is interpreted, understood, experienced, produced, or constituted (Mason, 2002). The idiographic knowledge produced from qualitative inquiry can form the foundation of a program of research (Sandelowski, 1995a) and ultimately inform quantitative studies aimed at model testing and intervention development and testing (Miller, 2010).

Summary

In this chapter, the need to investigate the epilepsy self-management experiences of older adults diagnosed with the condition in older adulthood was identified. While it is known that epilepsy self-management affects important outcomes such as healthcare resource utilization, seizure severity and frequency, and quality of life in younger adults, and epilepsy self-management targeted interventions have been developed for that age group, very little is known about the epilepsy self-management experiences of older adults and particularly those diagnosed with epilepsy later in life. Knowledge of what these older adults' epilepsy self-management experiences are comprised is necessary in order to develop self-management interventions specific to this population, the members of which are physiologically, developmentally, and socially distinct from younger adults (Rowan & Ramsay, 1997). The purpose of the study was to investigate the self-management experiences of older adults diagnosed with epilepsy at or after age 60 from those older adults' perspectives. The results of the study will (a) help clarify the concept of epilepsy self-management as it pertains to older adults diagnosed with

epilepsy late in life; (b) provide guidance for future, more explanatory and interpretive

qualitative studies; and (c) provide guidance for future quantitative studies, thereby

ultimately influencing the development of epilepsy self-management interventions

targeted for older adults diagnosed with epilepsy at or after age 60, as well as the

measurement of outcomes associated with the epilepsy self-management of older adults.

Qualitative description was chosen as the most appropriate method for the study.

CHAPTER II

REVIEW OF LITERATURE

Introduction

When executing a qualitative descriptive study, the researcher conducts a review of the literature in order to familiarize himself or herself with the current state of knowledge surrounding the phenomenon of interest (Corbin & Strauss, 2008; Sandelowski, 2000). Such a review makes the researcher aware of what is known about the phenomenon of interest, as well as what knowledge about the phenomenon is still lacking or incomplete, thereby informing the study's purpose and research questions. In comparison to those reviews of the literature appropriate for quantitative studies, as well as those seen in other types of more theory-driven qualitative studies, the review of literature in a qualitative descriptive study is somewhat broad and is meant to give the researcher an *overall* sense of what *is* known and *is not* known about the phenomenon of interest and to justify the need for the study. The review should not focus intently on concepts chosen a priori other than the phenomenon of interest (Corbin & Strauss, 2008; Sandelowski, 2000). Thus, an appropriate review of the literature for the current study should include a description of the state of the science of epilepsy self-management and particularly that in older adults diagnosed with the disorder at or after age 60. However, the epilepsy self-management literature is quite small and that for older adults is extremely limited. Thus, in this chapter, both the state of the science of epilepsy self-management, including that for older adults, as well as the state of the science of general chronic disease self-management, which is pertinent to epilepsy self-management and for which there is a much more well-developed literature, are described. The researcher completed the review via the use of Medline, CINAHL, PubMed, Cochrane,

and PsychLit databases, as well as via review of pertinent textbooks. The following

search terms were utilized: chronic disease, chronic illness, self-management, self-care,

adherence, compliance, interventions, older adults, elderly, epilepsy, and seizures. These

terms were combined in a variety of ways. For example, when searching for literature

pertaining to the effectiveness of chronic disease self-management interventions, the

terms chronic disease, interventions, and self-management were combined. The search

was limited to articles published in the English language between the years of 1990 and

2011. Studies involving pediatric participants (those age 17 years and younger) were

excluded.

The initial portion of this chapter includes a description of the degree to which

older adults in this country are affected by chronic diseases, including epilepsy, and the

costs associated with older adults' chronic diseases. The remainder of the discussion

includes a depiction of the current state of the science regarding chronic disease

self-management and epilepsy self-management, including that for older adults, in terms

of the ways in which self-management has been conceptually and operationally defined,

the outcomes of self-management, what variables affect and influence self-management,

and the effectiveness of self-management interventions in affecting outcomes. As well,

an explanation of the ways in which age-related physical and physiologic changes can

affect epilepsy self-management is provided. The results of a pilot study that was

conducted to evaluate the feasibility of the data generation and analysis methods of the

current study briefly are reviewed. Finally, a critique of the literature is offered, and gaps

in the literature are summarized. Appendix A provides a summary of the state of the

science of both sets of literature reviewed.

What is the Impact of Chronic Disease in Older Adults?

Chronic Disease Burden in Older Adults

Staggeringly, more than 80% of North American older adults live with one chronic disease, and 50% live with two or more chronic diseases concurrently. Further, the number of older adults suffering from at least one chronic disease is expected to triple in the next 40 years in the United States (Centers for Disease Control and Prevention, 2010a). The costs associated with chronic diseases in older adults is high ($30 billion annually) and continues to rise (Crystal, Johnson, & Harmon, 2000; Joyce, Emmett, Keeler, & Goldman, 2005; Naughton, Bennet, & Feely, 2006).

The best way to reduce chronic disease-associated costs is via chronic disease prevention (Boult, Altmann, & Gilbertson, 1996). However, in the United States, there are millions of older adults suffering from chronic diseases for whom prevention is not applicable. Diminishing the costs associated with chronic disease in older adults must be accomplished via effective long-term disease management in terms of improving disease-related outcomes such as mortality and healthcare resource utilization. Research evidence suggests that effective, long-term management of chronic diseases has the potential to drastically reduce chronic disease-related costs in the United States. Joyce and colleagues (2005) investigated the costs and life expectancy associated with six major chronic diseases afflicting older adults in the United States—diabetes, cardiovascular disease, hypertension, cancer, neurological conditions (including epilepsy), chronic obstructive pulmonary disease, and myocardial infarction—and the potential reduction in costs and mortality achieved via long-term disease management. The researchers examined a sample of 24,842 older adults using a microsimulation model

to project costs and mortality associated with the various diseases from persons age 65 years to death, determining that an older adult with a chronic disease accounts for $2,000 more in healthcare spending per year per chronic disease. Disease-associated costs were recalculated given *successful management*, defined in terms of the number of hospitalizations and utilization of healthcare resources, of the diseases, and the results projected a 70% decline in costs per disease per person and a lengthening of life expectancy up to six years (Joyce et al., 2005). Lorig (2003) and Holman and Lorig (2004) noted that an integral part of successful disease management is the self-management in which persons with chronic disease engage on a daily basis. It is thus vital that older adults with chronic diseases, in conjunction with their healthcare providers, be prepared adequately in order to effectively manage their chronic diseases over time.

Community-Dwelling Older Adults and Chronic Disease

Of the North American older adults suffering from chronic disease, five million live at home. Although these older adults maintain a degree of independence and remain in their homes, 75% of them have difficulty performing activities such as shopping and preparing meals, and most live with a family member or significant other who assists them, to some degree, with disease management (Centers for Disease Control and Prevention, 2010a).

Older adults with chronic disease(s) living in the community face unique challenges, are at increased risk for injury, and experience decrements in mood and quality of life (Anderson, Freedland, Clouse, & Lustman, 2001; Lawlor, Patel, & Ebrahim, 2003; Yohannes, Roomi, Baldwin, & Connolly, 1998). For example, in a

community-based sample of 4,060 older women, the number of chronic diseases helped

predict the number of at-home falls (Lawlor et al., 2003). Others have found that older

adults with diabetes had a three-fold increase in depression when compared with older

adults without the disease (Anderson et al., 2001). In addition, older adults with chronic

obstructive pulmonary disease living at home had a higher incidence of depression and a

lower quality of life when compared to older adults without the disease (Yohannes et al.,

1998). Older adults with chronic diseases have been shown to lack knowledge about their

disease(s). Investigators found that community-dwelling older adults with diabetes lacked

knowledge about the condition in terms of its causes, treatment, and consequences, and

lack of knowledge was associated with poor outcomes (Whitley, Fermo, Ragucci, &

Chumney, 2006).

Epilepsy and Older Adults

One chronic disease, epilepsy, is far-reaching in its effect on older adults. More

than 300,000 North American older adults currently suffer from epilepsy, and the

incidence of new-onset epilepsy is highest in those age 60 years and older (Centers for

Disease Control and Prevention, 2010b; Epilepsy Foundation, 2009; Faught, 1999).

Causes of new-onset epilepsy in older adults vary, but it is estimated that nearly half are

related to cerebrovascular accidents or atherosclerosis (Epilepsy Foundation, 2009;

Paradowski & Zagrajek, 2005; Rowan et al., 2005; Rowan & Ramsay, 1997). In more

than 50% of cases of new-onset epilepsy in older adults, however, the cause is unknown

(Rowan et al., 2005; Rowan & Ramsay, 1997). Unlike in younger adults with epilepsy,

for whom the most common type of epilepsy is complex partial arising from the temporal

lobes, the most common type of epilepsy in older adults diagnosed with the disorder late

in life is complex partial arising from the frontal lobes (Ramsay, Rowan, & Pryor, 2004). The clinical presentation of epilepsy in older adults is atypical, and they are often misdiagnosed with syncope, altered mental status, or dementia (Ramsay et al., 2004; Waterhouse & Towne, 2005). Treatment of epilepsy in older adults often consists of one or more anti-epileptic drugs and is accompanied by lifestyle modifications and restrictions, such as inability to drive and avoidance of seizure triggers (Leppik, 2001; Rowan & Ramsay, 1997). Less commonly, epilepsy in older adults is treated surgically (Gallo, 2006).

Older adults with epilepsy experience a variety of symptoms and complications, including: seizures; post-ictal fatigue and confusion; medication side effects such as nausea, somnolence, and cognitive effects; falls and fractures; hospitalizations; and institutionalization in an extended care facility due to epilepsy (Brodie & Kwan, 2005; Rowan & Ramsay, 1997). In addition, older adults with epilepsy have been shown to have a significantly poorer quality of life than older adults without the disorder (Laccheo et al., 2008).

Both the Epilepsy Foundation (2009) and the Centers for Disease Control and Prevention (2010b) recognize the need to increase understanding of how epilepsy affects older adults and have called for research in this area. In addition, in a recently published survey conducted by the Centers for Disease Control and Prevention-associated Center for Managing Chronic Disease (Center for Managing Chronic Disease, 2010), epilepsy self-management researchers and epilepsy clinicians noted that one population in great need of self-management research is older adults and especially those newly diagnosed and those managing co-morbidities.

How Has Self-Management Been Conceptually Defined in the Literature?

General Chronic Disease Self-Management

As pointed out by Lorig and Holman (2003) in their comprehensive review of the history and use of the term *self-management* as it pertains to those with chronic diseases, self-management has been conceptualized in a variety of ways over the past four decades. However, in the nursing literature, chronic disease self-management has been and continues to be represented primarily as a verb and refers to the behaviors that persons with chronic diseases execute in managing their diseases and associated effects. That is, what people *do* constitutes their self-management (Lorig & Holman, 2003). These actions may be in the form of direct, observable behaviors or cognitive strategies or decisions (Lorig & Holman, 2003). An example of an observable self-management behavior is a person setting an alarm to remember to take medications on time; a person with diabetes planning meals to ensure the ability to enjoy dessert at an important social occasion is an example of a cognitive self-management strategy. Similarly, in a more recent review of the chronic disease self-management literature, Unger and Buelow (2009) found that the way in which general chronic disease self-management, over the past decade, has been conceptualized in the nursing and medical literature can best be described as actions taken by persons with chronic disease concerning medication and treatment compliance, safety, event management, and lifestyle management.

Researchers have conducted investigations to specify and further explicate the self-management behaviors used by those with chronic diseases. Corbin and Strauss (1988), for example, based on a large-scale qualitative study with people living with a variety of chronic diseases, found that self-management behaviors occur within three

realms: medical management, adopting new behaviors or life roles, and dealing with associated emotions. Later, Lorig and her colleagues, in a Center for the Advancement of Health project (2002), based on 25 years of research with persons self-managing chronic diseases, a review of the literature, and a Robert Wood Johnson meeting on the topic of chronic disease self-management, identified five core self-management behaviors that occur as part of the self-management of most chronic diseases: problem-solving, decision-making, resource utilization, forming of a relationship with a provider, and taking action. These five core behaviors are executed in the three realms outlined by Corbin and Strauss (1988). Problem-solving is important in self-management given that self-management is problem-based (Lorig & Holman, 2003) and refers to identification of problems, generation of possible solutions, implementation of solutions, and evaluation (Center for the Advancement of Health, 2002). Decision-making refers to decisions made by those with chronic diseases during the problem-solving process as well as those day-to-day decisions they make in response to changes in their condition. Resource utilization refers to the use of a variety of resources (people, toll-free telephone numbers, and the Internet, for example) to find information to help them manage their diseases and associated effects. Forming of a relationship with a provider refers to persons with chronic diseases forming a long-term, ongoing partnership with care providers in managing their disease over time. This partnership is distinct from that in acute disease in which the care provider independently directs the diseased or injured person's treatment. Taking action refers to persons with chronic diseases devising action plans regarding a variety of disease-related decisions and issues then carrying out and evaluating those plans (Center for the Advancement of Health, 2002). Lorig and Holman

(2003) also noted that an additional core behavior of self-management is self-tailoring, which refers to persons with chronic disease using the afore-mentioned core behaviors based on personal evaluation of their own needs and not necessarily their healthcare providers' evaluation of their needs.

Three other key features of self-management, as it is conceptualized currently in the nursing literature, include that (a) it is a multi-faceted process, not an outcome; (b) self-management is not synonymous with compliance to a provider's instructions; and (c) self-management includes both family (biological or not) and the individual. Self-management researchers, though they recognize that the core of self-management is the behaviors and strategies executed by persons with a chronic disease in order to manage their disease and its effects, have noted that self-management is a fluid process based on many factors such as stage of disease, disease severity, and changes in personal circumstances including a decrease or increase in financial resources (Clark, 2003; Grey, Knafl, & McCorkle, 2006; Holman & Lorig, 2004; Lorig & Holman, 2003; Moore, 2009; Ryan & Sawin, 2009). Self-management, then, is not stagnant but dynamic and changing as the context in which the person managing the disease changes. Self-management is also neither an endpoint nor an outcome but a process that affects and leads to outcomes (Holman & Lorig, 2004; Osborne, Wilson, Lorig, & McColl, 2007). As articulated by Clark (2003), changing people's self-management behaviors is useless if those behaviors do not improve outcomes such as quality of life or health status. Ryan and Sawin (2009), too, noted that self-management is a process that affects important outcomes but that it is not an outcome. Self-management, then, is a portion of the means to an end—but not the end (Holman & Lorig, 2004).

Self-management researchers also agree that self-management does not, or should not, refer strictly to patient compliance or adherence to a provider's instructions such as taking medications as prescribed (Ruggiero, Glasgow, & Dryfoos, 1997). To conceptualize self-management in this way would be, according to Holman and Lorig (2004), a disservice to those with chronic disease. Grey et al. (2006), based on a comprehensive review of the self-management literature, differentiate self-management from treatment compliance by stating that self-management "is a dynamic means of maximizing health rather than the submission to prescribed orders implied by the term compliance" (p. 279).

Nurse researchers have been at the forefront of distinguishing self-management from patient compliance or adherence. Qualitative studies involving patients diagnosed with a variety of chronic diseases, including human immunodeficiency virus (Swendeman, Ingram, & Rotheram-Borus, 2009; Webel & Holzemer, 2009), diabetes (Morrow, Haidet, Skinner, & Naik, 2008), heart failure (Thornhill, Lyons, Nouwen, & Lip, 2008), epilepsy (Buelow, 2001; Schneider & Conrad, 1983; Unger & Buelow, 2009), and asthma (George, Campbell, & Rand, 2009; Martin, Beebe, & Lopez, 2010) have revealed that treatment compliance is only one facet, and often not the most important facet, of self-management for persons living with chronic disease. Rather, persons with chronic disease engage in self-management in order to live as normally as possible within the context of having a chronic disease. That is, persons with chronic disease engage in behaviors to ensure that their normal, everyday lives can coexist with their chronic diseases (Grey et al., 2006).

Further distinguishing chronic disease self-management from treatment compliance, Clark (2003), in her comprehensive review and synthesis of the self-management literature, notes that all persons with chronic disease, regardless of outcomes, are practicing self-management. All persons with chronic disease use self-management strategies—effective or ineffective, congruent or incongruent with provider instructions—to manage their diseases. For example, just as a person with asthma who monitors his or her symptoms and avoids triggers in order to prevent symptoms is practicing self-management, so is another person with asthma who overuses bronchodilators in order to alleviate symptoms. Thus, self-management refers to all the strategies used by persons in managing all aspects of their diseases. Self-management strategies often are personally derived, influenced by the person's context in the form of work, family, and friends, and strategies often are not related directly to or in line with provider instructions (Clark, 2003; Holman & Lorig, 2004).

More recently, investigators have addressed self-management from the family perspective. In a review of the self-management literature, Grey and colleagues (2006) found that chronic disease self-management involves and affects the entire family of the person with the chronic disease. Changes in the family, such as the addition or subtraction of members, changes in family priorities, and fluctuations in family income, cause changes in a person's self-management behaviors. As well, changes in a person's chronic disease, such as increased or decreased severity, affect the ways in which the family is involved in disease management (Grey et al., 2006). The family in which disease management occurs can consist of those not biologically related to the person with the chronic disease—such as friends, co-workers, or others to whom the person feels

close and responsible. It also is not necessary that the person with the chronic disease live with the family members assisting him or her with disease management (Grey et al., 2006; Ryan & Sawin, 2009). Ryan and Sawin (2009) and Clark (2003) reported findings similar to those of Grey and colleagues (2006) in their reviews of the self-management literature and accordingly have added a family dimension to their self-management models. Other researchers have designed self-management interventions for adults based on the family aspect of management. Moore (2009), in her ongoing research with cardiac rehabilitation patients, has found that these persons' self-management as it relates to weekly exercise is influenced greatly by the family, or system as it is referred to by Moore (2009), in which those persons live and exist. Accordingly, Moore and her colleagues (2009), as part of a National Institutes of Health-funded study (P30 NR010676), are in the process of devising and testing a self-management intervention that involves the entire family, or system, in which persons in post-myocardial infarction cardiac rehabilitation exist. Participants will design their own self-management action plans with others in their family or system, and action plans are devised with the needs and desires of the entire family or system in mind (Moore, 2009). Moore (2009) reports that the preliminary findings of the ongoing study are promising in terms of those participants undergoing the system-oriented self-management intervention exercising more often and more consistently than those receiving the individual intervention. With the emergence of self-management models and interventions that specifically consider the family aspect of self-management, it is clear that self-management is no longer being seen as an individual process but as one embedded within a system.

As this discussion of the conceptualization of chronic disease self-management has revealed, while key features of the concept appear in the literature, there is no single definition concisely answering the question, "what is chronic disease self-management?" The lack of such a precise definition is likely because self-management researchers themselves continue to grapple with defining this concept in a manner that does justice to its multi-faceted, complex, and process-like nature (Lorig & Holman, 2003). However, a definition of the concept as it is currently represented in the literature, and which depicts the key aspects of it (that it is action-oriented, an ever-changing process, implemented in various domains, context-dependent, and self-directed) can be extracted: chronic disease self-management is a dynamic, self-directed, action-oriented, ever-changing behavioral and cognitive process in which those with chronic diseases engage, within a family or other system, in order to manage various aspects of their disease and its effect on their lives in multiple domains. While it often involves aspects of compliance, self-management is not synonymous with this concept.

Epilepsy Self-Management

Though the well-developed general chronic disease literature provides a conceptualization of the way in which persons self-manage chronic diseases in general, that all chronic diseases differ in terms of their physiologic and psychological effects on those who suffer from them, and that each chronic disease is associated with unique treatments, symptoms, and general effects on people's lives, cannot be ignored. Holman and Lorig (2004) noted that, while general principles apply, self-management of individual chronic diseases is dependent on individual nuances of those diseases. It is

reasonable to expect that diabetes self-management might appear very different from and involve different issues than, for example, self-management of human immunodeficiency virus. Epilepsy is no exception—those who suffer from this condition face unique treatments, symptoms, and challenges. It is thus necessary to consider how self-management specific to the disorder of epilepsy has been defined conceptually in the literature.

Though relatively small and still developing, a literature specific to epilepsy self-management does exist. Both the medical and nursing professions have contributed to this literature, and each defines epilepsy self-management differently. In the medical literature, epilepsy self-management is conceptualized chiefly as medication adherence, which is not surprising given that the most prevalent medical treatment of epilepsy involves the prescription of anti-epileptic drugs (Epilepsy Foundation, 2009). In fact, 70% of those with epilepsy can become seizure-free with the consistent, appropriate use of anti-epileptic drugs (Epilepsy Foundation, 2009). Not surprisingly, and in accordance with the previous review of general chronic disease self-management, nursing scientists have expanded this conceptual definition to include areas in addition to medication adherence.

In their review of the epilepsy self-management literature, Unger and Buelow (2009) characterized the way in which nurse researchers have conceptualized epilepsy self-management over the last decade. They found that, as in general chronic disease self-management, epilepsy self-management is defined most prominently as a behavioral concept and these behaviors occur in the following domains: medication compliance, safety, seizure management, and lifestyle management. Medication compliance refers to

taking anti-epileptic drugs as prescribed. Safety refers to the maintenance of one's own and others' safety immediately before, during, or after a seizure. Seizure management involves the prevention of seizures via nonpharmacological interventions as well as the management of the issues that arise during and immediately after a seizure. Lifestyle management refers to the ways in which people with epilepsy manage daily activities (i.e., work, school, social relationships) in the context having epilepsy (Unger & Buelow, 2009).

DiIorio, who has contributed most substantially to the epilepsy self-management literature, with her colleagues Faherty and Manteuffel (1994), defines epilepsy self-management as "the sum total of steps taken and processes used by a person to control seizures and manage the effects of a seizure disorder" (p. 167). These steps and processes occur in five key management areas: treatment, information/support, seizures, safety, and lifestyle (DiIorio et al., 1994; DiIorio, Hennessy, & Manteuffel, 1996). Buelow (2001), based on a qualitative study exploring the self-management of adults with severe epilepsy, conceptualized epilepsy self-management as behaviors executed in three domains: those to manage seizures, those to manage medications, and those to manage life. Buelow (2001) also characterized epilepsy self-management behaviors as being proactive or reactive in nature—the only attempt to form such a taxonomy of epilepsy self-management behaviors.

One of the most recent conceptualizations of epilepsy self-management is offered by Unger and Buelow (2009) and is derived from a hybrid concept analysis of epilepsy self-management. In the study, the epilepsy self-management literature was reviewed in order to determine the ways in which epilepsy self-management had been defined and

measured in the literature. The results of the literature review were combined with findings from qualitative interview data collected from those newly diagnosed with epilepsy (within the previous year) in order to yield both a theoretical- and fieldwork-based definition of the concept. From the analysis, three interactive themes (emotional and physical comfort, functional ability, and self-management actions and behaviors) emerged. The concept analysis resulted in the following definition of epilepsy self-management:

> [Epilepsy self-management is] an interactive phenomenon in which persons with epilepsy continually evaluate their perceived health status (comprised of how they feel emotionally/physically and how they are able to function on a daily basis) and implement a variety of behaviors to manage their medications/treatments, seizures, safety, physical and emotional comfort, functional status, and other factors depending on their current perceived health. (Unger & Buelow, 2009, p. 94)

Thus, a person's epilepsy self-management might "look different" (Unger & Buelow, 2009, p. 94) from one day to the next depending on perceived health status. These authors note both similarities and differences in their definition of epilepsy self-management with those previously described. It is similar in that a key aspect of the definition is self-management behaviors and that those behaviors occur in the domains (e.g., medications, safety, and so on) which are included in the prior definitions. It is different in that it is more process-oriented and contextualized. Instead of epilepsy self-management being described as a list of behaviors that occur in different domains, what is *going on* with persons with epilepsy on a daily basis helps determine their epilepsy self-management, which is, as a result, ever-changing. DiIorio (2009), too, recently has developed an epilepsy self-management model to include the contextual variables of personal and environmental factors, though this model remains unpublished.

Nurse researchers, therefore, have conceptualized epilepsy self-management in a manner consistent with conceptualizations of general chronic disease self-management in terms of it involving the use of behaviors and strategies in multiple domains and also by recognizing that epilepsy self-management chiefly is concerned with maintaining a normal daily life within the context of epilepsy and less so with adhering to a prescribed regimen. Nurse researchers continue to work to incorporate some features of general chronic disease self-management, such as its dynamic, process-oriented, individualized, and context/system-dependent nature, into their definitions and use of the term epilepsy self-management. Unger and Buelow's (2009) definition of epilepsy self-management, as well as DiIorio's (2009) expanded model, demonstrate development in these areas, however. More specific research is needed to confirm that these key features exist, and how they exist, in those self-managing epilepsy. In addition, the concept of epilepsy self-management within a family context needs to be explored.

Researchers also portray epilepsy self-management as being particularly complex. An epilepsy diagnosis necessitates constant management by the person in terms of medication adherence, symptoms, monitoring for exacerbations, and the overall effect of the disease and its treatment on the person's life. Epilepsy requires complicated, and often synchronized, treatment. Persons with epilepsy face many problems with day-to-day functioning, are at high risk for anxiety, often face social stigma, and frequently have difficulty securing and maintaining employment (Center for Managing Chronic Disease, 2010; Jacoby, 1992; Unsworth, 1999).

Epilepsy is treated chiefly with anti-epileptic drugs, and management of these medications appears to be a main source of the complexity of epilepsy self-management

(Buelow & Smith, 2004; DiIorio, Faherty, & Manteuffel, 1992; DiIorio & Henry, 1995; Epilepsy Foundation, 2009; Feely, 1999). Persons with epilepsy take, on average, two to three doses of anti-epileptic drugs per day, and typically these medications must be on a strict time schedule to prevent seizures (Feely, 1999; Yeager et al., 2005). Many medications have unpleasant side effects, such as somnolence, dizziness, and cognitive effects (Krauss & Crone, 2001). Some anti-epileptic drugs also are highly expensive, and the effectiveness of generic anti-epileptic drugs remains under scrutiny. Thus, many persons with epilepsy find themselves in a position with no insurance coverage for the brand-name epilepsy medications required to abate their seizures (Epilepsy Foundation, 2009).

Lack of adherence to prescribed epilepsy medications by those with epilepsy has been well documented in the literature. Up to 60% of patients with epilepsy fail to adhere to their prescribed medication regimens (Krumholz, 2009; Leppik, 1988), often due to the complexity of the dosing schedule, side effects, or financial concerns (Unger & Buelow, 2009). Buelow and Smith (2004) found, via use of a medication events monitoring system, that there is a mismatch between persons' with epilepsy perceptions of their medication adherence and their actual adherence; persons who reported that managing their medications was not a problem actually did miss doses of epilepsy medications. Lack of medication adherence in epilepsy has been associated with a three-fold increase in mortality compared to individuals with epilepsy who take medications as prescribed (Faught, Duh, Weiner, Guerin, & Cunnington, 2008).

A diagnosis of epilepsy also necessitates major lifestyle changes and activity restrictions, leading to loss of independence. Persons with epilepsy commonly cannot

drive a vehicle or operate machinery. Other activity restrictions associated with their

disease, in addition to medication side effects, may prevent them from fulfilling everyday

roles related to parenting, work, and relationships. In fact, persons with epilepsy cite

inability to drive and alterations in role fulfillment as chief concerns in living with

epilepsy (Krumholz, 2009). Kobau and DiIorio (2003) and McAuley, McFadden, Elliott,

and Shneker (2008) found that individuals with epilepsy are less compliant with these

activity and lifestyle restrictions than taking their medications as prescribed. Also,

perhaps more so than in other chronic diseases, persons with epilepsy are at high risk for

bodily injury to themselves or others. Traumatic injury can occur during generalized

seizures and also during the post-ictal period. Thus, persons with epilepsy must make

special efforts to alter their environments and activities to maintain safety, and many find

these alterations at home and at work to be disruptive (DiIorio et al., 1996; Krumholz,

2009; Unger & Buelow, 2009).

How Has Self-Management Been Operationally Defined in the Literature?

General Chronic Disease Self-Management

Given its process-oriented nature, self-management is decidedly difficult to

measure (Clark, 2003; Holman & Lorig, 2004). As Lorig and Holman (2003) note,

self-management is not a *thing* that lends itself to measurement. Rather, the outcomes of

self-management (discussed later), and not the self-management process itself, should be

measured (Lorig, 2003). However, researchers working with a variety of chronic disease

populations have ventured to do so. Chronic disease self-management has been

operationalized in two chief ways: (a) as medication and treatment adherence, and (b) as

the engagement in certain behaviors.

Despite the fact that chronic disease self-management is espoused in the literature as distinct from, though perhaps overlapping with, medication and treatment adherence, it often is operationalized in this way. In their review of the self-management literature, Unger and Buelow (2009) found that, from 2000–2009, self-management in medical and nursing research studies most commonly was measured as treatment compliance and particularly medication adherence. In fact, in some studies, self-management has been measured solely via serum concentration levels of prescribed medications (Miura et al., 2001). More commonly, researchers have measured self-management via self-report of medication or treatment adherence. Persons who are more compliant with medications or other treatments (e.g., a person with hypertension who abstains from excess salt intake or a person with diabetes who performs proper foot care) are seen as practicing "good" self-management (Unger & Buelow, 2009).

Given that a core aspect of self-management is that it involves the execution of certain behaviors, some researchers have developed instruments designed specifically to measure the degree to or frequency with which persons with chronic diseases engage in self-management behaviors. Such scales exist for a variety of chronic diseases, including heart failure (Jaarsma, Stromberg, Martensson, & Dracup, 2003), diabetes (Charron-Prochownik, Zgibor, & Peyrot, 2007), epilepsy (DiIorio, 1997; DiIorio et al., 2004), and asthma (Berg, Dunbar-Jacob, & Sereika, 1997; Taylor et al., 1991). These instruments are self-report and most commonly ask respondents to rate, on a Likert-type scale, how often they engage in certain behaviors. The majority of the behaviors relate to treatment adherence, such as adherence to dietary restrictions in those with heart failure (Jaarsma et al., 2003). In general, the scales are scored so that the more frequently the

person engages in behaviors listed on the instrument, the "higher" or "better" his or her self-management is judged to be.

In many cases, researchers measure self-management via self-report of engagement in behaviors, though not via specific, published instruments. For instance, researchers may choose a list of behaviors they deem important in the self-management of a certain chronic disorder then ask study participants to report how often they engage in those behaviors (Unger & Buelow, 2009). In a self-management study involving women with diabetes, for example, researchers asked participants to report their engagement in prescribed dietary behaviors (Shultz, Corbett, & Allen, 2009).

Both the measurement of self-management as compliance and as engagement in behaviors is problematic given the conceptual definition of self-management discussed previously in this chapter. First, measuring self-management strictly as compliance is at odds with the basic premise of self-management—that it is self-directed and is mainly focused on helping the person to live normally despite having a disease. It also is incomplete; qualitative studies with those suffering from chronic diseases often have indicated that adherence to medications and other treatments often is least important to them in terms of managing their diseases. Second, to measure self-management as engagement in behaviors neither captures the process orientation nor the individualized or context-bound nature of the concept. It also is far too limiting because a scale with a pre-determined list of supposed helpful or positive strategies cannot possibly capture the unique and context-dependent ways in which people manage their chronic diseases, nor can these instruments detect the fluid, or changing, nature of self-management. Such a list of strategies also assumes that the use of the behaviors would be beneficial to all who use

them, even though the literature suggests, as discussed previously in this chapter, that self-management is highly individualized.

It is clear that the recent measurement of self-management in the literature is at odds with the conceptualization of the concept. As well, the appropriateness of the direct measurement of self-management is questionable (Lorig & Holman, 2003). Because self-management is a process, frank measurement of it should be avoided in favor of the characterization of it (via descriptive use of different types of strategies, for example) to provide insight into the processes of self-management that are most beneficial in given contexts (Lorig & Holman, 2003).

Epilepsy Self-Management

Despite the process-oriented conceptual definition of epilepsy self-management in the literature, as is seen in the general chronic disease self-management literature, researchers have attempted to directly measure epilepsy self-management. Unger and Buelow's (2009) review of the epilepsy self-management literature revealed that epilepsy self-management, the same as general chronic disease self-management, has been primarily operationalized as medication compliance and the engagement in epilepsy self-management behaviors.

In both the medical and nursing literature, epilepsy self-management has been measured predominantly as medication compliance. In their review of the concept of epilepsy self-management, Buelow and Johnson (2000) found that epilepsy self-management was operationalized nearly always this way, just as Unger and Buelow (2009), in a more recent review of the epilepsy self-management literature, found that in studies in which epilepsy self-management was being measured directly, most

researchers used medication compliance as the prime or sole measure of the concept. This measurement often is achieved via self-report, medication event monitoring-caps data, or blood concentration levels of anti-epileptic drugs (Buelow & Johnson, 2000; Unger & Buelow, 2009). As is seen in the general chronic disease self-management literature, those who comply with epilepsy medication regimens are seen as "high" or "good" self-managers (Unger & Buelow, 2009).

Just as general chronic disease self-management frequently has been measured as the degree to or frequency with which individuals with chronic diseases engage in certain behaviors, so too has been epilepsy self-management. One published instrument, the Epilepsy Self-Management Scale, developed by DiIorio (1997), commonly has been used in studies in which epilepsy self-management has been measured directly. The instrument is comprised of 38 questions that ask respondents to rate how often they use certain behaviors in the domains of medication adherence and, in the latest version, information, lifestyle, and safety. The scale items are epilepsy-specific, and the scale includes both positive (such as checking with the doctor before taking other medications) and negative (such as skipping doses of medication) self-management behaviors. Those engaging most in positive self-management behaviors and least in negative self-management behaviors, score highest on the scale and are seen as practicing better epilepsy self-management (DiIorio, 1997).

The measurement of epilepsy self-management both as medication compliance and as engagement in behaviors is problematic for the same reasons that were discussed previously in this section in the review of the ways in which general chronic disease self-management most commonly is operationalized: The use of compliance as the main

measure is at odds with the conceptual definition of epilepsy self-management and is incomplete in that it fails to capture other important aspects of the concept as supported by the epilepsy self-management literature. The use of engagement in behaviors to measure epilepsy self-management fails to capture the process orientation and individualized and fluid nature of the concept. Also, while the Epilepsy Self-Management Scale (DiIorio, 1997) was developed based on interviews with people with epilepsy, and thus includes behaviors relevant to those with the disorder, utilizing a close-ended list of behaviors is limiting in that it cannot possibly capture all the unique ways in which those with epilepsy self-manage the disease. Finally, to use such a list of behaviors assumes that all of the "negative" strategies included are indeed inappropriate for use in all those with epilepsy and that those labeled as "positive" would be equally helpful for all those practicing epilepsy self-management—which is an unfounded assumption given that epilepsy self-management, just as general chronic disease self-management, is beginning to be portrayed in the literature as highly individualized (DiIorio, 2009; Unger & Buelow, 2009). For example, one item on the Epilepsy Self-Management Scale (DiIorio, 1997) asks participants to rate the frequency with which they *stay out late at night* (item 6). According to the scale, a person who indicates that he or she often stays out late at night is not practicing appropriate epilepsy self-management, presumably because lack of sleep is a common trigger for seizures in those with epilepsy (Malow, 2004). However, staying out late at night does not indicate the number of hours that the person sleeps each night, and it is possible that he or she may sleep late into the morning or afternoon and is thus still sleeping enough to prevent a sleep deprivation-induced seizure. As well, sleep deprivation is not a seizure trigger for *every* person with epilepsy (Malow, 2004) and thus

staying out late at night or neglecting to sleep the recommended number of hours per night would not negatively affect every person with epilepsy in terms of increasing seizure frequency.

It should be noted that measuring anti-epileptic medication compliance and engagement in epilepsy self-management behaviors is not without benefit—medications are a key aspect of epilepsy treatment and knowledge regarding what people with epilepsy are doing on a daily basis to manage their condition is invaluable—but using these measurements as direct reflections of epilepsy self-management is inappropriate. A more beneficial approach would be to enrich the available descriptions of epilepsy self-management via categorization of epilepsy self-management behaviors and processes, as Buelow (2001) has done by labeling epilepsy self-management strategies as either proactive or reactive. Doing so would allow researchers to categorize persons' epilepsy self-management behaviors while still allowing for the individualized nature of them to be captured. The relationship between different types of self-management strategies/processes and important outcomes could thus be explored.

What Are the Outcomes of Self-Management?

Chronic Disease Self-Management

As discussed previously in this chapter, general chronic disease self-management is not, in and of itself, an outcome. Rather, self-management is a means to important outcomes (Lorig, 2003; Lorig & Holman, 2003). In this section of the chapter, outcomes of chronic disease self-management as they are most commonly represented and measured in the literature are discussed. The effect of self-management interventions on these outcomes are discussed later in this chapter.

A review of the general chronic disease self-management literature reveals that self-management outcomes are measured most commonly in terms of disease status or severity, health status or quality of life, and healthcare resource utilization. Lorig and Holman (2003) note that the desired outcome of self-management is the achievement of these outcomes in a positive way: decreased disease severity and less frequent exacerbations, improved health status or quality of life, and reduced healthcare resource utilization. In most research studies, these multiple outcomes are not measured or discussed in isolation but as a somewhat- or all-inclusive group.

Disease status and severity. One of the most common outcomes of self-management espoused in the literature is that of disease status or severity. Unger and Buelow (2009), via their review of the self-management literature, found that a key feature of the concept is that one of its chief outcomes is some degree of disease control or, perhaps more descriptively, current status or severity. For example, for a person with diabetes, a main outcome of the person's self-management could be the person's Hemoglobin A1C or daily blood glucose values (Speer et al., 2008). For a person with chronic obstructive pulmonary disorder, forced vital capacity, oxygen saturation, and arterial blood gas values are disease status outcomes (Bourbeau & van der Palen, 2009). Disease status and severity outcomes also can be viewed in terms of frequency of exacerbations, as is common in studies with the heart failure (Armbrister, 2008) and chronic obstructive pulmonary disease populations (Bourbeau & van der Palen, 2009). Similarly, others, such as Ryan and Sawin (2009), refer to the disease status or severity outcome of self-management as disease stabilization—or the degree to which, given that

there are no cures for most chronic diseases, the disease fails to progress to later, or more severe, stages.

The inclusion of disease status and severity as a self-management outcome is derived heavily from the medical, and not the nursing, model. In medicine, health is defined primarily as the absence of disease (Newman, 1986; Thomas, 1981); whereas in nursing, health is defined as a subjective illness/wellness experience, referring to somatic and emotional comfort and functional ability at or near one's perceived capability level, which can occur in the presence or absence of disease (Lyon, 2005; Nightingale, 1859/1969). From a nursing perspective, then, to consider disease status and severity as the sole outcome of chronic disease self-management is severely inadequate, though it often occurs in the medical literature (Barlow, Sturt, & Hearnshaw, 2002; Unger & Buelow, 2009). While nurse researchers recognize the need to track disease-related outcomes, the majority of their self-management research is focused on other outcomes, discussed later in this chapter, that are more congruent with nursing's definition of health (Barlow et al., 2002; Lorig & Holman, 2003).

Health status and quality of life. Given that nursing's orientation to chronic disease self-management is characterized chiefly by a view of persons with chronic disease engaging in self-management in order to ensure that their normal lives can coexist with their chronic diseases (Lorig, 2003), it is no surprise that nurse researchers support and most frequently track and measure self-management outcomes that consider the overall effect of chronic disease on people's lives. In their reviews of the self-management literature, both Barlow and colleagues (2002) and Unger and Buelow (2009) found that, in the nursing literature, and particularly in the last decade, the prime

self-management outcomes measured have included those that can be described best as health status and quality of life; further, Gordon and Galloway (2008), in their review of the effectiveness of self-management interventions, included health status and quality of life as key self-management outcomes. Health status is a general term and has been used in a variety of ways. It is comprised of multiple components. Lorig and colleagues (2001) define it in terms of symptom experience, disability, health distress, self-rated health, and social/role limitations. Others refer to it as psychological and physical health or well-being (Grey et al., 2006; Ryan & Sawin, 2009). Health status perhaps is best defined as a self-management outcome by comparing it to the concept of wellness in Lyon's (2005) definition of health as it pertains to nursing: a person's subjective evaluation of his/her emotional and physical comfort and ability to function at perceived capability level—in other words, a person's ability to live normally and comfortably despite having a chronic disease. Quality of life is closely related to health status and generally is defined as a person's perceived overall well-being or satisfaction with life (Moons, Budts, & DeGeest, 2006). Quality of life frequently is measured as an outcome of chronic disease self-management in the nursing literature and sometimes is used to capture both health status and quality of life outcomes simultaneously (Barlow et al., 2002; Lorig & Holman, 2003; Unger & Buelow, 2009). Of note is that the outcomes of disease status and severity are not always related to health status and quality of life. For example, higher levels of disease control have been shown to be negatively correlated with reported levels of quality of life (Clark, 2003).

Healthcare resource utilization. One self-management outcome that is seen in the medical and nursing literatures is that of healthcare resource utilization. In their

reviews of the self-management literature, Barlow and colleagues (2002), Gordon and Galloway (2008), and Unger and Buelow (2009) found that healthcare resource utilization, comprised of physician/clinic visits, emergency department visits, and inpatient hospital days, commonly were measured as an outcome of self-management. For example, Lorig and colleagues (2001), in their large-scale self-management studies, tracked participants' outpatient and emergency department visits, days in hospital, and number of times hospitalized, as self-management outcomes—as have researchers investigating self-management outcomes in a variety of disease populations (Gordon & Galloway, 2008). In addition, the Centers for Disease Control and Prevention (2009) supports healthcare resource utilization as a prime self-management outcome.

In recognition of healthcare resource utilization as an important outcome of self-management, researchers and theorists have begun including this outcome in their self-management models. Grey et al. (2006) include the self-management outcome of *utilization* in their model. Other researchers, such as Ryan and Sawin (2009), consider the previously listed direct healthcare resource utilization activities as self-management outcomes but also what they call indirect utilization costs in the form of fewer productive days at work/school as a result of disease-related symptoms or other effects. The Centers for Disease Control and Prevention (2009) also recognizes these indirect utilization outcomes of self-management.

Epilepsy Self-Management

What are considered, in the epilepsy literature, to be outcomes of epilepsy self-management are very similar to those of general chronic disease self-management previously discussed, though some are specific to those suffering from epilepsy. The

Commission on Outcome Measurement in Epilepsy (1998), in association with the International League Against Epilepsy, published a list of outcomes associated with epilepsy treatment, including self-management of the disease. This list includes seizure frequency/severity, health status and quality of life, and healthcare resource utilization. Of note is that quality of life as an outcome of epilepsy management is discussed in a relatively very small portion of the commission's report—suggesting that the authors viewed the important outcomes of epilepsy care and management from a medical model view. A review of the epilepsy self-management literature suggests that these outcomes—seizure frequency and severity, health status and quality of life and, to a lesser extent, healthcare resource utilization—have been adopted as the main outcomes of epilepsy self-management since the publication of the commission's report.

Seizure frequency and severity. The outcome of seizure frequency and severity is akin to the general chronic disease self-management outcome of disease status and severity, particularized for the epilepsy population. In a Cochrane review of epilepsy self-management interventions and associated outcomes, nearly all studies reviewed measured seizure frequency as an outcome of epilepsy self-management (Shaw et al., 2009). Buelow and Johnson (2000), in their review of epilepsy self-management and its outcomes, found that seizure frequency and severity are considered prime outcomes of epilepsy management and, in fact, that seizure frequency often is seen as the "end product of epilepsy self-management" (p. 333). Nine years later, Unger and Buelow (2009), in reviewing the epilepsy self-management literature, found that, even in nursing research studies, number of seizures and severity of the disorder were considered main outcomes of epilepsy self-management. DiIorio and colleagues (1994, 1995, 1996), for example,

measured seizure frequency as an epilepsy self-management outcome. Researchers and clinicians working with those with epilepsy have expressed that diminishing seizure frequency is a main self-management outcome for those with the disorder (Center for Managing Chronic Disease, 2010). Nurse researchers, and particularly Buelow and Johnson (2000) and DiIorio (1997), have begun to note that epilepsy self-management outcomes go beyond disease control in the form of seizure frequency and severity. In fact, the Centers for Disease Control and Prevention created the Managing Epilepsy Well Network (n.d.) to ensure that epilepsy self-management research aimed at enhancing other outcomes, namely health status and quality of life, is conducted.

McAuley and colleagues (2010) executed a study with the aim of comparing adult epilepsy patients' main concerns about the disease with those of their healthcare providers. Both patients and their healthcare providers were asked to rate, in order of importance, their top five concerns regarding the patients' epilepsy from the following choices: having a seizure unexpectedly, ability to drive, memory problems, being a burden to family members, fear of being injured during a seizure, seizures not being controlled, and medication side effects. Patients were more concerned with *life issues* (memory impairment and being a burden to others) while practitioners were more concerned with *clinical issues* (seizure control). The most significant finding was regarding patients' concern for memory problems. Regardless of seizure severity or control, a major concern for patients was memory problems, while practitioners did not even rate this as a top-five concern (McAuley et al., 2010). The results of the McAuley and colleagues (2010) study suggest that desired outcomes of epilepsy management

amongst persons with epilepsy and the practitioners who provide their medical treatment are not always congruent.

Health status and quality of life. Health status and quality of life, defined identically because they are in relation to general chronic disease self-management outcomes, have become prime outcomes of epilepsy self-management, particularly in the nursing literature. In a recent survey, epilepsy researchers and clinicians noted that preservation and improvement of quality of life is the main treatment and management outcome for individuals with epilepsy (Center for Managing Chronic Disease, 2010). In addition, Unger and Buelow (2009) found in their review of the epilepsy literature, that, in addition to seizure frequency and severity, nurse researchers most prominently considered the concepts of health status and quality of life as epilepsy self-management outcomes. Of note, however, is that, in most nursing research studies pertaining to epilepsy self-management, these outcomes have not yet been measured consistently. For example, while Buelow (2001) measured quality of life of those with epilepsy via Ferrans' Quality of Life Index-Epilepsy Version (1996), DiIorio and colleagues (2009), arguably the most substantial and active contributors to the epilepsy self-management literature, though they recognize and suggest that health status and quality of life are main outcomes of epilepsy self-management, have not measured them consistently as epilepsy self-management outcomes, even in epilepsy self-management intervention studies (DiIorio et al., 2009). Thus, in contrast to what is seen in the more well-developed general chronic disease self-management literature, the outcomes of health status and quality of life are espoused as primary to epilepsy self-management but have not yet been consistently measured in the epilepsy population. Despite this gap, it is clear that the

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importance of health status and quality of life as epilepsy self-management outcomes is becoming more recognized, especially with the emergence of the Managing Epilepsy Well Network (n.d.), a prime focus of which is facilitating research aimed at improving health status and quality of life outcomes for persons with epilepsy. In addition, the most recent models of epilepsy self-management include health status and/or quality of life as epilepsy self-management outcomes (DiIorio, 2009; Unger & Buelow, 2009).

Healthcare resource utilization. The epilepsy self-management outcome of healthcare resource utilization in the form of outpatient/emergency department visits and hospitalizations is indicated by the Commission on Outcome Measurement in Epilepsy (1998), but it is not tracked widely or measured in the epilepsy self-management literature. For example, a Cochrane review of epilepsy self-management interventions (Shaw et al., 2009) revealed that healthcare resource utilization was measured only sporadically in the studies reviewed. Resource utilization also is not included as an outcome in any of the published epilepsy self-management models. It is unclear why healthcare resource utilization is measured less frequently as an outcome of epilepsy self-management compared with general chronic disease self-management. However, as in general chronic disease self-management, researchers are beginning to recognize the need to consider number of productive days, which are generally fewer in those with epilepsy due to seizures, medication side effects, and unpleasant emotional symptoms in the form of depression, as a potential epilepsy self-management outcome (Center for Managing Chronic Disease, 2010).

Gaps in Knowledge Regarding Self-Management Outcomes

The previous discussion of the outcomes of both general chronic disease and epilepsy self-management would be incomplete without reference to noticeable gaps in both sets of literature. First, it must be noted that many chronic diseases, including epilepsy, tend to occur across the lifespan and affect individuals of all ages. However, neither the chronic disease nor epilepsy self-management literatures differentiate self-management outcomes across the lifespan. That is, researchers have yet to take into account the effects of different developmental stages on the pertinence of outcomes. It cannot be assumed that the self-management outcomes for a 6-year-old with diabetes are identical to those of a 68-year-old with the condition. Outcomes also are not discussed in terms of length of time since diagnosis. The self-management outcomes of a person diagnosed with asthma two months ago, versus those for a person diagnosed 25 years ago, are likely different. The ways in which developmental stages and length of time since diagnosis could alter the outcomes of self-management must be explored in order to ensure that self-management interventions are targeting and affecting appropriate outcomes for all. To address the gap surrounding epilepsy self-management outcomes, the Managing Epilepsy Well Network (n.d.) has formed a work group dedicated to improving outcome measures for persons with epilepsy.

What Affects and Influences Self-Management?

General Chronic Disease Self-Management

Throughout the chronic disease self-management literature, researchers have demonstrated that a multitude of variables seem to influence the ways in which people self-manage their chronic diseases and some appear to influence self-management

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outcomes directly. The relationships between these variables and self-management have informed self-management theory and model development with researchers, and particularly nurse researchers, including such variables in their theories and models. The ways in which these variables are labeled in the literature differ. Some, such as Ryan and Sawin (2009) and Grey et al. (2006) refer to them as risk and protective factors. Others, such as Clark (2003), call them interpersonal and external factors, and still others, such as Lorig (2003), refer to them simply as variables that affect self-management. In this section of the chapter, those factors most commonly demonstrated in the empirical and theoretical literature as influencing self-management are discussed and, to simplify the discussion, are organized into the logical categories of contextual, internal, and external factors.

Contextual factors. Contextual factors influencing self-management are generally those variables about a person that cannot be changed but must be considered: disease severity, age, gender, and socioeconomic status. Grey and colleagues (2006), in developing their family-based self-management theory, reviewed the literature to determine ways in which these variables influence self-management. They found that those suffering from more severe or advanced diseases require and engage in more complex self-management. Regarding age, they found that younger and older persons with chronic disease have greater self-management needs and generally require more complex self-management. Evidence regarding differences between men and women and their self-management has been variable and inconclusive and those of lower socio-economic status demonstrate poorer self-management outcomes (Grey et al., 2006).

Internal factors. Internal factors refer to those within the person, and they are usually cognitive in nature. Three main internal factors influencing self-management can be extracted from the literature: knowledge and beliefs, self-efficacy, and self-regulation.

Knowledge and beliefs. A person's knowledge and beliefs generally refer to his or her current understanding of facts and beliefs about the chronic disease with which he or she has been diagnosed, as well as his or her knowledge about its associated course and treatments. In their reviews of the self-management literature, both Ryan and Sawin (2009) and Clark (2003) found that one's knowledge and beliefs about his or her chronic condition and its treatment affect the way a person self-manages at a basic level. For example, in the human immunodeficiency virus literature, research findings have indicated that changing the views of persons who are human immunodeficiency virus seropositive about their disease to *a chronic disease*, instead of *a death sentence*, resulted in them being more interested in learning how to self-manage (Moskowitz, Henneman, & Young-Holt, 2002). Lorig, too, based on her work with Laurin and Holman (1984), in which they reviewed the concept of self-management, including its antecedents and consequences, asserts that disease and treatment knowledge are essential to self-management. However, it also is recognized that disease and treatment knowledge and beliefs are variables that often significantly affect self-management by virtue of their relationship with other variables, most notably self-efficacy (Marks et al., 2005a). In other words, a person's knowledge and beliefs about his or her chronic disease act as building blocks of his or her self-management and are thus essential to self-management. However, as will be discussed later, a person's self-management as well as

self-management outcomes cannot be expected to change based only on a change in his or her knowledge and beliefs (Marks et al., 2005a).

Self-efficacy. The concept most pervasively discussed in the general chronic disease literature as influencing self-management is self-efficacy, a core concept of Bandura's (1997) social cognitive theory. All of the major chronic disease self-management models (Grey et al., 2006; Holman & Lorig, 2004; Ryan & Sawin, 2009) include self-efficacy and its other components as prime antecedents of self-management and self-management outcomes. In fact, Marks et al. (2005a, 2005b), based on their review of existing self-efficacy-enhancing interventions to improve self-management, suggested that self-efficacy is at the crux of self-management and self-management outcome improvement. Broadly, self-efficacy refers to a person's confidence in his or her ability to carry out behaviors or to change a cognitive state, regardless of circumstances, to achieve desired outcomes by doing so. Outcome expectancies, a concept related to self-efficacy, refer to a person's beliefs about how engaging in certain behaviors or cognitive states will affect an outcome important to him or her. Self-efficacy does not refer to a person's actual ability to engage in behaviors, only his or her *confidence* to do so. Self-efficacy is not a global concept—a person with high self-efficacy to perform one behavior may have very low self-efficacy regarding a different behavior (Bandura, 1997).

According to Marks et al. (2005a), self-efficacy as it applies to self-management involves three separate domains: having tactic task knowledge and skills, having an explicit sense of confidence in one's ability to mobilize motivational and cognitive resources needed to perform a skill, and having confidence in one's ability to execute a

specific skill in a specific context. Marks et al. (2005a, 2005b) published a two-part review of the role that self-efficacy plays in influencing self-management and its outcomes. The results of the review are discussed in the following paragraphs.

First, self-efficacy has been demonstrated to have a direct influence on engagement in certain health behaviors. Marks et al. (2005a) cite and review several studies involving those with heart disease, asthma, and other chronic diseases in which baseline levels of self-efficacy and changes in self-efficacy were associated with changes in behaviors. Those with higher levels of self-efficacy engaged more frequently in desirable health behaviors. These behaviors involved those of compliance (medication adherence) as well as others for managing other aspects of the diseases (managing stress) (Marks et al., 2005a). However, as discussed previously, improved outcomes, and not engagement in self-management behaviors, is the desired endpoint of self-management.

There is much evidence indicating that higher levels of self-efficacy are associated with better self-management outcomes. As pointed out by Marks et al. (2005a), self-efficacy independently can predict health outcomes. This phenomenon has demonstrated short-term in outcomes such as functional ability and disease status in a variety of disease contexts (Marks et al., 2005b). The most staggering evidence of this phenomenon resulted from two of Lorig and colleagues' large studies, one involving those with arthritis (Lorig, Mazonson, & Holman, 1993) and the other of those with a variety of chronic diseases (Lorig et al., 2001), in which, up to two years following a self-efficacy-based self-management intervention, participants demonstrated improved health status (in the specific area of health distress) as well as decreased healthcare resource utilization. Interestingly, engagement in self-management behaviors (which also

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increased) was not associated with the changes in self-management outcomes, but baseline measurements and changes in self-efficacy were positively correlated with these improved outcomes. Similar findings exist in the asthma literature, where higher levels of asthma management self-efficacy have been associated with higher levels of quality of life and physical functioning 18 months following intervention (Katz, Yelin, Eisner, & Blanc, 2002; Mancuso, Rincon, McCulloch, & Charlson, 2001). These studies utilized covariates to control for other variables (disease severity, for example) that could have influenced reported outcomes. The synthesis offered by Marks et al. (2005a, 2005b) also points out that self-efficacy can influence self-management in other, less direct ways. Self-efficacy beliefs can influence mood, motivation levels, and attitudes regarding health promotion behaviors, despite previous disconfirming experiences. That is, one's self-efficacy can influence how likely that person is to engage in behaviors that may improve his or her outcomes. Self-efficacy also affects the ways in which people set goals, including those associated with their chronic disease self-management (Marks et al., 2005b).

To summarize, baseline levels of self-efficacy, as well as changes in levels of self-efficacy, are associated with and influence chronic disease self-management and its outcomes. Self-efficacy can predict the adoption of health behaviors and, more importantly, mediate important self-management outcomes (Marks et al., 2005a, 2005b).

Self-regulation. Yet another cognitive concept that is associated with self-management is self-regulation. Self-regulation is a cognitive process that occurs when a person observes, makes judgments, and reacts accordingly to reach a personal goal by changing or continuing his or her behaviors (Bandura, 1986). In the context of

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self-management, self-regulation is the process by which persons with chronic disease derive the strategies and behaviors they use in managing their diseases (Clark, 2003). Both Ryan and Sawin (2009) and Clark (2003) included self-regulation as a key factor associated with self-management in their self-management models. In Ryan and Sawin's (2009) model, self-regulation is an antecedent to self-management, while in Clark's (2003) model, self-regulation acts as a sort of context within which self-management occurs.

Both Ryan and Sawin (2009) and Clark (2003) reviewed the chronic disease self-management literature in order to identify the influence of self-regulation on self-management, and these authors report similar conclusions. Self-regulation indirectly is related to self-management in that it is positively correlated with self-efficacy. Self-regulation also is positively associated with engagement in health-promoting behaviors (Clark, 2003; Lorig, Ritter, Laurent, & Fries, 2004; Lorig et al., 2001; Ryan & Sawin, 2009). Other studies have demonstrated that, as with self-efficacy, self-regulation has been positively associated, at least in the short-term, with self-management outcomes such as quality of life, disease status, and healthcare resource utilization (Barlow et al., 2002; Lorig, Ritter, & González, 2003; Wagner, Austin, & von Korff, 1996).

External factors. External factors refer to those outside of the person self-managing the chronic disease. Two of the most frequently discussed external factors in terms of a relationship to self-management are social support and access to healthcare. These variables are included in multiple models of self-management, including Ryan and Sawin's (2009), Grey et al.'s (2006), and Clark's (2003).

Social support generally is conceptualized in the self-management literature as the degree of emotional, informational, and other support available to the person from family, friends, and healthcare providers (Grey et al., 2006). Thus, healthcare access is embedded in the variable of social support in terms of a person's access to support from his or her healthcare providers (Ryan & Sawin, 2009).

In the literature, social support and healthcare access have been shown to be positively associated with engagement in health protective and promotion behaviors. Barlow et al. (2002), in reviewing the self-management literature, and Lorig et al. (1993), in a self-management intervention study involving persons with arthritis, found that those with higher levels of social support and healthcare access engage more frequently in health promotion behaviors such as exercise, smoking cessation, and medication adherence. In fact, most of the literature regarding social support and healthcare access and self-management has been related to compliance with treatment regimens and, although the results of such studies have demonstrated that those with higher levels of social support and better healthcare access are more compliant, self-management is not synonymous with compliance. Social support and healthcare access have not been shown to independently affect self-management outcomes (Barlow et al., 2002).

Despite knowledge that social support and healthcare access have not been associated with self-management outcomes, many researchers include these variables in their self-management models. Ryan and Sawin (2009) justify the inclusion of social support/access to healthcare in their model by pointing out its relationship to other variables important in self-management: knowledge and beliefs and self-regulation. In studies involving people with a variety of chronic diseases, those with higher levels of

social support/access to healthcare consistently have demonstrated higher levels of knowledge and beliefs and self-regulation abilities, as discussed previously, that are involved in self-management (Ryan & Sawin, 2009).

Epilepsy Self-Management

Most of the key variables related to and influencing general chronic disease self-management also appear in the epilepsy literature as influential to epilepsy self-management. Contextual, internal, and external factors are discussed in this section. Of note is that the epilepsy self-management literature is less well-developed than the general chronic disease self-management literature in terms of the existence of empirical data demonstrating the ways in which variables affect epilepsy self-management, largely because epilepsy researchers have drawn from findings in the general chronic disease self-management literature in developing their epilepsy self-management models.

Contextual factors. As in general chronic disease self-management, these variables include disease severity (seizure frequency and severity), age, gender, and socioeconomic status. Throughout the epilepsy self-management literature, those with more severe seizure disorders are assumed to have different and more complex self-management needs than those with less severe cases of the condition. DiIorio et al. (1996) found that some persons with epilepsy do require much more complex treatment regimens than others with less severe epilepsy, but no studies have been executed to ascertain that their self-management is different than that of other people. Others have found that the complexity of an epilepsy medication regimen can influence self-management in the compliance domain (Leppik, 1988). No studies have been executed to determine the precise relationship between age and gender and epilepsy

self-management, though Begley and colleagues (2010) found no significant relationship between socioeconomic status and epilepsy self-management as measured by the Epilepsy Self-Management Scale (DiIorio et al., 1994).

Internal factors. In the epilepsy self-management literature, the same internal factors, apart from self-regulation, as those associated with general chronic disease self-management have been considered (based on drawing from the general chronic disease self-management literature) or shown, via research with persons with epilepsy, to influence epilepsy self-management.

Knowledge and beliefs. Both Shope (1996) and DiIorio (2009) included knowledge (or information), particularly about seizures and their treatment, in their models of epilepsy self-management. Neither of these researchers, nor any others, however, actually measured the relationship between knowledge and beliefs and epilepsy self-management in a sample of persons with epilepsy. Instead, they justified their inclusion of this variable in their models via citations of studies from the chronic disease self-management literature that demonstrate the relationship between knowledge and beliefs and self-management. DiIorio et al. (1996), in testing their original epilepsy self-management framework, did examine the relationship between knowledge and self-efficacy and found that the two variables were positively related in a population of persons with epilepsy just as in those with other chronic diseases. Epilepsy self-management researchers recognize that knowledge and beliefs do not, by themselves, change behavior or outcomes but that they are foundational to the epilepsy self-management process (DiIorio et al., 1996).

Self-efficacy. Just as is in the general chronic disease self-management literature, discussions and explorations of self-efficacy and its relation to epilepsy self-management and its outcomes are prevalent throughout the epilepsy literature. Unger and Buelow (2009) found that self-efficacy is measured consistently in studies investigating epilepsy self-management and that it is a concept closely related to epilepsy self-management. Self-efficacy also is included in models of epilepsy self-management. For example, in DiIorio's (2009) latest version of her epilepsy self-management model, self-efficacy influences decision-making, epilepsy self-management behaviors, and epilepsy self-management outcomes. While epilepsy self-management researchers do draw from findings regarding the relationship between self-efficacy and self-management from the chronic disease self-management literature (Unger & Buelow, 2009), some, and particularly Kobau and DiIorio (2003), have investigated the precise relationship between self-efficacy and outcome expectancies and epilepsy self-management in samples of persons with epilepsy.

In a descriptive study, Kobau and DiIorio (2003) examined the self-efficacy and outcome expectancies of persons with epilepsy in relation to their epilepsy self-management in the areas of medication and lifestyle management. These investigators, then, did not investigate the relationship between self-efficacy and epilepsy self-management but described how confident persons with epilepsy felt in managing their disease strictly in terms of compliance. Participants demonstrated significantly higher self-efficacy and more positive outcome expectations in the realm of medication management, suggesting they are much more confident in and expect better outcomes by taking their medications as prescribed than in adhering to lifestyle modifications. In a test

of their theoretical model of epilepsy self-management, DiIorio et al. (1996) did examine the relationship between self-efficacy and epilepsy self-management, but only in the form of self-reported medication compliance, and found that the two were significantly positively related.

The two studies discussed in this section are the only two in which self-efficacy and its relationship to epilepsy self-management has been explored in those with epilepsy. Of note is that, in both studies, epilepsy self-management was treated exclusively as compliance. More research is needed to determine the relationship between self-efficacy and other aspects of epilepsy self-management.

External factors. External factors pertinent to epilepsy self-management include those discussed previously in reference to chronic disease self-management: social support and healthcare access. Very little research has been done to determine the precise relationship between these variables and epilepsy self-management; epilepsy self-management researchers tend to cite and draw from the general chronic disease self-management literature to justify their use of these variables in their epilepsy self-management models (DiIorio, 2009; Shope, 1996). In studies regarding the way in which these factors affect self-management in those with epilepsy that have been done, however, findings have been mixed.

DiIorio et al. (1992) measured the relationship between social support (conceptualized as informational and emotional support) and medication compliance, and found a significant positive relationship. However, this relationship was not as large as that between self-efficacy and medication compliance. Later, in testing their theoretical model of epilepsy self-management, DiIorio et al. (1996) investigated the relationship

between what they called *specific support*, which basically referred to a family member or friend reminding the person with epilepsy to take medications as prescribed, and compliance with medications. There was a negative relationship found between specific support and medication compliance, which the authors explained by noting that such support was positively correlated with anxiety. The authors concluded that having a person constantly reminding the person with epilepsy about his or her medications actually interfered with medication adherence.

How Effective are Self-Management Interventions?

A prime goal of chronic disease and epilepsy self-management researchers is to determine ways in which those with chronic diseases can be helped—that is, how can researchers intervene with those suffering from chronic diseases, and particularly epilepsy, to improve their outcomes? What follows in this section is a synthesis of both the general chronic disease and epilepsy self-management literatures in terms of the degree to which self-management interventions have been shown to influence the outcomes of disease status and severity, health status and quality of life, and resource utilization. Gaps in the literature regarding the effectiveness of self-management interventions also are identified and discussed.

Chronic Disease Self-Management

Over the last two decades, various literature reviews and syntheses have been conducted in order to establish what is known about the effectiveness of general chronic disease self-management intervention effectiveness. Some common conclusions have been reached: (a) Self-management interventions are distinct from and more effective than straight educational interventions; (b) Self-management interventions based on

theory, specifically self-efficacy theory, and those that teach varying skills, such as problem-solving, are most effective, though there is an exception to this finding in the population of persons with heart failure; (c) In persons with common chronic diseases—arthritis and asthma—there is evidence that self-management interventions improve self-management outcomes; (d) Evidence regarding the impact of generic self-management interventions that target those with a variety of chronic diseases has recently become available and suggests that these programs impact self-management outcomes; and (e) Limitations and gaps in knowledge regarding self-management interventions persist and include, most notably, that outcomes generally are measured in the short-term and rarely have been tracked for longer than four years post-intervention, improvements in outcomes have been shown to fade over time, and outcomes have not been measured consistently.

Self-management interventions are superior to education. A recent Cochrane review (Coster & Norman, 2009) regarding self-management intervention effectiveness, as well as reviews of the self-management intervention literature (Lorig & Holman, 2003; Marks et al., 2005a, 2005b), demonstrate that straight educational interventions rarely are effective in improving outcomes and much less effective than those that involve a true self-management intervention. For instance, in persons with diabetes, for whom interventions have been shown to lack a theoretical basis and to be predominantly information-based and devoid of problem-solving skills, so-called self-management interventions rarely have been effective in affecting outcomes and never for longer than six months (Coster & Norman, 2009). In a review of self-management interventions for those with asthma, out of the 12 studies reviewed in which no improvements in outcomes

were noted, only 4 studies qualified as actual self-management interventions, with the rest being purely educational (Gibson et al., 2002). Lorig and Holman (2003) differentiate between educational and true self-management interventions. Educational interventions provide persons with factual information and teach skills. They are generally not theory-based. Clark (2003) refers to these interventions as "home grown" (p. 299) and notes that such interventions, which focus primarily on the delivery of information, are less successful in altering outcomes. In true self-management interventions, people are provided with education about their disease and its treatments but also learn problem-solving skills that are useful to solve problems from their own points of view. Problems with management are identified by the persons with the diseases, not the healthcare providers, and skills are applied to these individualized areas. The goal in true self-management interventions generally is increased confidence, or self-efficacy, to manage one's disease in multiple, personally important domains (Lorig & Holman, 2003).

The literature clearly demonstrates that, in a variety of chronic disease populations, straight education in the form of delivery of information is not as effective in significantly changing behavior, self-efficacy, or outcomes when compared to self-management interventions (Coster & Norman, 2009; Lorig & Holman, 2003; Marks et al., 2005a, 2005b). However, there is an exception to this finding in the population of those with heart failure. Powell and colleagues (2010), as part of the large-scale Heart Failure Adherence and Retention Randomized Behavioral Trial, reviewed the heart failure self-management literature and concluded that, overall, self-management interventions teaching problem-solving skills and fostering self-efficacy are no more

effective than straight educational interventions in improving disease status, health status, and healthcare resource utilization. Powell and colleagues (2010), who hypothesized that previous interventions had not been shown to influence outcomes as the result of methodological flaws, designed a self-efficacy-based self-management intervention that included learning problem-solving skills and devising and executing an action plan and implemented it in a large ($N = 902$) and rigorous randomized controlled trial. In this trial, individuals with heart failure who received an educational intervention (reception of disease-related information via pamphlets) and a self-management intervention demonstrated no differences in various disease status, quality of life, and utilization outcomes when compared at three months, two years, and three years post-intervention. The reason for the lack of superiority in self-management interventions when compared solely to educational ones in this population is not known (Powell et al., 2010).

Theory-based interventions are superior. Multiple reviews of the effectiveness of self-management interventions on key outcomes, mainly disease status and severity, health status and/or quality of life, and healthcare resource utilization, reveal that theory-based self-management interventions, and particularly those based on the theoretical frameworks of self-regulation and self-efficacy, are most effective at improving outcomes. Six self-management intervention studies utilizing self-regulation as an organizing framework have yielded significant results in terms of improving outcomes in a variety of chronic disease contexts (Clark, Gong, & Kacitori, 2001; Clark et al., 1997; Janz et al., 1999; Sawicki, 1999; Shegog et al., 2001; van Genugten, van Empelen, Flink, & Oenema, 2010). Of note, however, is that self-regulation has been shown to improve self-efficacy (Clark, 2003; Ryan & Sawin, 2009), and thus, the

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positive changes in outcomes seen in these studies may have been the result of positive changes in self-efficacy.

More evidence exists to support the ability of self-efficacy-based interventions to positively affect self-management outcomes. For example, in a review of 23 self-management intervention studies with persons with asthma, researchers found significant and desirable changes in outcomes of health status and healthcare resource utilization in 63% of studies in which self-efficacy was the guiding framework (McGowan & Green, 1995). More recently, Martin and colleagues (2009) developed an asthma self-management intervention based on principles of self-efficacy, primarily via teaching problem-solving and self-efficacy skills. At follow-up, those in the intervention group demonstrated improved quality of life, self-efficacy, and decreased healthcare resource utilization when compared to the usual care (straight education) group. Self-efficacy-based interventions with other populations, including macular degeneration (Brody et al., 1999) and diabetes (Mazzuca et al., 1986), have demonstrated superior effectiveness in positively affecting outcomes when compared to other self-management interventions designed for those populations based on other theories (Lorig & Holman, 2003). Lorig and her colleagues (2001) provided the most convincing evidence regarding the use of self-efficacy-based self-management interventions to improve outcomes. These researchers, in four large-scale, randomized control trials, implemented a self-efficacy-based self-management intervention in three samples of persons with arthritis (Lorig, González, Laurent, Morgan, & Laris, 1998; Lorig et al., 1993) and later with a sample of persons with multiple chronic diseases (Lorig et al., 2001). Persons undergoing the intervention were taught problem-solving skills as well as skills in the

following areas: techniques to deal with problems such as frustration; fatigue; pain and isolation; appropriate exercise for maintaining and improving strength, flexibility, and endurance; appropriate use of medications; communicating effectively with family, friends, and health professionals; nutrition; cognitive symptom management; and how to evaluate new treatments. These skills were taught in highly participatory group classes (Lorig et al., 2001). The investigators found that persons in all studies demonstrated improvements in health status (health distress) and resource utilization (physician visits). Baseline and changes in self-efficacy were positively and independently associated with these improvements (Lorig et al., 2001).

Self-management interventions affect outcomes in asthma and arthritis. Substantial evidence demonstrates that self-management interventions, and particularly those based on self-efficacy theory, can improve self-management outcomes in the common chronic diseases of asthma and arthritis. In a Cochrane review of asthma self-management intervention studies (Marks et al., 2005b), significant and desired changes in disease status, health status (measured most commonly in terms of symptom frequency and severity and quality of life), and resource utilization (measured most commonly in terms of emergency room visits and hospitalizations) have been demonstrated in 11 random controlled trials in which self-efficacy was used as the intervention basis. These effects were noted to persist no longer than 18 months post-intervention (McGowan & Green, 1995). In a more recent Cochrane review of asthma self-management interventions, Gibson and colleagues (2002), in reviewing 25 asthma self-management intervention studies, found that persons undergoing the interventions had fewer hospitalizations and emergency room visits, fewer nighttime

symptoms, and more productive days than those without asthma. More recent evidence indicates that true self-management interventions designed for those with asthma are effective in improving outcomes (Janson, McGrath, Covington, Cheng, & Boushey, 2009).

As mentioned previously, Lorig and colleagues' work (1993) has demonstrated that self-efficacy-based self-management interventions positively influence the outcomes of those with arthritis, particularly reduction in pain by 20% and resource utilization by 40%, up to four years following intervention via their Arthritis Self-Management Program. Health status, in the form of health distress, also was decreased, though this effect attenuated over the follow-up periods (Lorig et al., 1993). Investigators conducting a subsequent cost-effectiveness study of the Arthritis Self-Management Program estimated that it has the potential to save $2.5 million over four years if implemented with 10,000 persons with arthritis (Kruger, Helmick, Callahan, & Haddix, 1998). To investigate the stability of the improvements associated with the Arthritis Self-Management Program over a longer period of time, Barlow and colleagues (2008) re-assessed 125 participants who completed the Arthritis Self-Management Program eight years post-intervention and found that the effects on some outcomes that occurred between baseline and the initial four-month follow-up were maintained: reduction in pain and improved self-efficacy and psychological functioning. Decreases in healthcare resource utilization, however, failed to be maintained at the eight-year follow-up. As well, anxiety increased over the follow-up periods, and initial improvements in physical functioning attenuated by the eight-year reassessment (Barlow et al., 2008). Several other investigators have found that their self-efficacy-based self-management interventions

similarly improve self-management outcomes in those with arthritis (Alderson, Starr, Gow, & Moreland, 1999; Kovar et al., 1992), though sample sizes in these studies were generally small ($N = 30$ and $N = 47$, respectively), and outcomes were not measured beyond six months.

Other arthritis self-management intervention studies and reviews of such studies revealed that some asthma self-management interventions based on self-efficacy theory positively affect some self-management outcomes but not others. In a Cochrane review of 24 studies testing rheumatoid arthritis self-management interventions, Reimsma, Kirwan, Taal, and Rasker (2002) found that these interventions, more than 80% of which were based on self-efficacy theory or problem-solving, were effective in improving overall health status (akin to quality of life), psychological status, and healthcare resource utilization. Reimsma et al. (2002) noted, in contrast to findings associated with the Arthritis Self-Management Program (Lorig et al., 1993), that a significant reduction in pain was not noted in most studies, and outcomes in the studies reviewed generally were measured no longer than six months post-intervention (Reimsma et al., 2002). More recently, in a large ($N = 812$) sample of persons with osteoarthritis, Buszewicz and colleagues (2006) implemented an arthritis self-management intervention based on self-efficacy theory, which resulted in improved levels of self-efficacy and reduced anxiety but failed to affect experience of pain or physical functioning. Because it has been shown to positively affect the most self-management outcomes, over the longest period of time and for the greatest number of people, the Arthritis Self-Management Program, developed by Lorig and colleagues (1993) and Lorig, Lubeck, Kraines, Seleznick, and Holman (1985), has become the *gold standard* self-management

intervention for individuals with arthritis. In fact, the Centers for Disease Control and Prevention (2010c) advertises and supports the use of the Arthritis Self-Management Program, which continues to be offered throughout the United States and abroad.

Generic self-management interventions can be effective. Compared with what was seen in the asthma and arthritis literature, relatively less research has been done to investigate the effectiveness of generic chronic disease self-management interventions—those that can be implemented with persons with a variety of chronic diseases at the same time. Lorig and colleagues (2001), however, via their Chronic Disease Self-Management Program, a self-efficacy-based intervention designed for persons with a variety of chronic diseases, have provided initial evidence that such generic chronic disease

self-management interventions can improve outcomes up to two years post-intervention. Based on the original Arthritis Self-Management Program, the Chronic Disease Self-Management Program was delivered to over 900 persons with arthritis, diabetes, chronic lung disease, and stroke. As part of the intervention, participants (and their family members who could participate if they desired) learned about cognitive symptom management, exercise program adoption, fatigue and sleep management, medication and community resource utilization, emotions (fear, anger, and depression) management, problem solving, and decision making; they also received training in how to effectively communicate with a healthcare provider (Lorig et al., 2001). At two years post-intervention, significant and desirable changes were noted in healthcare resource utilization (in terms of frequency of emergency room visits), health status (in the form of health distress), and experience of the symptom fatigue. Perceived disability in terms of

functional ability was improved at one year, but this result did not persist to the two-year follow-up assessment (Lorig et al., 2001).

Since the publication of the Chronic Disease Self-Management Program intervention results (Lorig et al., 2001), other researchers have implemented this program with groups of persons suffering from a variety of simultaneous chronic diseases. Gordon and Galloway (2008), in partnership with the Centers for Disease Control and Prevention, reviewed 13 studies in which the Chronic Disease Self-Management Program was implemented with persons with a variety of chronic diseases. The authors concluded that this program, in general, is effective at improving quality of life and physical and emotional outcomes, and can decrease healthcare resource utilization. A reduction in pain and other symptoms was seen in half of the studies reviewed. The authors also concluded that the program saved sufficient money in healthcare expenditures in one year to pay for the program. The authors noted that, in all studies, the follow-up periods were no longer than six months. In addition, the variation in outcome measures used across the studies reviewed made comparison of outcomes difficult. Sample sizes also were generally adequate and ranged between 171–1140 participants (Gordon & Galloway, 2008). The initial evidence regarding the ability of a multi-chronic disease self-management intervention to affect at least some important outcomes is promising, though the more long-term benefit of such an intervention remains unknown. In addition, the intervention has not been implemented in persons with some common chronic diseases, including epilepsy.

Critique and gaps in knowledge. While evidence suggests that self-management interventions, and especially self-efficacy-based ones, can improve self-management

outcomes, there are weaknesses in the current state of research which limit the

conclusions that can be drawn regarding the effectiveness of these interventions. In two

Cochrane reviews of chronic disease self-management intervention studies, both sets of

authors noted that the majority of studies reviewed were underpowered due to small

sample sizes and that very short follow-up periods (generally three to six months) most

commonly were used (Barlow et al., 2002; Coster & Norman, 2009). As mentioned

previously, though some studies have demonstrated effects on outcomes up to four years

post-intervention (Lorig et al., 1993), these effects are generally smaller than at six

months to one year post-intervention (Barlow et al., 2008), and other investigators have

found that the effects are completely gone after five years (Caplin & Creer, 2001).

Clearly, for persons with chronic diseases that last a lifetime, achieving desired effects

for only four years is insufficient. In addition, though many interventions have led to

changes in outcomes, the ways in which these outcomes were measured and what they

truly represent must be considered. For example, in Lorig and colleagues' (2001)

large-scale Chronic Disease Self-Management Program study, health status was

measured in multiple domains: health distress, disability, perceived health, and social/role

changes. The only portion of health status that was significantly improved two years after

the intervention was health distress. And, while there was a decrease in emergency room

visits, hospitalization frequency was not affected. Thus, it is logical to question the

degree to which these outcomes actually were affected. While self-management

interventions have shown success in improving outcomes, or portions of outcomes, for

persons with chronic diseases, even the most effective self-management interventions can

be improved. Researchers must endeavor to discover ways in which to achieve more lasting and comprehensive effects on self-management outcomes.

Epilepsy Self-Management

Self-management interventions specific to those with epilepsy have been created and tested, though the number of existing interventions specific to this population is small in comparison to those that exist for other chronic diseases such as asthma, arthritis, and diabetes. Unfortunately, the epilepsy self-management intervention literature, at this point, is so underdeveloped that not many conclusions may be drawn regarding the best ways in which to intervene to improve outcomes specific to those with epilepsy. The results of the latest Cochrane review aimed at evaluating the effectiveness of self-management interventions for individuals with epilepsy, as well as findings from studies in which epilepsy self-management-enhancing interventions have been implemented since the Cochrane review was published, are discussed in the sections that follow.

In 2009, a Cochrane review (Shaw et al., 2009) was completed to determine the effectiveness of interventions for improving the epilepsy treatment and self-management outcomes put forth by the Commission on Outcome Measurement in Epilepsy (1998). As a consequence of poor study designs, only two intervention studies were evaluated and both of them were considered to be of marginal quality. Both studies involved the implementation of purely educational interventions aimed at providing participants with information regarding medical aspects of epilepsy, social and emotional aspects of epilepsy, coping, and accessing epilepsy-related information. Neither study reviewed cited a theoretical base. In both studies, significant changes from baseline to six months

were seen in knowledge regarding seizures and their treatment, while a small but significant decrease in seizure frequency was noted at six months post-intervention in one study (Shaw et al., 2009). The authors stated that based on the two studies reviewed, both of which had small sample sizes, methodological limitations, and a higher percentage of participants with partial seizures than is seen in the population of persons with epilepsy, no conclusions could be made regarding the best ways in which to improve the self-management outcomes specific to those with epilepsy (Shaw et al., 2009). Since the time of Shaw and colleagues' (2009) Cochrane review, DiIorio and colleagues (2009), as a part of the Managing Epilepsy Well Network (n.d.), have implemented an Internet-based epilepsy self-management-enhancing intervention called WebEase. The intervention is based on self-efficacy theory as well as behavior change theory and motivational interviewing. The objective of the intervention is to encourage those with epilepsy to take medications as prescribed, manage stress, and engage in good sleep habits. Participants take part in online modules that, based on their answers, provide them with semi-tailored information and strategies for improving self-management. A new intervention, WebEase has been implemented with only 35 individuals. Results indicate that, at six weeks post-intervention, there were small but statistically significant differences in epilepsy self-management (measured via the Epilepsy Self-Management Scale), medication adherence, sleep quality, and self-efficacy. Thus, it is not clear how this intervention has affected or may affect epilepsy self-management outcomes.

Clearly, the epilepsy self-management intervention literature is very limited. The use of more theory-based epilepsy self-management-enhancing interventions is needed.

The Managing Epilepsy Well Network (n.d.) was created in order to ensure that such interventions are developed and tested in those with epilepsy.

Self-Management in Older Adults

General chronic disease self-management. A small amount of literature specific to chronic disease self-management in older adults exists. This literature largely describes the effects of chronic diseases on older adults' lives and less so their actual self-management experiences.

Research pertaining to older adults with common chronic diseases—hypertension, arthritis, and cancer, for example—has been executed, and the findings of such studies provide potential insight into the self-management of older adults. Results of studies focused on older adults with arthritis and diabetes suggest that older adults' overall health is affected negatively by the presence of chronic disease. In a cross-sectional survey of 5,000 older adults with arthritis, respondents reported 4.9 more unhealthy days per month than the average person living in the United States. More than 80% of participants indicated that arthritis-related symptoms accounted for unhealthy days, and 42% reported that decreased physical functioning was to blame (Centers for Disease Control and Prevention, 2000). In a similar cross-sectional survey of 100,000 individuals with diabetes, 20% of whom were older adults, participants experienced 4.8 more unhealthy days per month than those without the disease; 76% traced unhealthy days back to symptoms such as fatigue, and another 32% blamed stress resulting from self-management of the disease (Centers for Disease Control and Prevention, 2001).

The results of some self-management studies involving both young and older adults have revealed that there are specific strategies and behaviors commonly used by

older adults in managing a chronic disease. These self-management strategies include

planning (Buetow, Goodyear-Smith, & Coster, 2001; Funnel & Anderson, 2004), seeking

assistance (Funnel & Anderson, 2004), self-treatment (Buetow et al., 2001), altering

schedules and responsibilities (Funnel & Anderson, 2004), using reminders (Yusuff,

Olubunmi, & Bonatson, 2008), collaboration (Lewis, 2007), and intentional

non-adherence (Lowry, Dudley, Oddone, & Bosworth, 2005). Some of these strategies

and behaviors—seeking assistance and collaboration—are used more frequently by older

adults than younger ones (Diaz & Herring, 2006).

Self-management interventions specifically targeting older adults with chronic

diseases have been implemented. Researchers conducting a meta-analysis evaluating

self-management interventions delivered to older adults with hypertension, diabetes, and

arthritis found strong support for the effectiveness of self-management interventions

(particularly those based on self-efficacy theory) in improving outcomes. These

interventions are most effective in older adults with hypertension and diabetes (Chodosh

et al., 2005). Chodosh et al. (2005) noted in the analysis that the pool of studies reviewed,

however, was small, and outcomes were measured over too short of a time period to

allow for many conclusions to be made.

Epilepsy self-management. No studies regarding the epilepsy self-management

of older adults, including those diagnosed in older adulthood, was found in the literature.

Researchers, however, have investigated the concerns older adults with epilepsy

have with regard to their condition as well as their quality of life. Martin and colleagues

(2005) completed a study with a sample of 33 older adults with intractable partial

epilepsy in which participants were given a blank piece of paper and asked to list, in

order of importance, any concerns they had about having epilepsy. Participants' concerns were tallied. Participants listed between one and six concerns each, and 28 unique concerns were identified. The most frequently listed area of concern was difficulty with transportation (36% listed it as the primary concern), followed by concern with anti-epileptic drug side effects (21% listed it as the primary concern). Other prominent concerns included safety issues, costs of medication, and job loss (Martin et al., 2005).

While the study conducted by Martin and colleagues (2005) provides insight into some of the concerns held by older adults with epilepsy, its results do not address the gaps in the literature related to older adults diagnosed with epilepsy in older adulthood that were discussed in Chapter I. First, as the authors of the Martin and colleagues (2005) study note, limitations of the study include that the sample included very few older adults on the *older* end of the spectrum (greater than 70 years of age) and did not focus on older adults diagnosed in older adulthood (only three participants were diagnosed in older adulthood). Thus, these results may not fully reflect the concerns of the oldest older adults with epilepsy and those diagnosed with the disorder late in life who are just learning to manage the condition. Further, the sample in the Martin and colleagues (2005) study was comprised only of older adults whose epilepsy was intractable, and all participants had partial epilepsy. Their results, then, do not reflect the concerns of older adults who experience fewer or less severe seizures nor those with other varieties of epilepsy.

The methods used by Martin and colleagues (2005) do not qualify the study as a qualitative research endeavor. According to Sandelowski (2000), studies which render survey-type data that have not been deeply analyzed and do not provide

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context-dependent descriptions of participants' experiences with the phenomenon do not fall under the umbrella of qualitative research. Rather, the study conducted by Martin and colleagues (2005) would qualify more as what Sandelowski (2000) describes as *quantitative* description in which the researchers tabulate participants' responses without analyzing them for context or meaning. The results of such studies do not include important contextual factors that can explain the presence or absence of variables in the sample (Sandelowski, 2000).

The Martin and colleagues (2005) study, thus, fails to elucidate the contributing factors that *lead* to these older adults' concerns, how they handle these concerns, how these concerns affect their lives, and what they need from healthcare providers in order to address these concerns.

Regarding the quality of life of older adults with epilepsy, in a review of randomized controlled trials regarding the effect of epilepsy medications on the quality of life of older adults, Martin and colleagues (2003) found very little empirical evidence to guide the treatment of older adults with epilepsy in terms of improving their quality of life. Martin and colleagues (2003) noted that there exists no information regarding older adults' goals for epilepsy treatment outcomes and that all available data on the topic has been collected from younger adults. These authors called for systematic investigation of the needs and preferred treatment outcomes of older adults with epilepsy. More recently, Laccheo and colleagues (2008) found that older adults with epilepsy have a significantly lower quality of life than those older adults without the disorder, though precisely what accounts for or contributes to this discrepancy is unclear.

Older adults with epilepsy, by virtue of being advanced in age, experience a number of physiologic and cognitive changes that can affect their epilepsy self-management (Boss & Seegmiller, 1981; Rowan & Ramsay, 1997). First, the pharmacokinetics of medications is altered in older adults. Liver and kidney metabolism are slowed with age, affecting drug metabolism. In older adults with epilepsy, anti-epileptic drugs are less bound to serum albumin than in younger adults, putting these older adults at higher risk of medication toxicity (Perucca, Berlowitz, & Birnbaum, 2006). Medication toxicity with anti-epileptic drugs is dangerous and can cause myocardial infarction, electrolyte disturbances, and confusion (Leppik, 2001; Rowan & Ramsay, 1997). In addition, most older adults do not have a single chronic disease but two or more (Centers for Disease Control and Prevention, 2010a). The different medications that older adults take for the various diseases they are managing can interact with one another, causing dangerous reactions or yielding anti-epileptic drugs less effective (Karceski, 2005; Leppik, 2001; Rowan & Ramsay, 1997). The addition of co-morbidity and co-medication to the already demanding treatment regimen associated with epilepsy could give rise to unique problems for older adults managing this disease, though no research has been conducted to explore how such age-related changes affect the ways in which older adults manage their epilepsy.

Second, cognitive functioning, and specifically working memory and attention, declines with age (Sweeney, Rosano, Berman, & Luna, 2001), potentially affecting the ability of older adults to manage the complex treatment regimens that accompany an epilepsy diagnosis. Further, in nearly half of older adults with epilepsy diagnosed at or after age 60, the underlying cause of the disorder is a cerebrovascular accident, which is

associated with even further decrements in cognitive functioning (Rowan & Ramsay, 1997). Such cognitive changes can render an already complex disease regimen even more difficult for an older adult with epilepsy.

In addition, older adults with epilepsy demonstrate significantly poorer cognitive functioning than older adults without the condition. Martin and colleagues (2005) administered standard neuro-cognitive functioning tests to matched pairs of community-dwelling older adults with epilepsy and community-dwelling older adults without epilepsy. The authors found that older adults with chronic epilepsy demonstrated significant impairments across all measures in comparison with older adults who were not diagnosed with epilepsy (Martin et al., 2005).

Finally, older adults are at increased risk for falls and other injuries as a consequence of advanced age (Fuller, 2000). Side effects of many anti-epileptic drugs taken by older adults with epilepsy, especially in conjunction with medications taken for other diseases and conditions, may cause dizziness, somnolence, or balance changes, further increasing the risk of injury in this population (Epilepsy Foundation, 2010; Krauss & Crone, 2001; Rowan & Ramsay, 1997). Indeed, older adults with epilepsy do experience more falls than older adults without the disorder (Rowan & Ramsay, 1997).

Both the normal age-related physiologic and cognitive changes, as well as the cognitive decline often associated with the underlying causes of older adults' epilepsy, have the potential to make the epilepsy self-management of older adults unique, and likely more difficult, from that of younger adults with epilepsy. Existing epilepsy self-management-targeted interventions do not take these unique circumstances and needs of older adults into account.

Pilot Study Findings

In order to evaluate the feasibility of the inclusion/exclusion criteria and the interview guide of this study (discussed in Chapter III), a pilot study involving older adults diagnosed with epilepsy at or after age 60 was completed. Following Indiana University–Purdue University Indianapolis Institutional Review Board approval, five older adults (mean age 68 years; two women, three men; mean length of time since diagnosis 3.5 years) were recruited via self-referral from January 2010–April 2010 using the inclusion and exclusion criteria indicated in Chapter III. Older adults were interviewed face-to-face to generate the data set. Interview questions were intended to elicit respondents' experiences with epilepsy self-management, including how their lives changed since epilepsy diagnosis, problems encountered in managing the disease, management strategies used, and the overall effect of the disease on daily functioning. Data were analyzed via the content analysis techniques detailed in Chapter III.

Three main themes emerged: (a) perceived life changes since diagnosis, (b) problems, and (c) types of epilepsy self-management strategies, comprised of sub-themes. Respondents reported marked and mostly undesirable changes in their lives since being diagnosed, including lifestyle changes, changes in perceived well-being, and physical and emotional changes in the form of unpleasant symptoms. Respondents also reported problems associated with managing epilepsy, including difficulties in receiving a correct diagnosis, receiving inadequate education at the time of diagnosis and feeling unprepared for the seriousness of the disease, problems maintaining pre-diagnosis levels of independence, and difficulties involving medications. The use of two types of epilepsy self-management strategies—those aimed at managing the disease itself and those aimed

at managing the life changes and problems associated with having epilepsy—were reported. Strategies can be categorized as proactive or reactive. Four out of five participants reported that a significant other (three adult children, one spouse) consistently assist them with their epilepsy management (Miller & Buelow, 2010).

Figure 1 provides a schematic depicting the pilot study findings. When an older adult is diagnosed with epilepsy, the disease and its required treatments lead to the experience of both major life changes and problems. The person perceives undesirable lifestyle, physical/emotional, and well-being changes. Each of these changes can influence the others. For example, the experience of the physical symptom of fatigue can negatively affect one's lifestyle and thus subjective well-being. Problems with diagnosis, medications, and maintenance of independence also are encountered, and these problems influence perceived life changes. For example, difficulty maintaining independence can affect lifestyle by preventing the person from being active in usual social settings and can cause subsequent negative emotions. Epilepsy self-management strategies are aimed at managing perceived life changes, problems, and the disease of epilepsy and associated treatments. Proactive epilepsy self-management strategies are well planned, systematic, flexible, and generally effective. Participants tend to use more proactive strategies later into their diagnosis because time and experience with the disease are needed in order to develop them. Reactive strategies are unplanned, unpredictable, and often not effective or can worsen a situation. Reactive strategies are more common in the early period following diagnosis, though some respondents report using the strategies years following diagnosis. The use of epilepsy self-management strategies in turn affects the disease

(number of seizures experienced, exacerbations, other symptoms) and the degree or

amount of perceived life changes and problems experienced (Miller & Buelow, 2010).
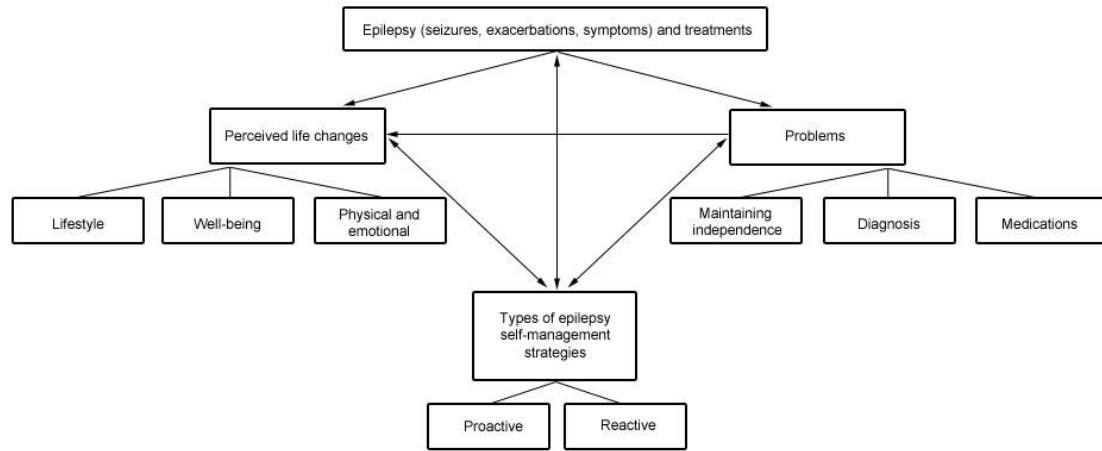
Figure 1. Results of pilot study show the interrelationships of three themes of

self-management in adults diagnosed with epilepsy at or after age 60.

This small pilot study provides initial insight into the epilepsy self-management

of older adults and suggests that older adults diagnosed with the disorder at or after age

60 may have some epilepsy self-management experiences and needs and are at risk for

certain undesirable life changes and management problems that are not all found in the

younger adult epilepsy self-management literature. This pilot study was conducted in

order to evaluate the appropriateness of inclusion and exclusion criteria and data

generation and analysis proceedings discussed in the following chapter as well as to give

the researcher experience in collecting and analyzing qualitative data. The sample of

older adults interviewed was insufficient to result in informational redundancy, and thus,

these findings do not address adequately the gap in knowledge identified in Chapter I.

However, the results of the pilot study led to the addition of a research question

concerning older adults' experiences with being diagnosed with epilepsy. When the pilot

study was initiated, there was no such research question or any interview questions

specifically pertaining to this topic. All five pilot participants, however, spoke of difficulties encountered after being diagnosed. Thus, a research question was added to the pilot study after the first two interviews were completed, and this research question also exists in this study.

Summary and Critique

State of the Science of Self-Management

In reviewing the general chronic disease and epilepsy self-management literatures, as well as those specific to older adults, several conclusions can be reached and remaining gaps in the literature identified.

First, there is no single definition of chronic disease self-management. While the concept historically has been represented in the literature as behaviors in which those with chronic diseases engage, more recent conceptualizations of self-management portray the concept as a dynamic, action-oriented, self-directed, ever-changing cognitive and behavioral process in which those with chronic disease engage, in the context of a family or other system, to manage various aspects of their disease in multiple domains of life. Epilepsy self-management has been conceptualized similarly, though the process, complex, and system-embedded nature of the concept has been recognized only recently and still is being integrated into epilepsy self-management researchers' use of the concept. Despite self-management experts espousing that self-management is not amenable to direct measurement given that it is a process, researchers have attempted to measure directly both chronic disease self-management and epilepsy self-management as medication and treatment compliance and as engagement in certain behaviors. Both of these approaches are inappropriate given the process-like nature of self-management and

its conceptual components. Researchers must consider the value in characterizing, as opposed to directly measuring, self-management and epilepsy self-management.

The outcomes of chronic disease self-management and epilepsy self-management are similar and include disease status and severity, health status and quality of life, and healthcare resource utilization. From the medical perspective, outcomes generally are measured in terms of disease status and severity, while nurse researchers are more attentive to other outcomes that address the ways in which living with a chronic disease affects all aspects of life. Researchers must begin to consider the ways in which developmental stages and length of time since disease diagnosis affect the pertinence of self-management outcomes. Factors influencing self-management and epilepsy self-management include contextual, internal, and external ones. Most influential appears to be levels of self-efficacy that, in general chronic disease self-management, have been shown to directly affect self-management outcomes. Less is known, however, about the effect of self-efficacy on epilepsy self-management.

Conclusions that can be made regarding the effectiveness of self-management-enhancing interventions are limited by the small number of high-quality studies that have been executed, measurement of outcomes only in the short-term, and use of varying measurements for outcomes. While there is strong evidence suggesting that self-efficacy-based interventions improve self-management outcomes in some disease populations, the effects have not been shown to be long-lasting. Regarding epilepsy self-management-enhancing interventions, the literature on this topic is so underdeveloped that how best to improve epilepsy self-management outcomes is not yet known. More research is needed to determine the best way to achieve

improvements in both general chronic disease self-management and epilepsy self-management outcomes over the long-term.

Finally, there is a complete lack of literature regarding the epilepsy self-management of older adults and limited literature regarding the self-management of general chronic disease in older adults. The effectiveness of self-management-enhancing interventions in improving outcomes for older adults is not known due to the small number of high-quality studies that have been executed to test these interventions.

Need for Current Study

In the United States, older adults are affected profoundly by chronic disease, costing the nation billions of dollars annually. One chronic condition notably affecting those age 60 years and older is epilepsy. Older adults are more likely than those in any other age group to receive a new epilepsy diagnosis. By its nature, epilepsy demands complex self-management, and the unique characteristics of older adults (age-associated physiologic and cognitive changes and the presence of multiple co-morbidities, for example) have the potential to make epilepsy self-management for this population distinct from and more difficult than that of younger adults with epilepsy. No studies involving investigation of epilepsy self-management of older adults, including those diagnosed with the condition at or after age 60, were found in the literature. The limited amount of research regarding the epilepsy self-management of younger persons may not be applicable to older adults diagnosed with the condition in older adulthood. There thus exists a gap in knowledge regarding the epilepsy self-management of older adults diagnosed with epilepsy later in life. Research, beginning with an initial description of this population's epilepsy self-management experiences, must be undertaken in order to

inform the design of interventions aimed at improving the epilepsy self-management

outcomes of older adults diagnosed with epilepsy in older adulthood.

CHAPTER III

METHODOLOGY

This chapter describes the research approach and methods that were used to examine older adults' epilepsy self-management experiences. The chapter begins with a description and rationale for the research approach. Sampling methods and procedures then are delineated, followed by a detailed discussion of data generation, preparation, management, analysis, and interpretation techniques and processes. Finally, ways in which validity were protected throughout the study are discussed.

Research Design

Background and Description of the Qualitative Descriptive Method

According to Sandelowski (2000), the qualitative descriptive method, also known simply as qualitative description, is a distinct qualitative research method that should be used when the goal of the research study is to describe phenomena about which very little is known. Sandelowski (2000) has described qualitative description as the "least theoretical" (p. 337) of the qualitative research methods, given that researchers employing this method, when compared to those utilizing other qualitative methods such as phenomenology or grounded theory, are less constrained by a priori theories or philosophies. Instead, qualitative description derives from the more general assumptions of naturalistic inquiry (Patton, 2001; Sandelowski, 2000), which is a philosophical orientation committed to studying phenomena in their natural states (Lincoln & Guba, 1985). Thus, in qualitative description, in order to ensure that the phenomenon of interest is allowed to present itself as though it were not under study, variables of interest are not selected a priori, and, though targeted research questions guide data generation, analysis, and interpretation, the researcher must remain open to viewing the phenomenon however

it naturally presents itself (Sandelowski, 2000). The end product of a qualitative

descriptive study is a data-near descriptive summary of the phenomenon that best fits the

data and that is represented in a useful (in that research questions are adequately and

clearly answered) way (Sandelowski, 2000). As plainly stated by Sandelowski (2000),

researchers using the qualitative descriptive method strive to "get the facts, and the

meanings participants give to those facts, right and then convey them in a coherent and

useful manner" (p. 336) and achieve this goal by providing a "straight descriptive

summary of the informational contents of data organized in a way that best fits the data"

(p. 338).

Though primarily a method that is focused on providing a comprehensive

summary of events or phenomena, qualitative description also involves *interpretation* of

data. That is, the end product of a qualitative descriptive study presents the data in a

moderately (as compared to that in grounded theory, ethnographic, and

phenomenological studies) transformed manner (Sandelowski, 2000). For example, a

researcher seeking to describe the experiences of a particular population with a specific

phenomenon will not simply list respondents' experiences, as is characteristic of survey

research, but present them in a novel and useful way (Sandelowski, 2000, 2010b). The

descriptive summaries yielded by qualitative descriptive studies serve as valuable,

stand-alone products and provide idiographic knowledge that can be applied directly in

nursing practice (Sandelowski, 2000). Qualitative descriptive findings also serve as entry

points for further, more interpretive qualitative research studies, which can influence

intervention and instrument development. Furthermore, findings rendered from a

qualitative descriptive study can influence immediately and directly, in some cases,

intervention and instrument development. Such findings, given their idiographic nature, also can be used to investigate unexpected findings in quantitative studies. For example, findings from a qualitative descriptive study can help explain why the effectiveness of an intervention is not equal to its efficacy (Miller, 2010; Sandelowski, 2000).

The qualitative descriptive method is characterized by several defining features that are shared by all qualitative methods. Qualitative methods attempt to ascertain how the social world is interpreted, rely on an iterative approach to sampling, data generation, analysis, and interpretation, produce idiographic (as opposed to nomothetic) generalizations, provide an interpretive reframing of data, are characterized by a somewhat emergent research design, emphasize case-oriented analysis, and use data generating and analysis techniques that are systematic, yet flexible (Sandelowski, 2010a).

Rationale for Approach

The qualitative descriptive method was chosen as the most appropriate for this study for the following reasons:

1. Virtually no research has been done with the population of adults diagnosed with epilepsy at or after age 60 regarding their epilepsy self-management experiences. A basic knowledge of this population's epilepsy self-management experiences is needed and can be generated best via a qualitative descriptive approach (Sandelowski, 2000, 2010b).

2. The purpose of the study was to explore the epilepsy self-management experiences of older adults, and qualitative description is appropriate for initial exploration of phenomena about which little is known (Sandelowski, 2000, 2010b).

3. Qualitative description has been a useful first step in programs of research that have focused ultimately on instrument development and the developing and testing of interventions to improve outcomes in those with chronic diseases (Ferrans & Powers, 1985; McSweeney et al., 2010).

4. The product of a qualitative descriptive study is a data-near descriptive summary of the informational contents of data (Sandelowski, 2000). Such a description provides a beginning knowledge base of what epilepsy self-management is comprised for older adults diagnosed with the epilepsy later in life and can inform future, more interpretive qualitative studies of the phenomenon as well as studies aimed at describing and testing the relationships pertinent to the phenomenon. Ultimately, the description of epilepsy self-management yielded by this study can inform the creation of interventions aimed at enhancing epilepsy self-management and its associated outcomes by elucidating the specific needs of older adults with epilepsy.

5. Utilization of a combination of Sandelowski's (2000, 2010b) and Patton's (2001) approaches to the method involves a systematic, step-by-step process, providing a beginning qualitative researcher with enough structure to reduce the likelihood of premature closure to analysis and threats to validity (Sandelowski, 1993).

Sample

Sampling Method: Purposeful Sampling

In a qualitative descriptive study, the goal of sampling is to obtain information-rich cases—that is, respondents who have experience with the phenomenon of interest. As per Sandelowski's (2000) and Patton's (2001) recommendations for qualitative descriptive sampling techniques, recruitment of respondents was achieved via purposeful sampling. When using this method, the researcher purposefully chooses respondents who have experienced and have knowledge of the phenomenon (Patton, 2001). The number of respondents needed to describe the phenomenon could not be predicted a priori and was based on the point at which informational redundancy was reached (Patton, 2001). Participants were recruited purposefully based on sampling needs that emerged throughout analysis (Sandelowski, 2010a).

Inclusion/Exclusion Criteria

Inclusion criteria for older adult participants consisted of the following: (a) diagnosis of epilepsy at or after age 60 years, (b) diagnosis of epilepsy at least six months prior to recruitment into the study, (c) prescription of at least one anti-epileptic drug, (d) community-dwelling, (e) able to speak and read English, and (f) able and willing to share epilepsy self-management experiences. Exclusion criteria included the (a) presence of a space-occupying lesion as the etiology of epilepsy and (b) cognitive impairment resulting in the inability to understand or answer questions related to epilepsy self-management.

Only those individuals diagnosed with epilepsy at or after age 60 were included because this was the target population of interest. Those who were diagnosed fewer than

six months before the time of recruitment into the study were excluded because, being very early in their disease course, these persons may not have been able to articulate their self-management experiences. Older adults having epilepsy but who were diagnosed earlier in life were excluded because they have lifelong experiences with epilepsy self-management, which could influence their epilepsy self-management as an older adult, and the focus of the study was on investigating the self-management of adults managing the disease *beginning* in older adulthood. The inclusion of a prescription of at least one anti-epileptic drug was necessary because the vast majority of older adults with epilepsy are treated with at least one anti-epileptic drug. Respondents included in the study were limited to those living in the community because those in inpatient, extended care facilities are not practicing self-management as it is defined conceptually in the study. Older adults living in assisted living communities (those in which residents live in their own homes, condominiums, or apartments and receive various types of assistance with yard work, transportation, and delivery of meals but not 24-hour medical or nursing care) were considered to be community-dwelling and were not excluded. Those with operable or terminal space-occupying lesions serving as the cause of epilepsy were excluded because their epilepsy is potentially transient, and the focus of the study was on the self-management of *chronic* epilepsy. Such an underlying condition also could prove terminal, in which case chronic disease self-management would not be applicable. Those with a degree of cognitive impairment preventing them from understanding or answering questions were excluded to ensure successful data generation.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Age 60 or older	Presence of operable or terminal
Diagnosed with epilepsy at or after age 60	space-occupying lesion as etiology of
Community-dwelling	epilepsy
Prescribed at least one anti-epileptic drug	Cognitive impairment preventing the
Speak and read English	person from understanding and
Willing to share epilepsy self-management	answering interview questions
experiences	

Sample Size

According to both Sandelowski (1995b) and Patton (2001), sample sizes in

qualitative research cannot be ascertained a priori. In her article describing proper

sampling in qualitative research, Sandelowski (1995b) warns against the use of sample

sizes that are either too small to support plausibly the notion of informational redundancy

or are too large to allow for the deep, case-oriented analysis that is the hallmark of

qualitative research. Sample size in qualitative research should be based on the data and

should not be pre-determined (Sandelowski, 1995b). Thus, no pre-determined sample

size was used. Rather, sampling was based on ongoing data analysis findings. Sampling

efforts continued until informational redundancy was reached (Sandelowski, 1995b). The

final sample size, including the 5 participants from the pilot study, was 20.

Recruitment

Following approval of the study from the Indiana University–Purdue University

Indianapolis Institutional Review Board (Appendix B), respondents were recruited from

April 27, 2011, to July 22, 2011. The five participants recruited during the pilot study

were recruited between January 2010 and April 2010, and all were recruited via

self-referral based on advertisements (Appendix C) placed in three private neurology

offices in Bloomington, Indiana. Recruitment of the remaining 15 participants took place via collaboration with a private Bloomington, Indiana, neurology practice, Neurology Specialists. The physicians or their designees at Neurology Specialists identified patients under the care of the providers at their office who were potential participants for the study. The names, addresses, and phone numbers of any patients who were age 60 or older, had a diagnosis of epilepsy that was given at or after that age, and who were prescribed an anti-epileptic medication were provided to the researcher via encrypted e-mail. The total sampling pool consisted of 122 older adults. Potential participants were mailed physician-signed letters (Appendix D) informing them of the study. This letter explained to potential participants the purpose of the study, a description of what was involved in taking part in the study, and notification that a nurse researcher would contact them via telephone within a few days to provide them with more information about the study. The letter included a phone number that potential participants could call if they did not want to be contacted regarding the study; it also informed potential participants of the voluntary nature of the study and that taking part or not taking part would not affect the care they received from their neurologist.

As discussed previously, sampling in a qualitative descriptive study is determined by ongoing analysis findings, with the goal being the attainment of informational redundancy (Sandelowski, 1995b). In addition, ongoing data analysis led to the need for variation in the sample in terms of the gender and geographical location. Thus, letters were not mailed to all 122 potential participants, and mailings of letters were staggered. This strategy served two purposes. First, it allowed time for the researcher to become engaged in data analysis of early interviews and to render preliminary findings that

informed later recruitment and data collection efforts. Second, it allowed the researcher to more purposefully sample participants. For example, when it was determined that the experiences of more men were needed, the researcher was able to mail letters to a group of male potential participants.

Figure 2 depicts the detailed recruitment activities executed by the researcher. A total of 46 letters were mailed in three installments: April 19 (20 letters), June 26 (18 letters), and July 12 (8 letters), and the potential subjects to whom the letters were mailed were based upon analytical findings and emerging sampling needs (Sandelowski, 1995b). The recipients of the initial 20 letters were selected randomly by the researcher from the sample pool because it was known, based on the criteria upon which the members of the sample pool were identified, that they all had experience with the phenomenon of interest (Sandelowski, 1995b). The first 20 letters were sent to 12 women and 8 men. Potential participants to whom letters were mailed in the subsequent two installments were selected purposefully based on initial data analysis findings. For instance, in the second installment, the researcher purposefully chose to send letters to potential participants living in more secluded, rural areas because findings from early interviews suggested that participants living in such areas had experiences distinct from those living in more urban areas. In installment three, male participants were targeted because their experiences seemed distinct from those of women, but the researcher had not yet met redundancy regarding those findings. Table 2 depicts the demographic characteristics (in terms of gender and geographical location) of potential participants receiving letters during each installment.

Table 2

Demographic Characteristics of Those Receiving Letters

Installment	Male	Female	Rural	City-Dwelling
1	8	12	7	13
2	10	8	12	6
3	8	0	5	3

Within 72 hours of letter disbursement, the researcher began making phone calls to potential participants. The purpose of these calls was to determine if potential participants were interested in receiving more information about the study, screening interested participants for inclusion and exclusion criteria, describing study procedures to those interested participants meeting inclusion criteria, and scheduling a meeting for a face-to-face interview for data generation. In some cases, potential participants called the researcher (via the phone number provided in the letter) expressing interest in taking part in the study prior to the researcher contacting them.

One participant contacted the researcher to express a desire *not* to be contacted. A total of 38 phone calls were made by the researcher. Twelve potential participants called by the researcher were unable to be reached. Three participants called the researcher expressing interest in participating. Of the 29 potential participants with whom the researcher spoke, 10 declined to participate and 4 were unable to participate as a result of failing inclusion and exclusion criteria. Thus, the refusal rate for the study was 36%, and approximately 14% of potential participants spoken to by the researcher were unable to participate as a consequence of failing to meet inclusion criteria. Thus, 64% of eligible older adults who were contacted by (or contacted) the researcher agreed to participate. Of note is that following the cessation of recruitment efforts in July of 2011, the researcher received phone calls from four potential participants the researcher had been unable to

reach or who had not yet been called expressing interest in participating. These potential

participants were informed that the study was closed to recruitment.

All participants were screened over the phone regarding inclusion and exclusion

criteria. Current age, age at epilepsy diagnosis, length of time since epilepsy diagnosis,

and anti-epileptic mediation status were collected via verbal report from potential

participants. Cognitive functioning was assessed via the Six-Item Screener for Cognitive

Impairment (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). Respondents making

three or more errors during the cognitive screening ($n = 2$) were excluded from the study

(Callahan et al., 2002). Two additional potential participants were excluded as a result of

having been diagnosed with epilepsy prior to age 60.
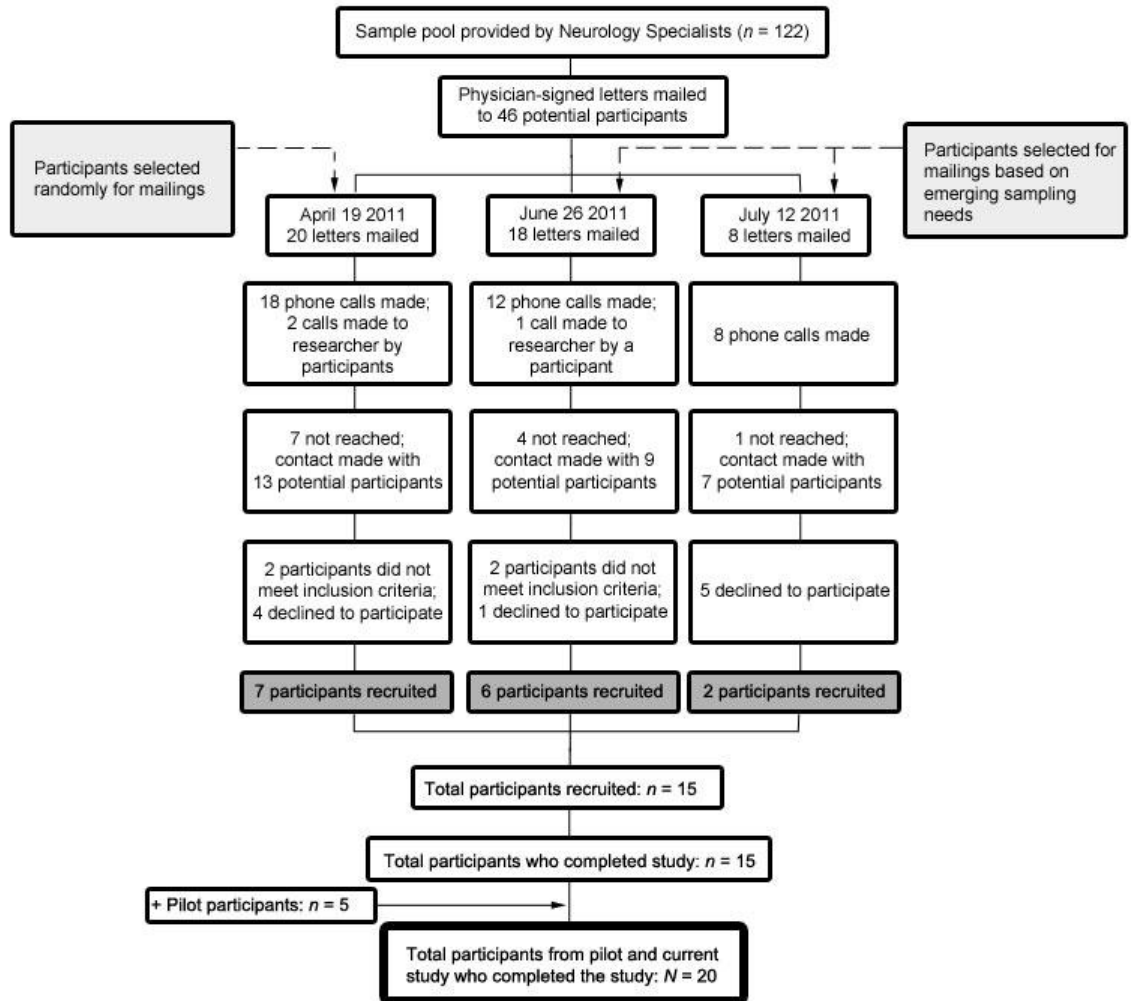
Figure 2. Flowchart demonstrates the recruitment activities for the study.

The details of study procedures were explained to all older adults who met

inclusion criteria and who wished to participate (*n* = 15). Participants were told that they

would meet with the researcher once, in a private location of their choosing, and that

following the attainment of informed consent, demographic data would be collected.

Participants also were informed that they would be completing the Mini Mental Status

Examination (Folstein, Folstein, & McHugh, 1975) and that it would be an

audio-recorded interview. Finally, participants were told that they would receive a $20

Wal-Mart gift card as a token of appreciation if they chose to be in the study. The

researcher then scheduled a face-to-face interview with each participant for data generation. Fourteen interviews were completed in individual participant homes, while one participant was interviewed at a conference room in the local library.

Ethical Considerations

Efforts were taken throughout the recruitment, data generation, and data analysis phases of the study to ensure the protection of human subjects. The researcher and her co-investigators (e.g., dissertation committee) had each previously successfully completed the human subjects protection course at the Indiana University Purdue–University Indianapolis campus prior to beginning recruitment procedures. No sampling or recruitment activities occurred until the study had been approved by the university's institutional review board.

The utmost care was taken during the recruitment process to protect potential participants' confidentiality. The names, phone numbers, and addresses that were provided to the researcher from the staff at the neurology practice were sent via encrypted e-mail. This e-mail could not be forwarded, and the contents were never printed. The contents remained on the researcher's password-protected computer and were deleted after the completion of recruitment efforts.

The recruitment letter sent to potential participants clearly explained the voluntary nature of the study and explained that the health care provided to potential participants would in no way be affected by any decision to take part or not to take part in the study. In addition, participants were provided with a phone number to call in the event that they should not want to be contacted by the researcher concerning the study.

The researcher conducted all interviews in private, quiet areas. Informed consent was obtained from all participants (Appendix E) immediately prior to data collection. Participants again were informed that participation in the study was voluntary and that they could withdraw at any time without consequence. In addition, participants were told that they could choose not to answer any interview questions that made them uncomfortable.

All audio-recorded data were deleted immediately after interviews were transcribed. Each participant was assigned a number, which appeared on his or her transcript. Names of and other identifying information about participants were not included in any transcripts, and signed consent forms were kept separately from all data. The transcribed interviews and other data collected (demographics, for example) were kept on a password-protected computer accessible only to the researcher. Transcripts were not printed, and were shared only with co-investigators via secure e-mail.

Data Generation

Instrumentation

Semi-structured interview. The goal of data generation in a qualitative descriptive study is to generate information regarding participants' experiences with the phenomenon, especially surrounding the specific research questions guiding the study, in their own words. Sandelowski (2000) suggests that the most appropriate means for achieving this goal is via the use of minimally to moderately structured interviews. Thus, face-to-face interviews were the primary means by which data were generated in this study. Sandelowski (2000) and Patton (2001) note that, while the precise way in which each participant is interviewed likely will vary, in order to create a comparable dataset

(Sandelowski, 2010a), the structure and basic content of the interview should be planned a priori. Therefore, before data generation was initiated, the researcher created interview questions that were used to direct data generation with participants. However, given the iterative nature of qualitative research, the structure and content of the interview changed for subsequent participants based on ongoing analyses. The development of the interview guide is discussed later in this section.

Patton (2001) specifies three types of qualitative interviewing: conversational, guided, and semi-structured. Conversational interviews are unstructured, informal, and similar to normal conversation. A guided interview technique involves preparing a list of topic areas about which the interviewer wants to ask but does not involve the use of pre-written questions. Semi-structured interviewing is characterized by the use of pre-planned interview questions and probes. When using any of these interview techniques, all questions asked are open-ended (Patton, 2001). Patton (2001) notes that the majority of the time a combination of these three approaches is necessary, and a combination approach was used in the proposed study.

Semi-structured interview questions were developed based on the research questions guiding the study. Table 3 identifies all semi-structured interview questions that were used and includes a rationale for the inclusion of each question. Questions that were added to the interview guide as a result of ongoing analyses also are included in Table 3. These questions served as the initial means of generating data during interviews. All questions were open-ended in order to allow participants to fully describe their experiences (Patton, 2001). Probes, as described by Patton (2001), were used to generate full and rich descriptions from participants. Conversational interviewing was used

throughout the interviews based on participants' answers. For example, if a participant

began to describe an experience about which the researcher had not planned on asking

but it was pertinent for that person's experiences with epilepsy self-management,

impromptu questions were asked in order to facilitate the participant's full description of

the experience. Finally, an interview guide was used (see Table 4). Pertinent topics were

listed on the guide, ensuring that before the close of the interview all important topics

were addressed. Also, as the content of the interview changed based on ongoing analyses,

topics were added to the list. Because the importance of precise aspects of these evolving

topics based on data analyses was not always apparent at first, no semi-structured

questions were written for them. Rather, the new topics added to the guide were explored

conversationally with subsequent participants. The researcher checked off these items

during the interview and reviewed the list prior to the close of the interview to ensure that

all pertinent topics were addressed.

Table 3

Interview Questions and Rationale

Interview Question	Rationale
Can you describe the process of how you were diagnosed with epilepsy?[a]	Research Question 1
Was it a good experience, why or why not? How long did it take to be diagnosed? Do you feel the provider prepared you for self-managing your epilepsy?[b]	
How has your life changed since being diagnosed with epilepsy?[a]	Research Question 3
How do you feel about the changes you have experienced? In terms of being able to do what you want to do, tell me how your life is different now, if at all, than before epilepsy. Can you describe a typical day for yourself now, and how your day might have been different prior to being diagnosed with epilepsy?[b]	

Interview Question	Rationale
Can you tell me about specific things that you or you and your family do on a regular basis to manage your epilepsy?[a]	Research Question 4
How do you access your medications? How do you remember to take them? How do you handle transportation? Is there anything that you do to prevent/control a seizure? Can you describe steps you take to make sure that you keep your commitments?[b]	
What problems have you experienced since being diagnosed with epilepsy?[a]	Research Question 2
Have you experienced problems directly related to the management of your epilepsy? Have you experienced problems that you feel are a result of having epilepsy?[b]	
Can you describe a situation for me related to your epilepsy that went very well?[a]	Research Question 4
What about the situation made it go well?[b]	
Can you describe a situation for me related to your epilepsy that did NOT go well?[a]	Research Question 4
What about the situation made it not go well? What would you have done differently?[b]	

Table continues

Interview Question	Rationale
What do you hope to achieve in self-managing your epilepsy?[a] *What outcomes are most important to you?*[b]	Research Question 5
Is there anything else you would like to share with me regarding your epilepsy, how you manage it, or how it has affected your life?[a]	This item ensured that participants discussed all topics important to them.
What information do you wish you had received at the time you were diagnosed?[a]	This item was added because participants reported not receiving enough information at the time of diagnosis.
Have you used any outside sources to find information about your condition?[a] *Do you use the Internet? Do you use the library? Do you rely on others to help you?*[b]	This item elicited additional information about how participants sought the information they did not receive at the time of diagnosis.
Do you feel comfortable telling others about your condition?[a] *Do your friends and family know that you have epilepsy? Why or why not?*[b]	This item was added because several participants spoke of not telling family/friends due to embarrassment, while others were very open with their family/friends about their epilepsy.

Table continues

Interview Question	Rationale
Do you ever self-adjust your seizure medication?[a]	This item was added after the sixth interview because three participants mentioned self-adjusting seizure medication.
Why do you self-adjust your medication? Do you tell your doctor about these adjustments?[b]	
Does having epilepsy differ from having (another chronic disease). If so, how and why? [a]	This item was added when it was noted that participants had different views of epilepsy than of their other chronic conditions.

[a]Indicates a question added during the study. [b]Indicates a common probe.

Table 4

Interview Guide

Topical Guide
Diagnosis
Strategies
Medications
Changes
Problems
Outcomes
Comparison with other conditions[a]
Informational sources[a]
Information needed[a]

[a]Topic added during the study

In favor of post-data generation member checks, Sandelowski (1993) and Maxwell (1992) suggest the use of active confirmation and summarization of participants' experiences *during* the interview process. Thus, throughout the interviews, the researcher confirmed with participants that she was hearing and interpreting their experiences correctly via providing summary statements at appropriate intervals and seeking clarification when needed. In the event that a participant's response was not heard or interpreted accurately, the question was revisited.

Throughout each interview, field notes and memos consistently were taken and made (Lincoln & Guba, 1985) describing observations that could not be captured on the audio-recording. For example, a respondent's facial expressions, gestural movements, or emotional responses all were potentially important in fully describing participants' experiences, and thus, were recorded via field notes and memoranda. Doing so and ensuring that such memos and field notes were included in transcripts helped ensure both descriptive and interpretive validity (discussed later in this section) of the study (Maxwell, 1992) and maintenance of an audit trail (Rodgers & Cowles, 1993). Field

notes and memoranda also were taken throughout the interview of any of the researcher's initial thoughts and reactions to the respondent's answers. As well, immediately following each interview, the researcher wrote down initial reactions and reflections about the interview. These reflections were kept in a reflective journal (Rodgers & Cowles, 1993; Sandelowski, 1993) and used as part of the audit trail, which was maintained to ensure descriptive and interpretive validity.

Mini Mental Status Exam. Participants also completed the Mini Mental Status Exam (Folstein et al., 1975; see Appendix F). The purpose of the use of this tool was to allow the researcher to describe the participants in the sample in terms of cognitive functioning given the advanced age of the participants, as well as the presence of a condition (epilepsy) that can alter cognitive functioning. Because of the small sample size, the study was underpowered to make statistical correlations with data yielded from this tool.

The Mini Mental Status Exam (Folstein et al., 1975) is a 30-item questionnaire used to assess cognitive status. There is substantial support for the reliability and validity of this instrument in both younger and older adults (Mitrushina & Satz, 2006). This questionnaire takes approximately 10 minutes for respondents to complete and assesses various cognitive functions including memory, orientation, language, complex commands, registration, attention and calculation, repetition, and recall. A score of 25 points or higher (out of 30 possible points) is a reflection of normal cognitive functioning. A score of 21–24 points is indicative of mild cognitive impairment, while a score of 10–20 points suggests moderate cognitive dysfunction. A score of nine or below

is indicative of severe cognitive impairment (Folstein et al., 1975). Of note is that this questionnaire was not administered to participants taking part in the pilot study.

Demographics. A demographic form (Appendix G) was used to collect the following demographic data from participants: gender, age, race, number of co-morbidities in addition to epilepsy, marital status, years of education, type of seizures (partial, grand-mal, or other), years since epilepsy diagnosis, years of school, employment status (working or retired), living situation (alone or with another), assistive significant other (yes or no), insurance coverage (Medicare, private, or none), and annual income (≤$20,000; $21,000–$40,000; $41,000–$60,000; $61,000–$100,000, and >$100,000).

Setting and Procedures

All data collection took place via face-to-face meetings with participants. Participants chose the setting in which they wanted to be interviewed, and 14 of them chose their homes, while one chose a private conference room in a local library. All interview settings were private and quiet. Prior to any data collection or generation, informed consent was obtained from each participant. A copy of the informed consent statement was given to each participant. Authorization for the release of health information also was obtained from each participant, and a copy of the authorization was given to each participant. After the attainment of informed consent and authorization for the release of health information, each participant was given a $20 Wal-Mart card. The researcher then collected demographic data from the participant. In order to capture potentially pertinent background information from the participants, the digital audio-recorder was turned on at this time (Sandelowski, 2010b). After the demographic

data was collected (except in the case of each pilot participant), the researcher administered the Mini Mental Status Exam (Folstein et al., 1975).

Following completion of the Mini Mental Status Exam (Folstein et al., 1975), it was explained to each participant that the interview would start at that time. Participants were reminded that they were not required to answer any question that made them feel uncomfortable, and that they could withdraw from the study at any time. Each interview opened with a staging commentary (Miles & Huberman, 1994) during which the researcher briefly reminded the participant of the purpose of the interview, the nature of the interview questions, and that the participant should feel free to provide any additional information that he or she felt was important. The interview commenced using the semi-structured interview questions described in Table 3. Probes and conversational interviewing were used in all interviews based on participants' responses to semi-structured questions (Patton, 2001). Interviews ranged in length from 40 minutes to two hours, and all consented participants completed all data collection and generation procedures.

Data Preparation, Management, and Analysis

Raw qualitative data must be analyzed in order for the researcher to render an interpretation of the data (Sandelowski, 1995a). Sandelowski (1995a) describes data analysis as the process by which generated data are broken up or down in a way that allows the researcher to see the data in a new way—a means to knowledge production involving the separation of elements of data according to, in the case of qualitative description, a data-derived system. Prior to being analyzed, however, data must be made docile to analysis (Sandelowski, 1995a, 2010a). That is, data must be prepared and

managed in a way that allows the researcher to *look for* things in the data. Sandelowski

(1995a) notes that data preparation and management occur somewhat concurrently with

data analysis. Preparing data for analysis, for instance, often will spur thoughts about and

evaluations of data—a rudimentary type of data analysis (Sandelowski, 1995a). To

facilitate clarity among the different processes, data preparation and management and

data analysis activities are discussed and described in this chapter as separate activities,

though it is acknowledged that they occurred somewhat simultaneously.

Data Preparation and Management

Data preparation occurred via transcribing interviews verbatim into Microsoft

Word™ in order to preserve all elements of the interviews as much as possible

(Sandelowski, 1995a). All interviews were transcribed by the researcher, a practice that

assists a beginning qualitative researcher in becoming very familiar with the data

(Sandelowski, 2010b). All spoken words from each interview were transcribed, and lines

were numbered to assist with later analysis. According to Sandelowski (2010a), the use

of a legend in transcribing interviews is necessary to protect descriptive validity. Thus, a

legend was used in order to describe aspects of the interview that cannot be typed, such

as pauses in a respondent's speech. For example, the researcher inserted a hyphen for

every second that a pause in the recording existed. A pause lasting three seconds, then,

was represented as "---." A similar system was utilized for periods of the recordings that

were inaudible or could not be deciphered. Following transcription, the researcher

proofread all transcripts for accuracy to support descriptive validity, as well as added

pertinent field notes, memoranda, and reflections to each transcript in order to protect

interpretive validity.

Data management refers to the ways in which the researcher organizes data to allow for easy access of the data, as well as maintenance of an appropriate audit trail (Sandelowski, 2010a). It is necessary to, a priori, establish a system for managing and organizing all data as doing so will not only facilitate the process of data analysis but also will allow for auditability of study proceedings and thus protection of validity (Sandelowski, 2010a). This system was established prior to the execution of the study. The following discussion pertains to the ways in which data were managed throughout generation and analysis and also articulates the ways in which other types of information, such as those contributing to the audit trail, were managed.

Using Microsoft Windows™ and Microsoft Word™, a folder was created for each participant. Each participant's transcript as well as any analysis documents pertaining to that transcript was placed in the folder. Such a system allowed for organization and easy retrieval of each respondent's materials (Sandelowski, 2010a).

A proper audit trail was maintained via the use of guidelines suggested by Rodgers and Cowles (1993) and Miles and Huberman (1994). The audit trail was kept to provide a record of all of the significant decisions and analytic proceedings that occurred throughout the study and led to the transformation and interpretation of raw interview data (Sandelowski, 1993). According to Rodgers and Cowles (1993), in creating an audit trail, four different types of documentation must be maintained throughout a qualitative study: contextual, methodological, analytic, and personal response. Contextual documentation refers to the researcher's descriptive accounts during data collection (field notes and memoranda). The field notes and memoranda recorded during data generation were added to each respective transcript in the appropriate places using Microsoft

Word's™ track changes functionality. For example, if it were noted that a respondent closed his or her eyes or looked away while answering a certain question, the researcher inserted a comment containing this information next to the response during in which it occurred. Methodological documentation refers to documentation of all methodological decisions made throughout the study. As previously mentioned, qualitative research, qualitative description included, relies on an emergent research design. Any methodological decisions that are made—such as a change in the structure or content of the interviews—were noted with specific rationale for the change, the date on which the change was made and any other pertinent information, then was placed in a separate methodological documentation folder. A running log of such methodological changes and decisions was kept throughout the study (Rodgers & Cowles, 1993).

Analytic documentation refers to maintaining a record of the researcher's thought processes in sorting, categorizing, and comparing data, and conceptualizing patterns found in the data (Rodgers & Cowles, 1993). Analytic documentation occurred in several forms. First, a standardized analytic log similar to that offered by Miles and Huberman (1994) was maintained for each respondent. Table 5 is an excerpt from the analytic log used for a participant in the study. This log was updated each time analysis proceedings were performed on a respondent's transcript. After each analytic session, the investigator recorded in the log, for each transcript analyzed, the date, a brief summary of data analysis activities that occurred (i.e., spent time reading the transcript and getting the essence of the case; extracted facts from the case; began initial coding), decision rules followed during coding, conclusions drawn, rationale for conclusions, and researcher comments regarding reflection on the data analysis session (Miles & Huberman, 1994).

Table 5

Excerpt from Analytic Log

Participant	Date	Analytic Activities	Conclusions
2A	4/29	Read over transcript to get a sense of it.	None made—initial pass.
2A	5/4	Getting a sense of the whole. Continue reading transcript to get a sense of the whole.	Summary typed up.
2A	5/9	Continuing to read over summary and the transcripts.	Beginning to extract facts.
2A	5/18	Deeper analysis—extracting facts and working on a time line. Initial codes identified.	Important facts extracted, time line made, very rough codes begun. Lack of awareness about the possibility of having epilepsy as an older adult is emerging.
2A	5/24	Dimensionalized timeline, finished coding.	Major finding today was that epilepsy is different for him—it's different than his other diseases.
2A	6/1	Beginning cross case analysis with 1A and 2A.	Most codes are there in both cases, but 2A seemed to be diagnosed more easily than 1A.

In addition to the maintenance of individual respondent analytic logs, a more general analytic log also was kept via a Microsoft Word™ document and placed in a separate folder. Rodgers and Cowles (1993) suggest the use of this type of log to develop a history of the data analysis processes and their progression. The researcher documented in this log on at least a weekly basis or following significant analytic moves or changes. For example, the researcher documented when patterns began to emerge into themes, how current themes accounted for existing data, new paths of analysis that needed to be

explored, and quotes that supported current conclusions. Data displays and enumeration charts used as part of analysis (discussed later in this section) as well as the coding guide with decision rules (discussed later) also were included in this log, complete with comments regarding the ways in which the information in them supports analytic decisions. Finally, as previously mentioned and as is described in detail later in this section, different versions of each transcript created as part of data analysis (for example, the abstract summaries of each transcript that were created as part of initial data analysis) were maintained in each respondent's folder.

Personal response documentation refers to the recording of the researcher's personal feelings and reflections throughout the study. As previously mentioned, immediately following each interview, the researcher documented in a reflective journal the thoughts, feelings, and reflections about the interview. During the period of active data generation and analysis, pertinent thoughts and reflections about the study as a whole also were documented regularly. The documentation of such information, though personal in nature, often proves an integral part of the audit trail and can serve to help support and verify research interpretations in ways that are not captured in the descriptions of only contextual, methodological, and analytical occurrences (Rodgers & Cowles, 1993).

In summary, data preparation strategies were used to ensure that data were made amenable to analysis. Data were prepared via verbatim transcription of interview data using legends. Transcripts were checked for accuracy and pertinent field notes and memoranda were infused into each transcript. Data management strategies were utilized to maintain an organized data set, facilitate efficient access to data, and to maintain a

proper audit trail, which helped to ensure the descriptive and interpretive validity of final interpretations. Management was achieved by organizing transcripts, as well as appropriate contextual, methodological, analytic, and personal response documentation, in separate folders using Microsoft Word™ and Microsoft Windows™.

Data Analysis

Data analysis refers to the process by which the researcher reconfigures (or "plays with") the raw data so that he or she can go from looking at data to looking *for* something *in* the data (Sandelowski, 1995a). Data analysis began once the first transcript was prepared and remained ongoing and concurrent with data generation/preparation until informational redundancy was reached. The researcher utilized analysis techniques as put forth by Sandelowski (1995a, 2000). Case-oriented, as opposed to variable-oriented, analysis of data occurred via the use of conventional content analysis as described by Hsieh and Shannon (2005). In the following sections, key features of the data analysis process as it occurred are discussed. These analysis proceedings occurred in tandem with continued recruitment and data generation.

Case- versus variable-oriented analysis. Before discussing the specific analytic activities that occurred in the study, it is important to differentiate between case- and variable-oriented analyses because all analysis procedures took place in a *case* analysis context. Sandelowski (1996) asserts that, above anything else, qualitative researchers are obliged to make sense of individual cases—to understand the particulars in the *all-together*. To meet this goal requires the use of case-oriented, as opposed to variable-oriented, data analysis. Thus, case-oriented analysis was employed in all data analysis procedures in the study. Variable-oriented analysis, which is the hallmark of

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quantitative research, is characterized by the study of disaggregated variables from many cases so that the relationships between the variables can be examined to explain variability among the different cases (Sandelowski, 1996). The goal of the researcher in qualitative research, however, is to understand the overall essence of individual cases. In case-oriented analysis, what Sandelowski (1996) calls the *features* of the cases are treated as an "ensemble" (p. 526) rather than being separated into variables. While the variable-oriented approach seeks to determine how different variables influence each other, the case-oriented approach is concerned more with the confluence of features and how they shape the experience for respondents. This case-oriented approach is necessary in order to arrive at the generalizations that are the goal of qualitative research—not nomothetic generalizations, which are the interest of quantitative researchers, but idiographic generalizations (Sandelowski, 1996).

According to Sandelowski (1995a, 1996), it is necessary to analyze each case *individually* prior to making *across-case* comparisons. Making across-case comparisons prior to individually analyzing each case is premature and can yield superficial results that lack credibility, which threatens interpretive validity. Thus, in the study, all cases initially were analyzed individually, using the guidelines described later in this section, prior to across-case analysis occurring. Doing so allowed the researcher to become sensitized to features that appeared important in individual cases and thus to determine if the same features were important across all cases (Sandelowski, 1996). It also ensured that outlying features unique to respondents' variable experiences were not lost (Ayres, Kavanaugh, & Knafl, 2003). Across-case analysis occurred by comparing analytic findings from individual cases of older adults with those of the other older adults. The

precise way in which these across-cases analyses occurred was emergent (Ayres et al., 2003) and was based on findings from initial case analyses. As is described later in this section, all transcripts initially were coded using the research questions as a guiding framework. After all individual cases were coded in this manner, the findings from each case, for each question, were compared and contrasted across cases in the dataset to find patterns, as well as aberrant findings, in the across-case data (Ayres et al., 2003).

   Initial steps. In her article, "Qualitative Analysis: What it is and How to Begin," Sandelowski (1995a) provides direction for novice qualitative researchers in how to begin analyzing their data. Sandelowski (1995a) suggests that the following steps be taken when beginning the analysis of qualitative data: getting a sense of the whole, extracting the facts, identifying key topics/storylines and dimensionalizing them, and using frameworks to reduce data. In a later publication related specifically to data analysis via content analysis in qualitative description, Sandelowski (2000) again supports the use of these initial techniques; therefore, they were used to guide the initial analysis steps in this study.

   Getting a sense of the whole. According to Sandelowski (1995a), the initial efforts involved in data analysis should be focused on understanding each transcript as a whole prior to developing a consistent approach to accounting for the data. The researcher, treating each case as individual and worthy of study, should read each transcript as many times as is necessary for him or her to understand its essential features. A summary or abstract of each case should be composed then—the purpose of which is to provide the researcher with a quick, yet descriptive, glance of the essential features of the transcript, and thus the respondent's experiences (Sandelowski, 1995a). Following

proper data preparation of each transcript, therefore, the researcher spent time reading

each transcript once, very carefully, in order to capture its essence. The researcher

avoided, as Sandelowski (1995a) suggests, underlining and line-by-line coding during

this process because doing so can interfere with the ability to grasp the essence of the

case (Sandelowski, 1995a). For each transcript, the researcher composed a descriptive

summary that represented the main features of the case. These summaries were placed in

individual participants' analysis folders.

Sandelowski (1995a) suggests that after getting a sense of the whole for each

case, a more disciplined approach—one that can be applied systematically to all data—is

needed. As was mentioned previously and will be discussed more thoroughly later in this

chapter, each technique and all rules that were applied to data during analysis were noted

in the analytic log as well as changes to analytic techniques and rules as they were made,

along with supporting rationale for those changes. Sandelowski (1995a) suggests the use

of three initial techniques that often prove helpful for organizing data—extracting the

facts, extracting and dimensionalizing storylines, and using frameworks to reduce data.

All of these techniques were utilized during initial analysis.

Extracting the facts. Sandelowski (1995a) suggests, once each transcript has been

carefully read and summarized, using the technique of extracting the facts from each case

that are likely to be important in contextualizing respondents' stories. Thus, for each case,

the researcher extracted facts such as length of time since epilepsy diagnosis, type of

epilepsy, presence of other co-morbidities, and other factors that appeared pertinent to the

telling of respondents' stories. In staying consistent with case-oriented analysis, facts

were extracted on a case-by-case basis. Sandelowski (1995a) recommends creating, based

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on these extracted facts, event histories for all respondents by plotting factual information

for each respondent on a timeline. Such timelines were made for each participant.

Figure 3 demonstrates a sample timeline that was constructed during analysis. Timelines

were referred to throughout data analysis assist the researcher in maintaining a

connection between pieces of data and the stories from which they come.
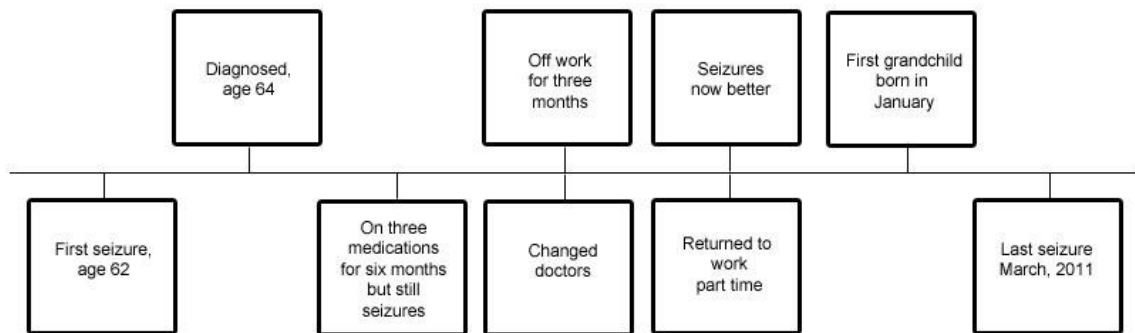
Figure 3. Sample timeline constructed to demonstrate event history.

    Storylines. Another method that was used to immerse the researcher in the data

was the extraction of major storylines from each case. Storylines are identified as

significant events occurring in the respondent's experience, such as being diagnosed with

epilepsy (Sandelowski, 1995a). For each case, the researcher extracted storylines, using

as few words as possible, to form a list of major storylines within the case. The goal in

creating such a list for each case was to provide the researcher with a parsimonious, but

complete, index of the major storylines in each case. Next, the storylines were

dimensionalized—that is, the investigator added descriptions to each storyline. For

example, if the storyline of *being diagnosed* was extracted, the researcher described it

with pertinent information such as how long it took the older adult to be diagnosed, how

he or she was diagnosed, and so on. While each case was comprised of unique storylines,

common storylines, such as being diagnosed with epilepsy, were seen across cases.

Storylines were referred to by the researcher throughout data analysis. Table 6 displays a

dimensionalized storyline list constructed for one of the participants.

Table 6

Storyline List Sample

Storyline	Dimensionalization
First seizure	Occurred at age 72 on a camping trip. Grand-mal during sleep. Taken to ER in a small hospital, referred to his primary physician.
Diagnosed	Diagnosed within a week or so of first seizure. Primary physician ran tests and referred to a neurologist. He found time-to-diagnosis acceptable. He did not know what he had was called "epilepsy" until months later.
Started medication	Initiated at ER, changed by neurologist upon diagnosis. Changed to Dilantin^{TM} from Tegretol^{TM}. Tolerated side effects much better. No subsequent seizures from this point on.
Children visited	Kids came to stay for the first time since diagnosis. Anxiety-provoking because he feared he would have one in front of his grandkids.
Driving	Six months after diagnosis, he was allowed to drive for the first time. He had been driving a little while on restriction, but only around his neighborhood. His wife had taken over most of the driving.
Disclosure	Several months after diagnosis, he felt comfortable and found it necessary to tell neighbors about condition. He does not tell others outside his family.

Using frameworks to reduce data. Another way to begin analyzing data is via the

application of an a priori framework to organize the data. Sandelowski (1995a) gives

examples of ways in which to do this: organizing data by research questions, interview

questions, or by searching for structures, processes, and outcomes. In qualitative

descriptive research utilizing conventional content analysis (discussed later in this

chapter), it is necessary that analysis be data-derived. That is, a priori coding schemes are

not used. However, while a researcher conducting qualitative description via conventional content analysis should not be looking for particular codes in the data, Sandelowski (1995a) supports the use of interview and research questions for guiding initial content analysis in qualitative description, with the requirement that the researcher recognizes the use of these questions to organize data as purely *initial* and is not closed off to other avenues of analysis. Sandelowski (2000), however, also notes that, given that the main purpose of qualitative description is to describe the phenomenon in terms of the research questions asked about it, organizing data by research questions is often a fruitful strategy in this method and allows for the answering of the research questions. Thus, data initially were reduced using the research questions as an organizing framework (Sandelowski, 2010a). For example, using the research question, "What problems do older adults face in self-managing epilepsy?" the researcher read each case searching for the discussions of problems faced by the older adult. The displays and lists of storylines generated in the previous analysis steps also were referred to during this process while addressing each research question. The process of reducing the data via these questions was facilitated using color-coding. Data that did not pertain to the research or interview questions were partitioned via the use of color coding for later analysis. Once the data were reduced and organized via research and interview questions, as is described in the discussion of content analysis later in this chapter, data-derived codes were developed and applied.

  Content analysis. The data analysis method of choice for qualitative descriptive studies is content analysis (Patton, 2001; Sandelowski, 2000), which is a method aimed at summarizing the informational contents of the data (Sandelowski, 2000). Three types of

content analysis—conventional, directed, and summative—exist (Hsieh & Shannon, 2005). The method of content analysis employed depends on the purpose of the study, and the three types of content analysis differ regarding how initial codes are developed. In conventional content analysis, codes are data-derived, and a guiding theoretical framework, other than general research questions, is not used. In directed content analysis, codes are theory-based and established a priori, making this method most applicable to theory testing and expansion. In summative content analysis, a list of keywords of interest to the researcher is developed a priori, and the frequency with which the words are found in the data is tabulated (Hsieh & Shannon, 2005). Given that very little research has been done and virtually no theories exist regarding the phenomenon of epilepsy self-management in older adults, conventional analysis was most appropriate to employ in the proposed study (Sandelowski, 2010a). In employing this method using little direction other than general research questions, the researcher allowed codes and themes to emerge naturally from the data.

Following the use of the previously mentioned initial data analysis activities (getting a sense of the whole, extracting facts, etc.), conventional content analysis was used to derive an initial coding scheme for the dataset. With the knowledge generated from the initial data analysis steps serving as a context, and the research questions serving as an organizing framework (Sandelowski, 1995a), the researcher re-read each case very carefully, paying close attention to respondents' words and phrases that seemed to capture important concepts, both those related and those not directly related to the research questions. Codes related and not directly related to the research questions emerged. Once this process had occurred for each case, it then occurred across cases

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(meaning that codes from different cases were compared with one another to ensure all data had been accounted for and to determine how prevalent each code was), resulting in an initial coding scheme that was comprised of 36 distinct codes. Over the course of the study, 12 additional codes were generated. The final scheme, complete with decision rules, is depicted in Table 7.

Table 7

Coding Scheme

Code	Decision Rule
Delayed Diagnosis	Appropriate when a participant reports the existence of an unacceptable time frame (to that person) between first seizure and diagnosis or when the participant failed to seek medical attention for seizures for a prolonged period of time resulting in a delayed diagnosis. Any circumstances that resulted in a delayed diagnosis, meaning more than three months, from first seizure to diagnosis should be counted.[a]
Prompt Diagnosis	Appropriate when a participant reports that his or her epilepsy was diagnosed promptly (i.e. within three months).
Dismissive Care Providers	Appropriate when a participant reports that he or she feels that personal care providers, either primary care, neurologists, or other providers, initially dismissed participant concerns or symptoms as not important or serious.
Shock	Appropriate when a participant reports being shocked/surprised about the diagnosis or any other aspect of the disease.
Stigma	Appropriate when a participant reports feeling (or being in fear of feeling) that epilepsy could cause him or her to be stigmatized against.
Lack of Information	Appropriate when a participant reports not knowing as much about the condition as preferred.

Table continues

Code	Decision Rule
Feeling Unprepared	Appropriate when a participant reports not feeling prepared for the diagnosis or for the management of the disorder.
Positive Spin	Appropriate when a participant reports looking at the disorder in a positive light, as in making the best of the situation.
Intentional Non-adherence	Appropriate when a participant reports knowingly not adhering to provider instructions regarding epilepsy medications, treatments, and lifestyle restrictions.
Unintentional Non-adherence	Appropriate when a participant reports unknowingly not adhering to provider instructions regarding epilepsy medications, treatments, and lifestyle restrictions (forgetting to take medications, for example).
Finances	Appropriate when a participant discusses how his or her financial situation affects the epilepsy diagnosis or management in any way.
Feeling Different	Appropriate when a participant discusses feeling different from others because of having epilepsy or due to its treatments or restrictions.
Co-morbidities	Appropriate when a participant discusses co-morbidities in the context of it affecting his or her epilepsy diagnosis or management.
Spouse's Health Problems	Appropriate when a participant discusses a spouse's health problems in the context of it affecting his or her epilepsy diagnosis or management.
Medication Side Effects	Appropriate when a participant reports undesirable side effects of seizure medications.
Self-titration of Medications	Appropriate when a participant reports altering medication dosages (including time and frequency of administration) without consulting with his or her provider.
Management Strategies	Appropriate when a participant discusses a specific strategy he or she uses in managing epilepsy.

Table continues

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Code	Decision Rule
System	Appropriate when a participant reports other people and things assisting in epilepsy management.
Commitments	Appropriate when a participant discusses how epilepsy has affected his or her commitments.
Changed Roles	Appropriate when a participant discusses how his or her (and possibly his or her spouse's) roles are changed since epilepsy diagnosis.
Going Forward	Appropriate when a participant discusses moving on with life.
Normalcy	Appropriate when a participant discusses maintaining his or her normal life.
Staying Seizure-free	Appropriate when a participant discusses the desire to stay seizure-free.
Safety	Appropriate when the participant discusses safety (of self or others).
Dependence/Independence	Appropriate when the participant discusses how his or her independence or dependence has been affected by epilepsy.
Positive Changes	Appropriate when the participant reports positive changes that have come from having epilepsy.
Negative Changes	Appropriate when the participant reports negative changes that have come from having epilepsy.
What is Epilepsy?	Appropriate when the participant expresses lack of understanding about what epilepsy is (at or since the time of diagnosis).
Denial	Appropriate when the participant reports (or suggests) that he or she chooses to deny the diagnosis and/or the treatments and lifestyle changes associated with it.
Information-seeking	Appropriate when the participant discusses seeking information about his or her epilepsy, its treatments, etc.

Code	Decision Rule
Communication	Appropriate when the participant discusses communicating with others (care providers, family members) about his or her condition.
Isolation	Appropriate when the participant discusses feeling isolated (or not a part of things/events/groups) due to his or her epilepsy or its related treatments and restrictions.
Emotions	Appropriate when the participant discusses experiencing emotions related to his or her epilepsy or its related treatments and restrictions.
Loss	Appropriate when the participant reports experiencing loss (in any form) related to his or her epilepsy or its treatments and restrictions. Though the participant may not use the word *loss*, it is appropriate to use this code when the participant tells a story that demonstrates a feeling of loss.
Control	Appropriate when a participant discusses control in his or her life or over epilepsy.
Acceptance	Appropriate when a participant discusses accepting his or her epilepsy. Other words or phrases, such as *getting used to* or *coming to terms with* also fall under this code.
Planning	Appropriate when a participant discusses ways in which he or she plans or has planned managing something to do with epilepsy. Other words or phrases, such as *got things in order*, also fall under this code.
Symptoms	Appropriate when a participant reports the experience of unpleasant symptoms since epilepsy diagnosis. Symptoms can be physical or psychological.
Denial	Appropriate when the participant overtly reports denial related to his or her epilepsy or when the participant tells a story demonstrating denial of epilepsy or its associated treatments, restrictions, and effects on the person's life.
Fantasy	Appropriate when the participant describes a story in which he or she pretends to not have epilepsy.

Table continues

Code	Decision Rule
Proactive	Appropriate when the participant describes anticipating problems that may occur as a result of epilepsy and taking action to prevent or manage those problems before they occur.
Reactive	Appropriate when the participant describes not anticipating problems that may occur as a result of epilepsy before they occur, and basing his or her responses to the problems on his or her initial reaction(s) to the problems.
Adaptation	Appropriate when the participant reports adapting, or getting used to, having and managing epilepsy over time. Also appropriate when the participant reports adapting expectations, lifestyle, commitments, etc., to epilepsy and its treatments.
Changed Roles	Appropriate when the participant reports that his or her roles have changed since the onset of epilepsy, or those of family members or friends have changed. This also may refer to not being in expected roles as a result of epilepsy.
Lack of Awareness	Appropriate when the participant reports that he or she was not aware (at the time of diagnosis or currently) that new-onset epilepsy affects older adults.
Memory Problems	Appropriate when the participant reports memory loss related to epilepsy or since the epilepsy diagnosis.
Life Altering	Appropriate when the participant tells a story in which he or she reports that being diagnosed with and/or having/managing epilepsy has been life-changing.
Epilepsy is Different	Appropriate when the participant expresses that there is a difference between epilepsy and other chronic diseases from which he or she suffers in terms of diagnosis, management, as well as other aspects.

[a]The time period of three months was used because it is the mean length of time that passes for a person to be diagnosed properly with a chronic disease (Centers for Disease Control and Prevention, 2009).

Codes then were partitioned into clusters using research questions as the organizational framework (Sandelowski, 1995a). Codes not directly relevant to the research questions were clustered and placed under separate headings (Table 8). At this stage of analysis, some codes were associated with multiple research questions, which alerted the researcher of the interactive nature of the phenomenon under study.

Table 8

Coding Scheme Clustered by Research Questions

Research Question	Coding Scheme
1	Delayed Diagnosis; Prompt Diagnosis; Dismissive Care Providers; Shock; Communication; Lack of Information; Feeling Unprepared; Shock/Surprise; Stigma; What is Epilepsy?; Lack of Awareness
2	Life-Altering; Independence/Dependence; Symptoms; Isolation; Stigma; Loss; Communication; What is Epilepsy?; Safety; Commitments; Medication Side Effects; Feeling Different; Changed Roles; Lack of Information; Control; Dismissive Care Providers; Memory Problems; Unintentional Non-Adherence; Emotions; Control
3	Feeling Different; Negative Changes; Positive Changes; Altered Roles; Life Altering; Independence/Dependence; Commitment; Isolation; Loss; Emotions; Control
4	Strategies; Proactive; Reactive; Planning; Adherence; Intentional non-adherence; Fantasy; Denial; Moving Forward; Information-Seeking; Communication; Adaptation; System; Control; Positive Spin; Acceptance
5	Normalcy; Staying Seizure-free; Acceptance
Other	Epilepsy is Different; Information-seeking; What is Epilepsy?

Following the development of the scheme, which was based from both within- and across-case analyses, a coding guide (or *code book*) was developed for the dataset and also maintained as part of the analytic log. In this guide, decision rules for each code were maintained. Sandelowski (1995a, 2010a), Patton (2001), and Miles and

Huberman (1994) strongly espouse the need to use explicit decision rules for all codes. A decision rule explicates *what counts* as the existence of a code in the data and is important in maintaining rigor throughout the data analysis process as well as in establishing an audit trail (Sandelowski, 2010a). For example, when the code of *surprise/shock about being diagnosed* was derived, the researcher wrote a rule regarding this code so that it could be applied consistently to *all* data. These rules specified what type of content had to be seen in a case for this code to be applicable, how many times it would have to appear, and so on. The coding guide was a work-in-progress throughout the study, as it was formed soon after the first data were generated, and continually was revised based on new data. The initial coding guide was tested for completeness by applying codes to all existing data (in the form of raw data, summaries, and storylines) to determine the degree to which the guide accounted for all the data. There were points at which the researcher discovered that the coding guide did not account for certain portions of the data, and made revisions to the guide, decision rules, or both, and the guide was tested again. This iterative process occurred until all pertinent data were accounted for and informational redundancy was achieved (Sandelowski, 1995a, 2010a). Informational redundancy refers to the point in the analysis at which new data fail to generate new codes (Patton, 2001). Informational redundancy was met after the researcher analyzed data from the 20th participant.

In order to develop themes, which refer to statements that express salient characteristics of the experience in response to the aims of the study, from the data-derived codes, a data matrix was utilized (Miles & Huberman, 1994). The goal of the matrix was to display codes in a way that allowed for potential relationships and

linkages of them, as well as the frequency with which codes appeared in the data, to be seen in order to allow the researcher to situate codes under descriptive themes (Miles & Huberman, 1994). In order to remain congruent with the purpose of the study and the research questions guiding it, the researcher derived and arranged themes to ensure that the purpose of the study was being fulfilled and that research questions were being answered (Sandelowski, 2010a). For example, the purpose of the study was to describe older adults' experiences of epilepsy self-management and not to describe the meaning to those individuals of having epilepsy (as potentially would be the case in a phenomenological study); thus, the researcher did not generate themes that would speak only to the meaning of epilepsy to the respondents, as doing so would not fulfill the study purpose.

To summarize, following (and in conjunction with) the use of the initial data analysis techniques espoused by Sandelowski (1995a) described previously, conventional content analysis was used to analyze all data. Data-derived codes were generated and tested in terms of their ability to account for data within and across the cases. Codes, situated in clusters, were revised as needed in order to account for all data. Data matrices were utilized to assist with the transition from cluster-nested codes to descriptive themes. Themes were developed based on the way in which clusters of codes best addressed the study purpose and driving research questions.

Counting and visual displays. Counting and visual displays were used throughout data analysis proceedings. Sandelowski (2001) strongly encourages the use of counting and enumeration in qualitative research and particularly in qualitative descriptive research. According to Sandelowski (2001), though qualitative research is

often seen as "anti-number" (p. 230), counting can be an effective way to demonstrate the complex work involved in qualitative research and to generate meaning, as well as to document, verify, and test researcher conclusions. Sandelowski (2001) explains that enumerating key features of cases, especially those found during across-case analysis, and organizing those features in a numerical display can generate meaning via allowing for the emergence of patterns of the generation of new hypotheses and lines of analysis. In this study, counting and visual displays were used to document and verify conclusions as well as to generate meaning based on techniques provided by Sandelowski (2001). For example, when the researcher had an impression that women in the sample had more difficulty in receiving an accurate epilepsy diagnosis than the men in the sample, the researcher constructed a table enumerating the percentage of women versus men reporting a delayed diagnosis of epilepsy (Table 9). The researcher added each participant to this table to help verify her impression.

Table 9

Delayed Diagnosis by Gender

Participant	Gender	Delayed Diagnosis
1	F	Yes
2	M	No
3	F	Yes
4	M	No
5	F	Yes
6	F	Yes
7	M	No
8	M	No
9	M	No
10	F	No

Table continues

Participant	Gender	Delayed Diagnosis
11	M	Yes
12	F	Yes
13	F	Yes
14	F	Yes
15	F	No
16	F	Yes
17	F	Yes
18	F	Yes
19	M	Yes
20	M	Yes

Table 9 allowed the researcher to track and confirm initial impressions that the women (83%, 10/12) who took part in the study were more likely than the men (37.5%, 3/8) who took part in the study to have experienced a delay in diagnosis. This confirmed impression led the researcher to focus her attention on possible causes or circumstances that led to this discrepancy in participants' experiences. The researcher expanded the chart represented by Table 9 to include other demographic characteristics that emerged as potentially important. Table 10 depicts an expanded version of the visual aid used by the researcher in determining that geographic location (rural versus city-dwelling) and symptom presentation (classic versus ambiguous) may contribute to delay in diagnosis.

Table 10

Delayed Diagnosis and other Demographics

Participant	Gender	Delayed Diagnosis	Geographic Location	Symptom Presentation
1	F	Yes	CD[a]	Classic
2	M	No	CD[a]	Classic
3	F	Yes	Rural	Ambiguous
4	M	No	CD[a]	Ambiguous
5	F	Yes	Rural	Classic
6	F	Yes	CD[a]	Classic

Table continues

Participant	Gender	Delayed Diagnosis	Geographic Location	Symptom Presentation
7	M	No	Rural	Classic
8	M	No	Rural	Classic
9	M	No	CD[a]	Classic
10	F	No	CD[a]	Classic
11	M	Yes	Rural	Ambiguous
12	F	Yes	Rural	Classic
13	F	Yes	CD[a]	Ambiguous
14	F	Yes	Rural	Classic
15	F	No	CD[a]	Classic
16	F	Yes	CD[a]	Ambiguous
17	F	Yes	Rural	Ambiguous
18	F	Yes	Rural	Ambiguous
19	M	Yes	CD[a]	Ambiguous
20	M	Yes	Rural	Ambiguous

[a]CD = City-Dwelling

The researcher used the visual aid represented by Table 10 throughout the study, ultimately adding the demographic variables of level of education and income to it as well. Further visual aids were made to determine which factors were most prevalent in those who had a delay in diagnosis, as well as in those who did not. Creating meaning via the use of counting and visual displays refers to supporting findings from the study by providing the reader of the study with a visual display of data that led to the findings. All visual displays used by the researcher were maintained as part of the analytic log in order to protect validity.

Iteration. The previous discussion of data analysis has been necessarily segmented in order to describe the different steps of data analysis that occurred throughout the study. However, it is necessary to emphasize that qualitative data analysis procedures occur iteratively, within the analysis process itself as well as with data generation and interpretation. For example, in the study, new analyses constantly

informed later analyses (both within- and across-case), which guided sampling and data generation by influencing the need to recruit participants with experiences of particular variations of the phenomenon, shaping the interviews used to generate data, as well as interpretations.

Data Interpretation

Data interpretation refers, ultimately, to the finished product of qualitative inquiry—if data analysis is the process of breaking data up or down to see something new out of it, interpretation is the reassembling of data in a new way so that a new whole is formed (Sandelowski, 1995a). The final interpretation is the knowledge produced from the study and is characterized by the researcher rendering the data in a way so that something new is created from the data; yet, this new whole remains faithful to the data in their initial form (Sandelowski, 1995a). The interpretation rendered from a qualitative descriptive study is a data-near, descriptive summary, guided by the study's purpose and research questions; this summary is achieved most usually via the use of themes that reduce the data in meaningful ways (Sandelowski, 2000). Thus, the interpretation rendered from the study is in this form and presented in such a way that the experiences of epilepsy self-management from the perspectives of older adults is described and all research questions are answered. Sandelowski (2000) warns against simply giving a *list* of themes as the interpretive product of a qualitative descriptive study. Thus, steps were taken to ensure that final themes were dimensionalized, explained, and representative of the original data.

Per the suggestions of Sandelowski (1994) and Miles and Huberman (1994), supporting quotes were chosen to be presented in the final interpretation of data. Quotes

were chosen based on their ability to support claims embedded in the interpretation as well as to illuminate ideas and experiences of respondents (Sandelowski, 1994). The use of superfluous quotes, which can lead to "heaped data" (Sandelowski, 1994, p. 481) instead of a thick description, was avoided. Quotes selected were used in a way that remained faithful to the person who spoke the quote, as well as the researcher's interpretation of its meaning. Prior to choosing a quote for inclusion, its exact purpose was considered. No quote was included without the investigator considering, as well as documenting, the precise purpose of it—that is, to support the interpretation, to illustrate ideas, to demonstrate experiences, to evoke emotion, or to provoke responses (Sandelowski, 1994). Quotes also were appropriately staged. Immediately preceding the insertion of a quote, in order to guide the reader as to what he or she should "see" (Sandelowski, 1994, p. 481) in the quote, the quote is interpreted for the reader in terms of what it is meant to exemplify or support (Sandelowski, 1994).

Visual displays of enumerated data, as previously mentioned, also were used to support the final interpretation rendered from the study. These displays were used to describe the sample and also to support and justify interpretations and detail the ways in which the interpretation was spread across the cases.

In presenting the interpretation, the researcher used what Sandelowski (2010a) calls "parallel comparisons" (p. 15). The use of parallel comparisons, basically, refers to the consistent use of verbiage. For example, in the portion of the interpretation involving the theme of *self-management strategies*, the sub-themes comprising this theme, as well as the in-text discussion of it, were consistent with this label; that is, sub-themes and the discussion would be comprised of actual self-management *strategies*. Sandelowski

(2010a) warns that researchers who fail to use parallel comparisons risk not conveying their interpretations adequately or appropriately.

Validity

The proper way in which to ensure the validity of qualitative studies has been an ongoing controversial issue in the literature for the past two decades. Sandelowski's (1993) views on the insurance of validity in qualitative research served as the guiding principles for this study. Prior to discussing the ways in which validity was protected in the study, it is necessary to briefly discuss Sandelowski's (1993) views on both reliability and validity in qualitative research. First, Sandelowski (1993) raised and supported the issue that it is not appropriate for researchers to seek reliability in qualitative research, and that doing so is a clear threat to validity. Sandelowski (1993) explains that, in qualitative research, a chief assumption is that reality is "multiple and constructed" (p. 3). Seeking repeatability in measurements (i.e., respondents' stories), then, is inappropriate, and validity in this type of research does not depend on replicable outcomes. Multiple researchers or respondents cannot and should not be expected to arrive at the same conclusions regarding a phenomenon. Sandelowski (1993) suggests that seeking reliability necessitates forcing an artificial "consensus" (p. 3) on the data analysis process, which will ultimately degrade the validity of the findings. For this reason, she rejects the notion of reliability in qualitative research, along with the use of techniques, such as member checks and expert review, highly espoused by other researchers (Lincoln & Guba, 1985).

Sandelowski (1993) explains that there are practical, theoretical, representational, and sometimes moral problems with executing member checks in the typical fashion of

returning to respondents after data have been generated, presenting respondents with

findings then asking them for confirmation. First, she notes that researchers generally

present members with the final interpretation—a more abstract view of the data that is

meant to represent the experiences of many respondents, not just one. Thus, participants

often have difficulty finding themselves in the interpretation, and many, as lay people,

simply do not understand the interpretive rendering of results. Participants may also

simply not remember their initial accounts or, more often, their stories, and feelings about

them may have changed since the data were generated. Respondents, upon hearing or

reading about themselves in an emotional state, also can call for the deletion or

manipulation of original data due to embarrassment or a desire to change how they

appear in the study. Some respondents, too, upon revisiting the interview, may wish to

add data. As well, many respondents simply are uninterested in reviewing their

transcripts or the study findings and do so only out of obligation. Thus, respondents'

confirming statements regarding the consistency and accuracy of the data are not very

useful (Sandelowski, 1993). Finally, Sandelowski (1993) notes that story-telling, a chief

way in which qualitative researchers generate data from respondents, is "revisionist in

nature" (p. 4). That is, the stories respondents tell researchers are memories of the past,

and these memories change regularly—the very act of telling or thinking of them can

change the story. Respondents' stories are ever-changing; thus, the notion of validating

the contents of a story previously told at a later date is a concept at odds with

story-telling. Sandelowski (1993) warns that researchers who look for consistency among

respondents' stories, as well as consistent interpretations from expert researchers, risk

making serious analytic errors. Thus, reliability was not sought in this study, and no

member checks or expert panel were used. However, the researcher consulted regularly with her dissertation committee and consultants during the data analysis process.

According to Sandelowski (1993) and Rolfe (2004), the validity of qualitative research cannot be judged using the criteria used in quantitative research, nor can any different set of blanket criteria be created for and applied to qualitative research to judge the validity of these studies. Given that there is no single qualitative research paradigm, the use of predetermined, generic criteria in evaluating the validity of qualitative research is inappropriate. Sandelowski (1993) asserts that the validity of a qualitative study is judged on an individual basis, and it is the job of the researcher to persuade the reader of the validity of the study via making his or her practices throughout the study visible and auditable. This is best achieved via the maintenance of an audit trail (previously discussed). Sandelowski (1993) considers the types of validity suggested by Maxwell (1992)—and not those supported by Lincoln and Guba (1985)—as the most appropriate for qualitative research. Both Sandelowski (2000) and Maxwell (1992) suggest that two types of validity—descriptive and interpretive—are sought in qualitative descriptive studies. Descriptive validity refers to "getting the facts right" (Sandelowski, 2000, p. 336)—that the researcher is not fabricating or distorting the interviews used as data, and that he or she is analyzing data as they actually were generated by respondents. When descriptive validity is achieved, an account of the events that people observing the same events (interviews) would agree is accurate is reached. Clearly, all other types of validity rest on descriptive validity, as interpretations gleaned from inaccurate data will not be valid (Maxwell, 1992). Interpretive validity refers to the researcher ascribing and explaining the *meanings* respondents give to the events (interviews) that occurred in a

way which the respondents and researcher would agree is accurate. As described previously and throughout this chapter, steps were taken throughout the study to ensure both descriptive and interpretive validity by treating and respecting the data so that it was maintained in its true form (descriptive validity) and all analytic and methodological decisions were logged (interpretive validity).

Efforts to ensure descriptive validity already have been described in this chapter, but are summarized here and include the following: audio-recording of interviews, verbatim transcription of interviews, proofreading of transcripts by the researcher, use of a legend in all transcripts to indicate pauses and inaudible time, and the use of counting and enumeration techniques. These actions ensured that data generated from respondents were represented as accurately as possible before and during analysis and interpretation. Many efforts were taken to ensure the interpretive validity of the final interpretation. Most of these strategies are those already discussed in relation to maintaining an audit trail that is complete with contextual, analytic, methodological, and personal response documentation, which ensures that decisions made throughout the entire study process are rationalized, supported, and made available for review (Rodgers & Cowles, 1993). As Sandelowski (1993) states, the use of an audit trail ensures interpretive validity by making all of the researcher's activities visible. For example, constructing and maintaining numerical visual displays supported interpretive validity by giving credence to final interpretations—so, too, did the coding guide and other logs that were kept throughout the study, as they provide a history of the rationale used to make methodological and analytic decisions. The use of active confirmation and summarization

during interviews also ensured, at the time of data generation, that the researcher was

hearing stories correctly, which also contributed to interpretive validity.

Summary of Data Generation, Analysis, and Interpretation Process

Threaded throughout this chapter has been the notion that qualitative inquiry,

including that used in qualitative description, is an extremely iterative process that is not

at all linear. Figure 4 presents a schematic designed to represent, in a more parsimonious

way, the iterative processes of data generation, analysis, and interpretation that occurred

in the study. The schematic depicts the process that occurred from the time that research

questions were raised and the method best suited to answer them was chosen.
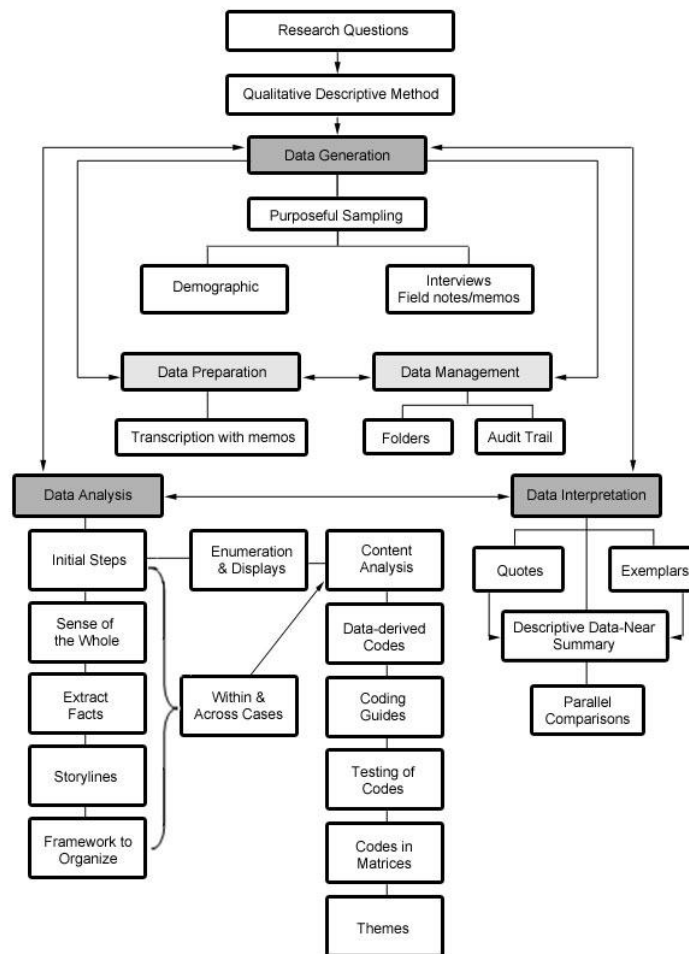
Figure 4. An iterative process was used in generating, analyzing, and interpreting data.

To summarize, data were generated via face-to-face interviews with older adults. These respondents were chosen via purposeful sampling in three installments. These generated data were prepared via verbatim transcription and managed using separate folders and an audit trail comprised of contextual, methodological, analytic, and personal response documentation for each participant. Generated, prepared data were analyzed via the use of initial analytic steps espoused by Sandelowski (1995a), and counting and enumeration techniques with the use of visual displays aided in this process. After these initial steps were completed within and across cases for the dataset, formal conventional content analysis, also utilizing counting/enumeration and visual displays, was used to derive data-driven codes. Codes were tested to ensure all data within and across cases had been accounted for. Data interpretation occurred via themes, in the form of a descriptive, data-near summary of the data that is in accordance with the study purpose and research questions. Quotes and exemplars from cases were used to support themes, which were presented via language that allowed for parallel comparisons. All three of the main processes—data generation, analysis, and interpretation—occurred concurrently and affected one another.

Summary

Because very little is known about epilepsy self-management in older adults diagnosed at or after age 60, a qualitative descriptive approach is most suitable to investigate this phenomenon. Purposeful sampling was employed to recruit older adults with various experiences regarding the phenomenon of interest. Data were generated via face-to-face interviews and analyzed via content analysis. Documentation was maintained throughout the study to form an audit trail and to protect descriptive and interpretive

validity. The final interpretation is presented in a manner that answers the research questions and remains faithful to the data. Findings rendered from the current study will provide the necessary basic understanding of what the epilepsy self-management of older adults diagnosed with the condition late in life is comprised, thereby ultimately informing the development of interventions designed to improve outcomes in older adults diagnosed with epilepsy late in life.

CHAPTER IV

RESULTS

This chapter presents the findings of this study. First, a description of the sample is provided. Next, each research question is answered via themes that emerged during analysis. Additional themes that do not pertain specifically to the research questions but that emerged during analysis also are discussed. A summary and exemplar of the findings then are presented.

Sample Characteristics

The data from 20 older adults were analyzed. Data from five participants were gathered during the pilot study, and data from the remaining 15 participants were gathered during this study. See Table 11 for demographic characteristics of the sample. Of those taking part in the study, 12 (60%) were women, and 8 were men (40%). There were 19 (95%) Caucasian participants and 1 (5%) African American. The mean age of the sample was 70 years, with a range of 60–80 years. The marital status of the participants was: 14 married, 4 unmarried (single/divorced/widowed), and 2 lived with significant others. Mean years of schooling was 13.5, with a range of 7 to 20. Among the participants, 2 had sixth grade educations, 10 had high school diplomas, 2 had some college, 2 held bachelor's degrees, 3 held master's degrees, and 1 held a doctoral degree. Employment status of the participants included: 5 who were working (3 part-time, 2 full-time); 14 were retired, and 1 was on disability as a consequence of epilepsy. The mean length of time since epilepsy diagnosis was 4.1 years, with a range of 0.5–10 years. One participant (5%) reported the daily occurrence of seizures. Two participants (10%) reported experiencing a seizure on a weekly basis, four (20%) experienced a seizure monthly, eight (40%) reported experiencing a seizure bi-monthly, four (20%) reported

experiencing a seizure every six months, and one participant (5%) experienced fewer than one seizure per year.

Regarding income: 20% of the sample ($n = 4$) earned less than $20,000 per year; 15% ($n = 3$) had an annual income between $21,000 and $40,000 per year; 30% ($n = 6$) had an income between $41,000 and $60,000 per year; 25% ($n = 5$) had an annual income between $61,000 and $100,000, and 10% ($n = 2$) had an income greater than $100,000 per year. Eighty-five percent of the sample ($n = 17$) received Medicare, 10% ($n = 2$) had private insurance, and 5% ($n = 1$) had no insurance. Seventy percent of the sample ($n = 14$) reported having a significant other—adult child, spouse, friend, or other relative—who directly assists with epilepsy management. Thirty percent ($n = 6$) did not report the existence of an assistive significant other. Twenty percent of the sample ($n = 4$) experienced primary grand-mal, tonic-clonic seizures, while 80% ($n = 16$) experienced partial seizures. All of those who reported experiencing partial seizures also had experienced at least one generalized seizure as a result of those partial seizures. The mean number of co-morbidities in addition to epilepsy was 2.5, with a range of one to four. The mean Mini Mental Status Exam score was 27.73, with a standard deviation of 1.67 and a range of 24-30.

Table 11

Demographic Characteristics of the Sample

Variable	*M(SD)*	Range	N
Age (in years)	70	60–80	
Years since diagnosis	4.1	0.5–10	
Education (years of school completed)	13.5	7–20	
MMSE Score[a]	27.73(1.67)	24–30	
Co-morbidities in addition to epilepsy	2.5	1–4	

Table continues

Variable	M(SD)	Range	N
Race			
Caucasian			n = 19
African American			n = 1
Gender			
Male			n = 8
Female			n = 12
Income (annual)			
< $20,000			n = 4
$21,000–$40,000			n = 3
$41,000–$60,000			n = 6
$61,000–$100,000			n = 5
> $100,000			n = 2
Employment			
Working full-time			n = 2
Working part-time			n = 3
Retired			n = 14
Disability			n = 1
Type of epilepsy			
Tonic clonic grand-mal			n = 4
Partial with experiences of grand-mal at times			n = 16
Assistive significant other			
Yes			n = 14
No			n = 6
Insurance			
Medicare			n = 17
Private			n = 2
None			n = 1
Relationship status			
Married			n = 14
Single (includes divorced or widowed)			n = 4
Living with significant other			n = 2
Seizure Frequency			
Daily			n = 1
Weekly			n = 2
Monthly			n = 4
Bi-monthly			n = 8
Bi-annually			n = 4
Fewer than one per year			n = 1

[a]Mini Mental Status Exams were not administered to the five pilot participants.

Emergent Themes

As discussed in Chapter III, the final interpretation of data rendered in a qualitative descriptive study is presented best in the form of emergent themes. Here, themes (and sub-themes) are organized by research question, and those not directly related to the a priori research questions are discussed separately. Themes are displayed in tables, summarized in a narrative, and each is then discussed in detail.

Research Question One

The first research question concerned older adults' experiences with the process of being diagnosed with epilepsy. Table 12 displays the main themes and sub-themes that emerged concerning this question.

Table 12

Themes for Research Question One

Theme	Sub-Theme(s)	Frequency
Type of Experience	Satisfactory	$n = 2$
	Unsatisfactory	$n = 13$
	Mixed	$n = 5$
From First Seizure to	Delay	$n = 13$
Diagnosis: Time Elapsed	Caused by Provider	$n = 8$
	Caused by Self	$n = 3$
	Mixed	$n = 2$
	No delay	$n = 7$
What is Epilepsy?	Older people get epilepsy?	$N = 20$
	Understanding of epilepsy	$N = 20$
	Misunderstanding	$n = 17$
	No misunderstanding	$n = 3$
	Post-Diagnosis Education	$N = 20$
	Satisfactory	$n = 5$
	Unsatisfactory	$n = 15$
	Patient/Provider Perspectives on	
	Impact of Diagnosis	
	Mis-Matched	$n = 13$
	Matched	$n = 7$

Three main themes regarding participants' epilepsy diagnosis experiences emerged. During interviews, participants were encouraged to relay experiences that occurred from the time of the first seizure experienced until they received an actual diagnosis of epilepsy.

Type of experience. The first theme that emerged for this research question is Type of Experience. Participants described their overall experience of being diagnosed with epilepsy as satisfactory, unsatisfactory, or mixed.

Satisfactory. Very few participants ($n = 2$) described their diagnosis experience as completely satisfactory. Both of these participants were male and indicated that they would not have changed anything about their experience of being diagnosed with epilepsy. For example, one of these participants stated, when asked what he would change about the process of being diagnosed, "Honestly, it was handled well. I had it, got to a hospital, and they gave the med…. I took it 'til I saw a neurologist, and he said keep taking it. It was quick, easy and that's fine with me." The other participant whose experience with being diagnosed was satisfactory reflected on his diagnosis experience similarly, stated, "Nah, I don't think I'd change a thing…. It was fine. They told us what happened and wrote the 'script. I can't imagine anything else they could do for me."

Common characteristics in the experiences of these two participants were identified. The first was speed of diagnosis. Both participants were diagnosed immediately following their first seizure, and both of them acknowledged that the short time elapse from their first symptom to accurate diagnosis and treatment contributed to their satisfaction with the process. "There was no waiting…wondering what this was. So

that was a relief because I had gone through not knowing with my back…. They told me immediately what this was."

The second characteristic common to both of these participants is a lack of desire for detailed information about their disease. Both men expressed a desire to know only what they needed to do in terms of medical treatment of the disorder, neither wanted to know the underlying cause or pathophysiology of his epilepsy. When asked how much and what kind of information he wanted about epilepsy upon diagnosis, one participant stated "I wanted bare bones…. All I need to know was what to do. And that was take pills. So I do. It doesn't matter why I have it…and I probably wouldn't understand if they tried to explain." Another participant reported not wanting to know the details of his disease, but specifically expressed that this desire was based on fear. He stated, in response to being asked if he had wanted more information at the time of diagnosis:

> Personally, no. I don't ever want to know all that stuff. It scares me…because I remember when my brother had cancer. They told him every damn detail…ended up knowing almost exactly when he was going to die. I didn't want to know all that so I was happy with the lack of info. I figure their job is to figure out what's wrong with me, and the only thing I have to do is whatever they tell me to do. Like military…no questions asked.

Lastly, both of these participants described their initial episodes as being unmistakably grand-mal seizures, and thus felt that the diagnosis was obvious. As one participant noted, "My wife called the ambulance…and she told the operator I had had a seizure. So it was clear to us what was going on before we ever saw a doctor." Both of these men demonstrated textbook symptoms of epilepsy during their first seizures, which likely led to the ease and swiftness with which they were diagnosed.

Unsatisfactory. Many participants (*n* = 13) found their experience of being diagnosed to be completely unsatisfactory. Among the participants, 11 women and 2 men

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did not report anything satisfactory about the experience through which they went in being diagnosed. "It was pure hell," stated one female participant when she was asked to describe the diagnosis process. Another participant—a male—answered the same question by stating "I have been really sick before…had a lot of things done to me, and this was by far the kicker in terms of being awful to figure out what it was. It was no good." Participants who initially expressed dissatisfaction with their experience were further questioned to determine if *any* aspect of the diagnosis process was pleasing to them. These 13 participants could find nothing acceptable about the process. As one female participant noted, "No, it was all bad. It was agony and I would change everything about it if I could."

The researcher questioned these participants further about what made the diagnosis process so dissatisfying. All 13 participants cited an unacceptable delay in diagnosis as the prime dissatisfying aspect of the process. "It just seemed to take forever," explained one participant who waited over six months for an accurate diagnosis. Lack of information about epilepsy, including its cause, pathophysiology, prognosis, and treatment, at the time of diagnosis also contributed to participants' lack of satisfaction with their diagnosis experience. "We got a lot of information [about epilepsy] ourselves. But from the doctors? Nothing at all," stated one participant when asked about the information she received at diagnosis. This participant continued, "I wish they had told me more when I was diagnosed." Specific reasons for and characteristics of the delays in diagnosis and lack of information given at diagnosis are described in subsequent themes.

Older adults who were not at all satisfied with their diagnosis experience demonstrated both classic ($n = 7$) and more ambiguous ($n = 6$) first seizure symptoms,

with more ambiguous first seizures being those unlike typical grand-mal seizures that involve full-body jerking.

Mixed. The remaining five participants, one woman and four men, were satisfied with certain aspects of the diagnosis process, but unsatisfied with others. For example, one male participant was dissatisfied with the length of time it took for him to receive an accurate diagnosis but was satisfied with the rest of the process, including the information given to him by his provider. He explained, "The waiting part was bad and I feel like we maybe wasted a lot of time, but other than that it was fine." This participant reported receiving limited information about his disorder but stated that he did not desire any additional information at the time of diagnosis. The other male participants ($n = 2$) who are included in the mixed experience category had very similar experiences—their dissatisfaction was in having to wait for a diagnosis, but they were satisfied with the information they received about their epilepsy. All three of these participants demonstrated ambiguous seizure symptoms, such as memory loss and strange behavior, at the time of diagnosis.

The remaining two participants (one woman and one man), however, were diagnosed quickly but were dissatisfied with other portions of the process. The female was not pleased with the information given to her about her condition, and explained that she asked the doctor who diagnosed her several questions about her condition and he was unwilling to answer them. She stated,

> After I asked him, he said "come back in four months and let's talk about it"…and I would say "no, I want to move on with my life." But he wouldn't, so that's when I had to find a new doctor.

The male participant cited his diagnosing physician's refusal to consider alternative therapies to treat his epilepsy as dissatisfying and stated that "he just did not listen to

me…. It was like I was not there. I wanted to be part of what was happening to me but instead I was ignored." This portion of his experience is similar to those of older adults who were categorized in the unsatisfied group previously and described their care providers as dismissive of their concerns.

Summary. Participants had one of three different types of epilepsy diagnosis experiences: satisfactory ($n = 2$), unsatisfactory ($n = 13$), or mixed ($n = 5$). Those who found the experience completely satisfactory were male, and both demonstrated classic seizure symptoms and were diagnosed rapidly. Neither of these participants desired in-depth information about their disorder at the time of diagnosis. The majority of the sample characterized their diagnosis experience as completely unsatisfactory. Most of these participants were female, and delay in diagnosis and lack of sufficient information about epilepsy, including its cause, pathophysiology, prognosis, and treatment, were seen by participants as most contributory to their negative experiences. The remaining participants described their diagnosis experience as mixed—certain aspects of it were acceptable, and others were not. The majority of the male participants fell into this group, and most identified a delay in diagnosis as the primary dissatisfying factor. Based on these findings, it is clear that the women in the sample had more purely negative experiences with diagnosis than did the men (Table 13).

Table 13

Type of Experiences by Gender

Gender	Satisfactory	Unsatisfactory	Mixed
Male	2	2	4
Female	0	11	1

The researcher investigated this discrepancy in order to more fully describe participants' experiences. Both the males and the females found a delayed diagnosis to be the most dissatisfying aspect of the process, but the women in the sample were more likely to find the information given to them at diagnosis unacceptable. All 12 women in the study noted a dearth of information at diagnosis, while only 3 of the 8 men had a similar complaint. However, the type and amount of information given to both the women and men in this sample does not appear, based on participants' descriptions, significantly different. All of the women, though, desired more, and more detailed, information while most of the men indicated that they desired less information and were satisfied if they were told only what their responsibilities were in terms of managing the disease (i.e., taking medications).

From first seizure to diagnosis: Time elapsed. As briefly discussed in relation to the Type of Experience theme previously, length of time to accurate epilepsy diagnosis was a significant aspect of the majority of participants' diagnosis experiences and greatly contributed to their satisfaction or dissatisfaction with the process. Participants' discussions of their epilepsy diagnosis experiences were so punctuated with stories about the time elapse from their first seizure symptoms to a diagnosis of epilepsy that this aspect of their diagnosis experiences emerged as an independent theme. Participants reported either a delayed or non-delayed diagnosis.

Delay. Sixty percent of the sample, 10 women and 3 men, reported that they experienced a delayed diagnosis—their epilepsy was not diagnosed within three months of the first seizure. Of the participants comprising the sample, 13 of the 20 were certain of the exact length of time between their first seizure and diagnosis, while the 7 others

could not remember precisely the duration of time between first seizure and diagnosis, though they were able to report a general idea of this length of time. The range in length of time to diagnosis for the 13 participants who experienced a delay was approximately six months to seven years, with the majority of the participants in this group ($n = 9$) reporting a delay of approximately 12 to 18 months. Participants attributed this delay to their own actions, those of their healthcare providers, or both. All 13 of these participants felt that the delay was unnecessary and could have been avoided, as evidenced by one participant's comment that "epilepsy is not some unknown disease. I think it shouldn't have been such a mystery to everyone what was wrong with me."

Among the participants, eight—five women and three men—attributed the delay in diagnosis they experienced to the actions of care providers to whom they went for treatment. In all but one case, participants identified their primary care providers (six physicians and one nurse practitioner) as the providers who caused the delay. In the remaining case, a female participant actually was referred to a neurologist by her primary care physician, but she felt that the neurologist was responsible for the delay in her diagnosis.

Some ($n = 3$) felt that the process took so long because their concerns were not taken seriously by healthcare providers. Interestingly, all of the participants who reported being dismissed by their care providers were female. A 72-year-old participant reflected on her experience of being dismissed by a neurologist to whom she was referred by her primary care physician after presenting with classic seizure symptoms:

> I'll never forget what the doctor said….He told me that maybe I was pregnant. At my age! I kid you not. He honestly did. I said that is impossible and since when did being pregnant make you slump over and start shaking? Then he said my symptoms had to be hormonal…and the

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last time I saw him he said maybe I was just cursed. This was a very reputable neurologist. So I went on having untreated seizures for seven years….I thought I was mentally ill when I actually had a disease. I can never get that time back.

Other participants (*n* = 3) felt that their diagnosis was delayed because the healthcare providers to whom they went for treatment simply did not know to consider epilepsy or seizures as a potential diagnosis. One participant voiced his frustration, stating,

> I always had it be a simpler thing. You're sick, ya go in, and ya tell 'em what's wrong. Then they fix it…but this took forever and I went through so many tests and waitin'. The truth is the doctor had no idea what it was. He should have sent me to the neurologist a lot sooner.

Another female participant relayed a similar experience in which her care provider did not consider epilepsy as the cause of her symptoms. She explained, "All those months while we were trying to figure it out…no one said anything about seizures. It was just not on the table…. A brain doctor was not involved until I asked for a referral."

Two participants explained that an accurate diagnosis was delayed because they first were misdiagnosed with other conditions. One female participant was initially told she was suffering from early-onset dementia. She explained:

> My main complaint was that I was losing and forgetting things. So he did the MRI and it was normal…and they said early dementia, like Alzheimer's. I took pills for that, and I just got worse. Every time I went back they would diagnose me with something different…so it took almost a year and a half to get the right diagnosis.

In all but one case, participants who contributed their delay in diagnosis to their providers felt that the delay was caused by their *primary* care providers—the providers to whom they first went for treatment. In most cases, once participants were referred to a neurologist, their diagnosis was made quite rapidly. "[The neurologist] knew what he was doing…. It just took a lot of time before I was sent to him. But after I saw him he knew

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just what it was," explained one participant. One female participant, though, had a different experience. Her primary physician referred her to a neurologist very quickly, but she identified the neurologist as causing a significant delay in diagnosis. "He never believed that I was having seizures…. He really made me believe I was just going nuts," she stated. She eventually was diagnosed, seven years later, by a different neurologist after having a generalized seizure during an out-of-state vacation and currently is being treated by a local neurologist.

Other participants ($n = 3$) expressed that their own actions caused the delay in diagnosis. All of these participants were women, and all of them experienced ambiguous seizure symptoms. Each woman reported not seeking medical care for her initial seizure symptoms for various reasons. One of those reasons was lack of time. "I was still working at the time…. It was low on my to-do list…. I just kept ignoring it because I didn't have time to deal with it," explained one participant who ultimately was taken to the emergency room after experiencing a seizure at work. These women also failed to seek treatment due to attributing their symptoms to normal signs of aging or other diseases. One participant's initial symptom was memory loss. "I thought it was just aging," she stated when explaining why she waited several months before seeking treatment. Another assumed she was falling victim to the disorder that took her father's life—Alzheimer's—and failed to seek treatment because she did not want to accept such a diagnosis. She explained, "The fluttering in my head started when I was 72…. I thought there was a possibility that maybe that was the beginning of Alzheimer's…but I just tried to wait and see because I didn't want to face that." Interestingly, two of these women reported that during the time of their initial seizure symptoms they saw their healthcare

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providers for other reasons, such as an upper respiratory infection, but did not mention their seizure symptoms. Both women felt uncomfortable mentioning these symptoms to their providers. Explained one participant,

> I don't know exactly why I didn't mention it to him…. I guess I was sort of embarrassed. My symptom was my husband was telling me I was acting silly and saying weird things…even though I didn't remember doing it. I didn't know who to tell.

Two participants felt that the delay was caused both by their primary care providers and themselves. These participants did not immediately seek treatment and, when they did, their providers did not refer them quickly to a neurologist. Their reasons for delay in seeking treatment were the same as some of those reported by participants who felt that they caused their delay in diagnosis themselves: lack of time and attribution of the symptoms to aging. "I just figured, you know, I'm 74. Things are starting to break down…. I thought it was a natural process until I fell and got hurt…that's when I went to the doctor," explained one participant. When he was seen by his doctor, he was misdiagnosed with syncope secondary to hypotension. He then was diagnosed with atrial fibrillation, and his physician attributed his seizure symptoms to that condition. "They kept finding stuff wrong, and every time they did they said 'Oh, that's what's causing it.' So it took quite some time to figure out it was seizures," he stated. The other participant in this group had a similar experience—her care provider initially attributed her symptoms to a thyroid disorder, which resulted in a delay in an accurate diagnosis.

No delay. Seven participants (two women, five men) were diagnosed with epilepsy within three months of experiencing their first seizure symptom. Three of the five men in this group sought treatment within a month of their first seizure treatment and quickly were referred by their providers to a neurologist. "No, there was no delay. The

first guy sent me to the second one, and he figured it out," explained one participant about his diagnosis process. These participants explained that they sought treatment quickly because their symptoms were interfering greatly with their daily activities or their loved ones urged them to do so out of concern. "After the first couple of episodes I was afraid to get on my ladder, and I was working on painting that barn back there…and I wanted it done before winter, so that's why I went to the doctor," explained one participant. Another went because his family was concerned about him. "My daughter thought I was having a stroke…. She told my wife…. So my wife knew, my daughter knew. They went on alert, watchin' my every move. And finally they convinced me to go in," explained one participant. The other two men did not seek treatment immediately but, when they did, they were referred to a neurologist quickly enough to allow them to be correctly diagnosed within three months.

Summary. When asked about their experiences being diagnosed with epilepsy, participants spoke chiefly of how long it took them to be accurately diagnosed. The majority of the sample (65%) experienced a delay in diagnosis due to actions of their care providers, themselves, or both. Care providers prevented a timely diagnosis by dismissing participants' concerns, not considering epilepsy as a possibility, and/or misdiagnosing them with other conditions or attributing the symptoms to an existing condition or to aging. Some participants failed to seek immediate treatment for their epilepsy symptoms due to lack of time to seek medical attention, attribution of symptoms to old age or other diseases, and embarrassment. The remainder of the sample experienced no delay in diagnosis and either sought treatment for their symptoms immediately and then were referred in a timely manner to a neurologist or did not seek treatment immediately but

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were referred immediately to a neurologist by their primary care providers and were thus diagnosed promptly.

Because participants found a delay in diagnosis to be so problematic, specific attention was given to this aspect of their experiences during analysis to determine characteristics of the sample that appeared more frequently in those who experienced a delayed diagnosis versus those who did not. The display of data represented by Table 10 was constructed to allow the researcher to determine the differing or common characteristics between and among women and men who experienced a delayed diagnosis, given that women more frequently experienced this phenomenon. One difference between women and men whose diagnoses were delayed is seen in the type of seizure symptoms most commonly seen in those who were diagnosed late. All three men who experienced a delay in diagnosis initially demonstrated ambiguous seizure symptoms, while five of the women whose diagnosis was delayed experienced classic seizure symptoms, and five of them experienced ambiguous symptoms. In both men and women, those living in rural areas were more likely to experience a delay in diagnosis than those living within city limits. Thus, participants who were female, presented with ambiguous seizure symptoms, and lived in rural areas most frequently experienced a delay in diagnosis. However, it is significant that men, regardless of rural or city-dwelling residence, were more likely to experience a delay when they demonstrated ambiguous seizure symptoms, while women demonstrating both classic and ambiguous symptoms experienced a delay in diagnosis.

To determine if women and men who experienced a delay in diagnosis were similar or dissimilar in terms of level of education or income level, Table 14 was

constructed. The majority of women receiving a delayed diagnosis were well-educated

(college graduates or beyond), while none of the men who were diagnosed late in life

held college degrees. Seventy percent of women diagnosed late in life had an annual

income greater than $60,000 annually, while all of the men diagnosed late in life had an

income between $21,000 and $60,000 per year. Thus, women who were *more* educated

and affluent experienced a delayed diagnosis, while the opposite was true for the men.

Table 14

Characteristics of Those with Delayed Diagnosis

Dwelling	Symptom Type	Education[a]	Income[b]
		Women	
Rural ($n = 6$)	Classic ($n = 5$)	< 12 ($n = 1$)	< 20 ($n = 1$)
City-dwelling ($n = 4$)	Ambiguous ($n = 5$)	12 ($n = 1$)	21–40 ($n = 2$)
		12– < 16 ($n = 1$)	41–60 ($n = 3$)
		16 ($n = 6$)	61–100 ($n = 3$)
		18 ($n = 1$)	> 100 ($n = 1$)
		Men	
Rural ($n = 2$)	Classic ($n = 0$)	< 12 ($n = 0$)	< 20 ($n = 0$)
City-dwelling ($n = 1$)	Ambiguous ($n = 3$)	12 ($n = 1$)	21–40 ($n = 2$)
		12– < 16 ($n = 2$)	41–60 ($n = 1$)
		16 ($n = 0$)	61–100 ($n = 0$)
		18 ($n = 0$)	> 100 ($n = 0$)

[a]Education in years. [b]Income in thousands of dollars.

What is epilepsy? Prominent in participants' descriptions of their diagnosis

processes were stories about their understanding of the disease of epilepsy. This theme is

comprised of four sub-themes: (a) Older People get Epilepsy? (b) Understanding of

Epilepsy, (c) Post-Diagnosis Information and Education, and (d) Patient/Provider

Perspectives on Diagnosis.

Older people get epilepsy? All 20 participants reported shock at receiving an

epilepsy diagnosis and had never considered epilepsy a disease that could strike in older

adulthood. The unexpected nature of the diagnosis was present in all cases, including

those for which the cause of epilepsy was unknown, as well as those in which there was a clear cause of the condition, such as a stroke. One participant reflected on her initial response to being diagnosed with epilepsy, stating:

> It was absolutely the last thing I expected in the world. I had spent all that time trying to figure out what's wrong with me, and I had all these ideas, but never that. I thought that little kids got seizures…. It never entered my mind that that was something I could pick up at the age of 78. We were totally thrown for a loop by it.

Somewhat surprisingly, the unexpectedness of the diagnosis was present equally in both those who experienced ambiguous seizure symptoms *and* classic seizure symptoms. Those who had had ambiguous symptoms were shocked at a diagnosis of epilepsy because their symptoms did not resemble those that they believed would have been associated with the condition. "I never would have guessed seizures…. What they were telling me [I was doing] did not sound anything like a seizure," explained one participant whose main symptom had been bizarre behavior, such as giving away her personal belongings to strangers. While those exhibiting classic symptoms often *did* recognize that they were having seizures, they did not expect to be diagnosed with the chronic disease of epilepsy. "I thought I had a seizure, yeah, but I never thought I was gonna keep having them and have to keep taking medicine forever," stated one male participant.

Many of the participants ($n = 17$) explained, without prompting by the researcher, that they had never known that older people were susceptible to new-onset epilepsy. The remaining three participants reported this same lack of knowledge when asked explicitly by the researcher if they had been aware that older people could get epilepsy. "I thought this was something that happened to babies, or to little kids…. Everyone I've heard about with it always got it young," said one female participant. Interestingly, over half of the

sample ($n = 12$) were still unaware, at the time of their interviews, that epilepsy is most commonly diagnosed in older adults. All 12 participants mentioned, at least once during their interviews, how rare they felt their conditions are for persons their age, as is evidenced by the following quote from a male participant,

> I guess I just got unlucky enough to get something like this at this age…. I've never heard of an old guy getting epilepsy…. Maybe that's why it has been so hard to control, because not that many old people have been through it.

Understanding of epilepsy. In addition to their lack of knowledge regarding older adults' risk for new-onset epilepsy, most participants ($n = 17$) had many other misunderstandings about their condition, including its potential causes, prognosis, and treatments. Some participants' ($n = 12$) misunderstandings existed only at the time of diagnosis and for a short time after. "I just assumed it was genetic, that it ran in my family but I just didn't know it…. Not until a year or so ago did I realize that was not true," explained one participant. Another participant had a misunderstanding about the prognosis of her epilepsy, and stated, "I left thinking I was gonna die. I mean it's your brain. I'd never heard the word epilepsy…. They didn't say seizure, they said epilepsy. I called my daughter crying, and she said 'Mom, it doesn't mean you're going to die!'" A male participant found himself initially confused about the treatment of epilepsy. He explained,

> After they told me, I got nervous because I had a friend who had brain surgery…. I just assumed that was gonna be me because of this. I took the pills for six months and finally asked my wife if she thought this doctor was going to do surgery on me…and she told me I didn't need surgery, just pills.

Five participants, at the time of their interviews, still had significant misconceptions about their epilepsy. One male participant believed that his anti-epileptic

medication would cure his condition. "I've been takin' it for a year now…. I reckon in another year it will have healed it." He also believed that if he ever stopped having seizures for more than a month, this would indicate the eradication of his epilepsy and he could discontinue his medication. A female participant explained that she still did not understand exactly what epilepsy is. "I don't know what happens…. I know there is a connection between my brain and rest of me when it happens, but I don't know what makes it happen," she said.

The remaining three participants indicated that from the time of their diagnosis they had a satisfactory understanding of what epilepsy is, as well as its causes, prognosis, and treatments. Two of these participants had known of other people with epilepsy, and one was a practicing nurse. "I knew what epilepsy was…. I knew it was something that I'd probably have forever and that taking the medications…was very important," explained a female participant.

The group of participants who had either initial or persisting misconceptions of epilepsy was comprised of 11 women (91% of all female participants) and six men (75% of all male participants), indicating that a significant portion of both genders in the sample had or have misunderstandings of epilepsy. Interestingly, the group also was comprised of participants with a variety of educational backgrounds: two had not completed high school, two had some college, four had high school diplomas, six were college graduates, two had master's degrees, and one held a doctoral degree.

Post-diagnosis information and education. Participants spoke often of the information and education that were given to them immediately after diagnosis. Among the participants, 15 were displeased with the information given to them at and after

diagnosis, while 5 participants were satisfied with the amount and type of information

they received about their condition. None of the participants reported receiving any

formal education about epilepsy or how to manage it. All participants received

information about their disorder from their neurologists or primary care providers.

Interestingly, the 15 participants who were displeased with the information they

received about their disorder reported that they were not as bothered by the lack of a clear

cause of their condition as they were by providers' unwillingness to discuss the topic. A

female participant relayed her frustration with her provider's refusal to even hypothesize

as to what caused her epilepsy, stating, "Once we knew there was no brain tumor, he said

it doesn't matter what caused it…that it would be treated the same no matter what…. But,

it mattered to me." A male participant described a similar experience. After he was

diagnosed with epilepsy, he was told that the cause was unknown. After much research,

he himself conjectured that an old high school football injury may have caused his

condition, though his physician was not interested in discussing it. This participant

explained, "[The healthcare provider] made it clear that he didn't care what caused it, and

he jokingly said something like if I wanted to believe it was a battle scar from football

that was fine…. That actually kind of hurt my feelings…and is why I changed

neurologists."

These 15 participants reported that lack of information given to them about the

pathophysiology, prognosis, and treatment of epilepsy was particularly troubling. Only

very basic information was given to these participants about their condition, and it was

often given in terms they found difficult to understand. One female participant stated,

They said the wiring in my brain misfired…but I didn't even know what that meant. I had this vision of wires in my brain. I didn't say anything at the time because I didn't want to seem stupid…but I had no idea what they were talking about.

Another older adult found herself unsure of her prognosis and treatment. She explained,

I didn't really know what this meant for me…. They didn't say if it would go away or not or if I should stop taking the pills when I felt better. They said the brain does this and that but not what that meant for my life.

Other participants could not remember the information that *was* given to them because the information was not provided in written form. A female participant noted, "I felt like I was supposed to know what epilepsy was…. They just started the conversation like I already had all of this information…. I was confused. Then I forgot everything by the time I got home." However, other participants complained that being given written information without any verbal explanation was just as dissatisfying; one male participant explained, "They handed us a brochure…like welcome to epilepsy. It had a lot of technical mumbo jumbo…. We aren't dumb but we didn't know anything about the brain so it was more irritating than helpful." Many of these participants ($n = 10$) noted that they were embarrassed to mention that they did not understand the information given to them. "I just didn't say anything…. I just decided to try to figure it out myself," explained one participant.

Some participants ($n = 11$) explicitly mentioned that they had expected and desired some kind of formal education about their epilepsy at the time of diagnosis or shortly thereafter. Some of these participants ($n = 7$) compared the information and education they received about their epilepsy to that which they received when they were diagnosed with other chronic conditions, and felt that they received much more

information and education about their other conditions than they did about epilepsy. One

participant explained,

> When I had my stroke, they gave me all kinds of information…a big bag
> full. I met with a nurse three or four times, and they told me about all the
> medications I would be taking, how things would change…. None of that
> happened with this…. It was like being served cold leftovers.

Another participant reflected similarly on her diagnosis with Crohn's disease. "That was

a big deal in terms of teaching. Lots of information…about diet, when to call the doctor.

When I was diagnosed with this, it was like nothing, like I just had a cold," she stated.

Only five participants, all of whom were male, were satisfied with the education

and information they were given at the time of diagnosis. As discussed previously, three

of these participants felt satisfied with the information they received because they did not

desire much information at all. The remaining two participants, however, found the

information that they received to be helpful and well-delivered. "When I left there I knew

what epilepsy was…. He explained all that to me. He also explained all about the

medication…so I'd say we were happy with that and knew what we were dealing with,"

stated one male participant.

Because the information received at diagnosis appeared so integral to participants,

the researcher specifically questioned them about the exchange during which the

information was presented from care providers to participants (in half of the cases,

participants shared this information without prompting). All of the participants reported

that information was given to them by their neurologists or primary care providers,

and 16 of them explained that the information given to them was not based on their

questions to their provider. "I didn't feel real comfortable asking too much…. I just

listened to what he said," explained one participant as she reflected on the information

she had been given about her disorder. These participants reported that they did not ask

questions, as evidenced by the previous quote, because they did not feel comfortable

doing so, or because they simply did not know what to ask. "I was in shock…and I was

also recovering from a seizure when they came in and told me. So I was groggy. I did not

realize until after I left…when I was living the epilepsy, what my questions were." The

remaining four participants explained that the information they received was offered from

their providers with and without questions being asked. "He told me some things then I

asked questions about it…about what he said," explained a male participant.

Patient/provider perspectives on diagnosis. In the majority of cases ($n = 13$),

participants expressed a mismatch between their and their providers' perceptions of the

seriousness of being diagnosed with epilepsy. Participants felt that providers downplayed

the seriousness of their disorder, leaving the older adults unprepared for the ways in

which their lives would be affected. For example, one participant likened his experience

to being diagnosed with the common cold. "They did not make over it like it was a big

deal…just like I had a cold or something. Nobody even flinched," he explained. Another

male participant, whose epilepsy was caused by a stroke, reflected on his experience of

being given information about his new diagnosis of epilepsy:

> I left the hospital not really even thinking about the epilepsy…. It was
> glossed over. Just kind of thrown in there by the doctor…barely
> mentioned. He had said I had to take these pills because I had a seizure.
> And that I had to see a neurologist, which I wouldn't do until three months
> later. My wife had asked him something about the seizure, and he literally
> said, "It's no big deal, just take the medicine." So we kind of assumed I
> probably wouldn't even have another [seizure]. But when we got home, a
> few weeks after that, it really *was* a big deal. At least for me…. He should
> try not driving for six months! When I got to see the neurologist, he was a

lot more informative, but still did not seem to recognize it as the major blow it was to my life…and to my wife's. My new neurologist, she gets it. But the first one I went to…he had not a clue what we go through…this disease is not simple, and it can change your life.

Other participants explained that they did not understand that epilepsy, if left untreated, could result in death. One female participant noted,

No, we had no idea…until we went back to the doctor because I was still having them. And she explained that it was so very important for me to take my medication, but for some reason when I was first diagnosed I did not get that…. I was not as careful with my medicine as I should have been because I did not think it was that serious.

Participants were asked to compare their providers' perspectives on their epilepsy diagnosis with those of their other chronic conditions. The majority of these participants ($n = 10$) felt that this mismatch in perspectives did not exist with their other chronic diseases, such as diabetes and Crohn's disease. Participants felt, when diagnosed with these conditions, that their care providers communicated the seriousness of the condition. "With diabetes…it was made real clear to me that I had to do these things or I could die. And I also knew my life was gonna change because of it," explained one participant. She went on to say, "it was not that way with [the epilepsy]…. I thought it was a big deal but my doctor didn't."

A small number of participants ($n = 3$) noted that they did experience a similar mismatch when diagnosed with other conditions, including hypertension and arthritis. "They never made a big deal about it…but the blood pressure medicine and everything, it was not pleasant…I stopped taking it, and I had a heart attack. I never knew I was that sick," explained a male participant.

No participants reported that their care providers perceived their epilepsy diagnosis to be more significant than they did themselves.

Research Question Two

The second research question pertained to problems participants have experienced while self-managing epilepsy. Table 15 displays the main themes and sub-themes that emerged regarding this question.

Table 15

Themes for Research Question Two

Theme	Sub-Theme(s)	Frequency
Maintaining	Transportation	$n = 8$
Independence	Continuing life as normal	$n = 16$
Medications	Financial concerns	$n = 11$
	Side effects	$n = 19$
	Polypharmacy	$n = 9$
	Remembering	$n = 12$
Achieving Goals		$n = 15$
Memory		$n = 13$

Maintaining independence. The majority of the participants in the sample ($n = 18; 90\%$) indicated that they had experienced or were experiencing difficulties maintaining their pre-diagnosis levels of independence. Some of these problems were related directly to issues surrounding transportation, and others were related to continuing life as normal.

Transportation. Among the participants, eight reported that since being diagnosed with epilepsy, they had struggled to maintain their independence as a consequence of driving restrictions. Interestingly, these participants comprised the youngest portion of the sample (mean age 63 years, range 60–65 years). As well, six of these participants lived in very rural areas without public transportation. All of these participants were unable to drive for six to nine months following their diagnosis, and two still were unable to drive due to lack of seizure control. These participants reported

difficulty in independently managing areas of their lives that required driving, such as

work or family responsibilities, as well as living spontaneously. As one participant

explained,

> It was so much more difficult to do simple things…like getting groceries. My husband works full time and my kids live out of state. We live out here in the middle of nowhere. There is no bus…. There is no grocery for almost 20 miles. So I had to get a ride. And I'll never forget the time I took a cab into town because I had to make a cake for church, and I didn't have the ingredients. The cab cost me almost $40. I got home, and realized I forgot to get condensed milk. I broke down in sobs. I was…so frustrated. All I wanted to do was make a cake…. It shouldn't have been that hard. I was at the mercy of others to get done what I was trying to do on any given day. And I spent another $40 and all day going back for the stupid condensed milk.

> Another participant felt that he was unable to live spontaneously due to his

driving restrictions and explained that he was forced to rely on others. He explained,

> It's sometimes been hard to recognize that this is still my life…. You don't realize how much you do or want to do until that's all taken away. I'm dependent now in many ways…and I hate it but I've had to deal with it.

> Of note is that almost all participants ($n = 6$) who had difficulties with

transportation, including those who were still unable to drive, felt that these problems

were worst immediately following diagnosis and tended to lessen with time. These

participants credited the attenuation of this difficulty to devising a system for

transportation. As one city-dwelling participant explained,

> It was horrible at first…because I never planned. Now I have this…system. I use the buses…. I figured out which ones are the quickest routes to where…. So, no, I can't drive anymore, but I still get around when I need to."

A participant living in a more rural area also had devised a system to assist with her

transportation needs. She stated,

We are on our own out here, and that was very tough…but there are some neighbors all around, you just can't see them because of these trees. We're mostly old out here…. I had the idea of putting together a women's car pool into town twice a week. I did it by saying it was to save money on gas…. They are very frugal. Of course that was not the real reason, but it worked for them. So we take turns driving…when it's my turn I just let one of them drive my car, so it's my gas and my car being used. I know I have two days a week…to get everything done in town. And I simply plan around that.

Continuing life as normal. Many participants ($n = 16$), including some who cited

loss of independence related to transportation, also had problems maintaining their

pre-diagnosis levels of independence in ways that were not related to transportation.

These participants found themselves less independent during their everyday activities due

to epilepsy, and thus had difficulty continuing life as normal. As one participant

explained,

It's the little things…. I can't change those light bulbs up there, the ones in the ceiling. I can't go getting on a ladder. If I seize and fall from there, I'm probably going to die. So those two lights there have been out for almost six months. I'm waiting for my son-in-law to come do it…boy, I wish I could still do those things myself again.

Another participant was forced to sell her home and move into an assisted living

facility because of her epilepsy. She explained,

They didn't feel right me being at home…. My daughter insisted that I move into some kind of community. It was too much for me to take care of my house with the lawn. And I need help with things now.

Other participants reported that their epilepsy, or the side effects of their seizures

and/or treatments, prevented them from living independently. One female participant

related that the frequency of her seizures and post-ictal fatigue forced her to move in with

her daughter and then eventually to an apartment near her daughter. She explained:

I literally could not take care of myself…if I wasn't having a seizure, I was so tired I couldn't do anything because of the meds. I wouldn't eat…. It just became a nightmare for my daughter trying to be with me all the time. It was just best that I moved near her…. She had to take care of me.

Unlike that which was seen in the sub-theme of transportation-related lack of independence, there does not appear to be a temporally related waning of non-transportation-related difficulties involving independence.

Medications. All participants reported experiencing problems with their medications—both those used to treat epilepsy and those they were taking for other conditions.

Financial concerns. More than half of the participants in the sample ($n = 11$) reported that they had financial difficulty paying for their epilepsy and/or other medications. All but one of these participants had Medicare insurance, while one was uninsured. Those receiving Medicare explained that financial problems surfaced when they entered the *donut hole*—a gap in Medicare coverage—each year. As one participant explained, "I'm usually okay until I get to that donut hole. Then I have to dip into my savings…and that savings just keeps shrinking. Not sure what to do when it's gone." Other participants did not have the luxury of a savings account and either relied on family to help them with medication costs or simply did not fill prescriptions for their anti-epileptic drugs. "Sometimes it's like pay the electric or get my medicine…. I want my lights on," explained one female participant.

Participants ($n = 10$) also explained that costs of their medications taken for other conditions often competed with costs required for their epilepsy medications, especially in the midst of a donut hole. Explained one male participant:

> It's not just one thing I'm trying to pay for during that time. I also have arthritis, diabetes, blood pressure, and gout. I mean what are you gonna do? You choose whichever ones are bothering you most right then, and you buy those. Skip the rest til the donut hole's over.

As well, nine of these participants had spouses who also had chronic health problems for which medications are required, which caused further financial strain for some of the participants. Explained one female participant, "Around the same time of my epilepsy, he was diagnosed with cancer…. We have a lot of medication bills each month, and if something has to be given up it's the seizure pills."

Some participants ($n = 3$), all of whom were women, noted that they often had difficulty purchasing their epilepsy medications because of general financial distress caused by non-epilepsy-related issues, such as continuing to support adult children or a significant other. These issues ranked higher in priority to participants than did purchasing their epilepsy medications. As one female participant relayed,

> I have a younger son, I'm helping him with money right now. It's more important for me to make sure he's got food on his plate than to make sure I don't have a seizure. I have a seizure, so what? Who cares? I wake up and I'm fine, right?

Side effects. All but one of the participants noted the regular experience of epilepsy medication side effects. Participants reported experiencing the following anti-epileptic medication side effects: somnolence (85%), fatigue (60%), impaired concentration (60%), dizziness (40%), gastrointestinal upset (30%), loss of appetite (30%), irritability (20%), and memory problems (5%). Participants explained that they often suffered from more than one side effect but, for the majority of participants ($n = 17$), somnolence and fatigue were the most troubling because of their effects on participants' abilities to carry out their normal activities. "I'm an avid reader…but on that medication I just fall asleep. I miss my reading," explained one female participant.

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Polypharmacy. None of the participants were managing epilepsy in isolation—all of them had at least one other chronic condition. As a result, some participants ($n = 9$) had problems stemming from polypharmacy. As mentioned previously, these participants' complex medication regimens can lead to financial issues surrounding medication. Others ($n = 7$) found that the mixing of medications exacerbated side effects or made them feel unwell. For example, a female participant explained, "It's just a lot. I don't just take these. I take some for high blood pressure, some for diabetes, some for thyroid. Taking them close together makes me feel sick and foggy." Many participants ($n = 12$) expressed that their already complex medication regimens were made even more so by the addition of epilepsy medications, as explained by a male participant who stated, "It's just one more variable to keep after…. I take over 12 pills a day now. With each new one, I get more confused about what I'm supposed to be doing."

Remembering. Among the participants, 12 reported having difficulty remembering to take their epilepsy medications, especially in the first year after diagnosis. Most of these participants ($n = 9$) claimed that they often take these medications late, while a minority of the participants ($n = 3$) reported that they miss doses on a regular basis. Participants blamed these late and missed doses on a decline in their memory since being diagnosed with epilepsy and the complexity of their medication regimens. "I just can't always remember," stated one participant. She continued, "I'm foggy up here…ever since I got this, it just takes me longer to remember things…. I've been being late on all my medicines since this." A male participant explained that he did not necessarily forget to take his epilepsy medication, but that he sometimes became confused about which of his nine medications should be taken at which time of day. This

confusion especially was pronounced at the time of his interview given that he had

recently experienced changes in both his epilepsy and Parkinson's disease medications.

He explained:

> I can't tell you exactly how many times I've made a mistake, but I know
> that sometimes I get really mixed up about what I should take and when.
> And I may get to the end of the night and realize…I didn't do it right. I
> have one left over or something. You can feel how heavy this box is….
> It's full of pills and I can't always keep it right on track…and they keep
> changing them, too.

Achieving goals. A majority of the participants ($n = 15$) reported that they had

experienced difficulty achieving some of their goals since being diagnosed with epilepsy.

The majority of these goals were related to their personal lives. In 12 cases, participants'

difficulties were related to their ability to be grandparents in ways they had imagined

before being diagnosed with epilepsy. They found that their lack of independence

coupled with seizure symptoms and medication side effects made grandparenting more

difficult than it was pre-diagnosis. One female participant reflected on the problems she

has faced in this area,

> Before…I saw them almost every day. They'd call and say "let us stay all
> night with you, granny." And you know I never said no. I would make a
> big dinner for them, and we'd watch movies and eat popcorn. Stay up late.
> I just…can't do all that now. I'm too sleepy from the medication or if I've
> had a seizure. And I can't drive to go pick them up. I have no energy for
> them, and it's devastating to me. This is not how I pictured being a
> granny.

Others noted that they did not feel it was safe for them to supervise small

children. One male participant explained, "I'm not fit to take them out on the fishing boat

anymore…the young one especially. It's hard for me but I can't do it anymore."

In three cases, participants became grandparents for the first time after being

diagnosed with epilepsy. These participants, in particular, found that they were not able

to grandparent in the ways in which they had imagined. One female participant explained, "That fantasy of being perfect grandma…taking care of the baby so mom and dad can sleep…it's just not going to happen for me."

Memory. Among the participants, 13 specifically mentioned having memory problems since being diagnosed with epilepsy. In all 13 cases, participants felt that their short-term memories had suffered. Participants noted problems not only with remembering to take medications, as described previously, but also misplacing items, forgetting appointments, and not recalling previously held conversations. These participants found this memory loss to be very distressing and problematic. Explained one male participant, "The worst thing since has been my memory. I can't keep track of anything…. It makes everything hard. I don't know if it's seizures or the pills, but I just forget things I never used to would've."

Research Question Three

The third research question pertained to the perceived changes in participants' lives that had occurred since the onset of epilepsy. Table 16 displays the themes and sub-themes that emerged for this question.

Table 16

Themes for Research Question Three

Theme	Sub-Theme(s)	Frequency
Negative Changes	Lifestyle	
	Social	$n = 13$
	Relationships with family and friends	$n = 12$
	Number of important commitments made	$n = 16$
	Daily functional abilities	$N = 20$
	Ability to fulfill age-appropriate roles and responsibilities	$n = 12$
	Changes in perceived well-being	$n = 9$
	Physical and emotional symptoms	$N = 20$
Positive Changes	Relationships with family and friends	$n = 4$
	Perspective	$n = 5$
	Spirituality	$n = 5$

Negative changes. All participants mentioned experiencing negative, or undesirable, changes since the onset of their epilepsy. These negative changes can be categorized as lifestyle changes, changes in perceived well-being, and physical and emotional changes.

Lifestyle changes. Participants described experiencing negative changes in their general ways of life. These negative changes are discussed in the sub-themes in this section.

Social. Participants ($n = 13$) reported that their social lives were affected undesirably by epilepsy and its associated treatments and restrictions. Some ($n = 6$) reported that lack of transportation kept them from enjoying their pre-diagnosis social life. "It's hard to get anywhere…. We used to go to the breakfasts twice a week with church. But [my wife] doesn't drive and now I'm not supposed to either…. We miss it," explained one male participant. Others ($n = 9$) found that stigma, or fear of embarrassment as a result of having a seizure, kept them from pursuing their usual social

endeavors. One male participant, who continues to work full time, explained that he now

forgoes socializing with his colleagues due to fear of having a seizure in front of them. "I

don't want to risk that…maybe later once I'm more used to it…but it would be

devastating to me for them to see that. So I just quietly avoid anything extra outside of

work," he stated. A retired female participant explained that she no longer ventures out of

her house alone for fear of having a seizure and embarrassing herself. "My social life…is

completely destroyed. But I won't do what I used to do…even little things like go to a

card party. I just don't want to make a fool of myself," she explained.

Others (*n* = 3) found that their usual social activities did not mix well with

epilepsy. "Whenever I get together with my colleagues, we have a few drinks. That used

to be fine, but on this medication I am drunk after two glasses of wine…so I just don't

go," explained a male participant. Another participant who enjoyed hiking with her

husband and their friends explained that she abandoned the hobby as a consequence of

fear of injury. "It was my favorite thing to do…but I have fallen so many times during an

episode that it is not worth the risk," she explained.

Relationships with family and friends. A majority of participants (*n* = 12) had

experienced undesirable changes in their relationships with family members and friends

as a result of their epilepsy. Alterations and reversals in usual roles were the cause of

changes experienced with family members. For example, many (*n* = 9) participants

became more reliant on family members and were unable to carry out their usual

responsibilities at home. One female participant explained:

> We've been together almost 40 years, and we love each other, but we've
> been real independent. I had my things…. He had his. With this, it was a
> big change there. He had to…for the first time ever, he had to help me.
> There was no more give-you-a-kiss and I'll see you later. He had to hover,

and I hated that. But it was necessary. And even now he hovers. My whole family does. It's like I went from being wife and mother to child.

Another participant reported a similar role reversal with her adult child. "She took care of me instead of the other way around…. It's not supposed to be that way," she stated.

Relationships with friends were altered most by the social isolation that resulted from the diagnosis. Participants felt that their lack of ability to participate in normal activities negatively affected their friendships. "I can't do what I used to be able to do. And that's not going to go away…. I don't think I'll ever be able to have fun with my friends like I used to," explained one female participant. Others found that they felt more comfortable isolating themselves from their friends as a consequence of embarrassment and a lack of desire to disclose their diagnosis. One male participant explained, "It was just easier to kind of fade out for a while so I wouldn't have to tell anybody…but by the time I wanted to come back in I felt like I'd distanced myself from [my friends] too much."

Number of important commitments made. Many participants (*n* = 16) also felt that they could no longer manage and keep as many important commitments as they could pre-diagnosis. Those who still were working began working fewer hours once they were diagnosed. Explained one male participant who worked as a crossing guard, "I went from part-time down to *really* part-time…one day every other week. It's all I can do now." A few participants (*n* = 2) found that they could no longer keep their jobs after being diagnosed. "They took my job away from me…that was the worst part, but I understood that it was not safe," explained a female participant who is now on permanent disability

due to her epilepsy. Others who no longer were working found that they simply could not keep as busy of a schedule. As one female participant explained:

> It took me a while to accept that I was going to have to put the brakes on. My volunteering was like a full-time job to me. At least six hours a day I was involved with the church or our missions groups. Seizures took that away. I can do a little bit but, no, not what I could do even right before all this started.

Daily functional abilities. All participants noted undesirable changes in their abilities to carry out normal, daily activities. These abilities included self-care and general household responsibilities. One female participant explained how even the way in which she gets dressed every morning has been altered. "I have to sit in a chair…and I don't do it in the bathroom. I fell once and got stuck between the tub and toilet. So to be safe I sit in a chair, but I wish I didn't have to," she stated. Others felt that seizure- and medication-related fatigued severely limited their ability to carry out normal functions. "It's hard to sit and wonder…will I have the energy to do what I have to do today. What I want to do is no longer considered," explained a female participant.

Ability to fulfill age-appropriate roles and responsibilities. Participants (*n* = 12) experienced undesirable changes in their ability to fulfill age-appropriate roles and responsibilities. As described previously, most of these changes surround the role of grandparenting. Participants felt that they could no longer fulfill this role in the same way that they could prior to diagnosis. One grandmother explained that this change was the most difficult she had experienced in relation to her epilepsy:

> What do most normal grandmas do? They take the baby for the parents…and no one worries about anything. That really is just not an option for me. My daughter won't leave her baby in the room with me unattended…and she won't let me babysit the older one anymore. I don't blame her, I guess, but it makes me very angry. All the sudden no one can trust me to do what I am supposed to be doing…what I've looked forward to doing since I retired two years ago.

A male participant whose wife lives in a nursing home expressed a similar sentiment regarding his ability to maintain what he felt were his responsibilities for her:

I can't go visit her every day like I want to anymore…. I used to spend all day, every day there with her. But I can't now because I don't have the stamina and I can't always get a ride. It's been horrible.

Other participants felt that their family members—in most cases, their spouses or adult children—had to take on responsibilities that they themselves should have been fulfilling. As one female participant explained,

My husband had to start doing the grocery shopping. What a mess! He kept saying he could do it but you should have seen what he brought home…. So I had to give him all types of instructions or go with him. It was a major change because groceries became such a big deal in our household.

Changes in perceived well-being. Many participants ($n = 9$) reported that they have experienced negative changes in their general well-being since being diagnosed with epilepsy. One female participant explained,

I have something now. Before this I was always pre-something… pre-diabetic, borderline hypertension. There is no borderline epilepsy. I just don't feel healthy anymore…. I'm sick now, and I'm always going to be because it can't be cured.

A male participant felt similarly, explaining, "It's just been kind of a big letdown. I really just don't feel well. I mean I'm here, but I'm like a walking zombie."

Physical and emotional changes. All 20 participants relayed that they have experienced unpleasant physical and emotional symptoms since the onset of their epilepsy. Physical symptoms were related to seizures and the after-effects of seizures, as well as medication side effects. One male participant described his physical ailments:

I get so tired from the meds and from the seizures. Dizzy, too. I'm just not as sharp. I can't stay awake. I sleep…until noon sometimes. The whole day is gone by the time I get up but I'm just wiped out. But I don't have a choice…. Stop taking the meds and I have seizures, and I'll feel the same way or even worse.

Emotional changes also were experienced. Participants reported experiencing, from the time of diagnosis until the time of their interviews, anger (60%), sadness or depression (50%), and anxiety (50%). These emotions often were the result of other changes and problems they experienced as previously described. One female participant shared her experience with anger:

I just…want to be able to do what I did. Go to work, pick up my grandkids, take them for ice cream…drive them around to see Christmas lights. I get so mad, and that is wrong. But I hear people talk…. They chatter about doing the things I want to do, that I ought to do, and I get mad. I just squeeze my fist hard and don't say anything…but it makes me boil.

Half of the sample indicated that they had experienced depression since being diagnosed, and that this depression was worse immediately following diagnosis. One male participant explained, "Yeah, I was depressed…. Who wouldn't be? Your life has just been turned upside down. I still am but it's being treated and I'm a lot better."

Participants (*n* = 10) also reported experiencing anxiety related to their epilepsy. Participants were anxious about having a seizure, hurting someone else or themselves, and the multitude of changes and problems they experience as a result of having epilepsy. One female participant explained, "I'm so nervous all the time…not just about having a seizure, but that at some point I'm not going to be able to do this anymore, to live here by myself."

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Positive changes. Some ($n = 6$) participants found that they experienced positive, or desirable, life changes since their diagnosis. Of note is that participants' positive changes did not occur, or they were not aware of them, until well after they were diagnosed.

Relationships with family and friends. Just as many participants experienced negative changes in their relationships with family and friends, several ($n = 4$) of those same participants also recognized that positive changes occurred in these relationships as a result of epilepsy. One female participant explained how her new-found dependence on her husband, while frustrating, ultimately brought them closer and improved their relationship. She explained:

> I've always been so independent…and he has, too. I mean we did things together, but once we were where we were going we would split up and do our own thing. When I first got this, we fought all the time. About the driving and how long should he give me at the grocery store before picking me up, that kind of thing. But then we found ourselves…laughing. And falling in love all over again. It felt like this had to happen to bring us back together, back to how we wanted to be.

Perspective. Several participants ($n = 5$) also reported that being diagnosed with epilepsy caused positive changes in their lives in terms of their perspective of life in general. These five participants spoke of finding comfort in having epilepsy instead of another, more life-threatening disease. "I've decided it could be a lot worse and I'm just thankful…I don't have cancer," explained one participant. Another remarked how fortunate she is to have a disease for which there is a well-established treatment. He explained, "Other things could be worse…Alzheimer's they don't know what to do for you. At least with this there is a pretty good idea of what makes it better…. I'm thankful for this and not having that."

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Spirituality. Among the participants (*n* = 5) experienced positive changes in their spirituality due to being diagnosed with epilepsy. All five of these participants saw epilepsy as a challenge that resulted in them ultimately feeling closer to their God. As one female participant explained:

> Epilepsy was the best thing to happen to me in a long time. I had drifted from Jesus. I was never a bad person but I wasn't going to church and living for God. This happened to me…. This horrible epilepsy hit me. And I had to turn back to Him for help…to survive it. He was there for me and now I am even closer to God…. So I am glad that it happened.

Research Question Four

Research question four was concerned with different strategies used by older adults in self-managing their epilepsy. Table 17 displays the themes emerging for this research question.

Table 17

Themes for Question Four

Themes	Frequency
Disease/Treatment-focused Strategies	*N* = 20
Life Changes and Problems-Focused Strategies	*N* = 20
Proactive	*n* = 13
Reactive	*N* = 20

Disease/treatment-focused strategies. All 20 participants reported the use of disease- or treatment-focused self-management strategies—strategies aimed at managing epilepsy symptoms (seizures and the post-ictal period) or treatments (medication adherence and side effects). For example, one male participant explained that he quickly learned that lack of sleep and dehydration were seizure triggers for him. Thus, he devised and uses strategies to prevent these triggers and, thus, seizures. "I avoid my triggers… I have a bed time just like a little kid. It may seem silly but it makes my life a whole lot easier," he explained. Many participants (*n* = 17) also claimed to use strategies designed

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specifically to manage medication adherence. Most of these participants relied on marked pill boxes, and over half of them ($n = 9$) relied on a spouse or adult child to help administer their medications correctly. "My wife takes care of that," explained one male participant when asked how he manages his multiple medications.

   Life changes- and problem-focused strategies. The remainder of strategies used by all 20 participants can be classified as life changes and problem-focused; that is, they are not used to managing the disease of epilepsy directly, but are used to managing the life changes and problems that arise from having the disorder and that were discussed in the previous themes. For example, 12 participants spoke of strategies used to manage problems regarding independence and transportation. One male participant stated, "Every time I wanted to go more than a mile became a production…. I wanted to deal with it my way. So I had to come up with a system…and that's when I started living by a schedule." This participant used a color-coded system in a daily planner to organize his transportation. He explained, "Days highlighted in blue, I have to take the bus…that's also the day I have to take my laundry in. Pink days I get a ride with my neighbor."

   Another example of a problem-related strategy used by several ($n = 4$) participants is self-titration of medications. Participants reported decreasing medication dosages as a result of lack of money to buy their medications and also to prevent side effects. As one participant explained, "I figure half a pill is better than no pill…so if we're low on cash I stretch them out." Another participant—a female—described how she alters her medication based on how she is feeling and on what activities she has planned for the day:

If I'm feeling good, and haven't had a seizure in a while…I might start taking less. Just a little at a time. And if I'm leading group at church, I always take only half of it. It just feels more confident up there if I'm more alert. So, yes, I mess with my medication a little bit without my doctor knowing.

Proactive versus reactive. All of the self-management strategies used by participants can be classified as proactive or reactive. Proactive strategies are characterized as systematic, flexible, and effective; whereas, reactive strategies are characterized as unplanned and unpredictable. Participants ($n = 16$) used both proactive and reactive strategies, while four used only reactive strategies. A female participant provided an example of use of a proactive management strategy:

It's like we've got a system set up…with [my friend] and the groceries….
I rely on her and I know that I have those certain days of the week to get to
the store. Otherwise, it wouldn't get done and I'd get desperate. I just plan
ahead to avoid that.

A male participant shared a story that demonstrated the use of a reactive management strategy. He explained:

I was with a group of friends from church, and I don't think they realized
why I no longer drive…. I think they thought that it was just because I
don't have a car. The man who was supposed to be driving was very sick.
So it was me, a very sick guy, and these two women. I didn't know what
to do. None of them knew about my seizures. I felt this huge urge to help
them because we needed to get him home. And I said I would drive the
rest of the way. And I did drive. And I'm not supposed to…. I shouldn't
have. I never should have done that…but I wanted to prove that I'm fine
and I'm just like them. But it bothers me to this day because…my seizures
are almost daily. I could have killed us.

Participants consistently reported having unpleasant experiences when using reactive strategies, and much more pleasant and successful experiences when using proactive strategies. One participant shared, "I'll never run out of medicine again. I went on vacation and didn't get it filled…. What was I thinking? It was bad."

While the majority of participants ($n = 16$) reported the use of both types of strategies, four of the participants did not appear to use any proactive strategies. Two of these participants were women, and two were men. All lived in rural areas, and all were fairly newly diagnosed with epilepsy (all were within one year since diagnosis). These participants also reported having the most and the most significant negative changes and problems since being diagnosed with epilepsy. None of these four participants seemed to have a well-defined plan when it came to managing their disease—their strategies were not executed until after a problem already had occurred.

Research Question Five

The purpose of research question five was to determine what outcomes older adults hope to achieve in self-managing their epilepsy—what they hope to achieve in managing their condition. The themes that emerged for this question are presented in Table 18.

Table 18

Themes for Question Five

Themes	Frequency
We Want to be Involved	$n = 15$
Normalcy	$N = 20$
Well-Equipped	$n = 8$
Seizure-Free	$n = 5$

We want to be involved. When asked what they hoped to achieve, a large portion of the sample's participants ($n = 15$) indicated that they wanted to become more involved in the treatment of their disorder. Participants expressed a desire to build a relationship with their care providers that would allow them to provide input regarding the treatment

of their epilepsy. At the time of their interviews, these participants felt that they lacked control over the treatment of their disorder. One female participant explained:

> I want more to do with it…. I want to be able to have some kind of say in what's going on, or at least have it all explained to me. I don't know what questions to ask them…but I can tell them what's bothering me and then we can talk about how to fix that. I don't just want to accept that I have this and there's nothing I can do about it. I want to work with the doctors…. Sometimes they miss the boat on what I'm needing.

Normalcy. All 20 participants indicated that they wanted their epilepsy self-management to allow them to carry on with their normal lives. Normalcy was, of course, different for every participant, but the goal was the same for each—live a normal life in spite of having epilepsy. One male participant stated:

> The most important thing to me is that it doesn't interfere with my life. The seizures or the treatments. Or the things I am not allowed to do. Let's figure something out and make it work for me so that I can still build stuff out in my shed…so I can take my grandson fishing. That's where I want to get. I want to be a normal retired guy doing the stuff he likes…. I'm not there yet and…I'm not sure that my neurologist understands that.

For many participants, normalcy meant being very involved with their grandchildren. "I want to be able to babysit my grandbaby unsupervised," explained one female participant. Another participant indicated that she wanted to be able to stay up and watch movies with her granddaughter. She stated, "I don't want to be so drowsy…. I want to keep up with her."

Many of these participants (*n* = 9) indicated that they did not feel their healthcare providers were aware of their goals. "We've never talked about it," explained a male participant. A female participant indicated that her neurologist is focused mostly on the frequency of her seizures. She explained:

> Well I just love [my neurologist]…but I guess the most important thing to them is how many seizures am I having. And, to me, sometimes the seizures are not as bad as the medicine, but I don't think they know that. I

think sometimes I'd be better off just having the seizures. They don't hurt…and the medicine makes me feel worse than they do.

Well-equipped. Nearly half the sample ($n = 8$) shared that they hoped that, through managing their epilepsy, they would become well-equipped to handle the disorder more effectively and more independently. "I want to know what to do [about my epilepsy] without having to ask someone or think about it," explained a female participant. She continued, "It's such a weird disease that I don't always know…and I want there to be no second guesses. I just want to be able to know what I or my family should do," she explained.

Others expressed a desire to know, through their management, more about epilepsy so that they could explain it to their family and friends. "I want to know it inside and out, and understand it…. So many people think it's a mental illness. So I should be an expert to explain it to them that it's not," stated a male participant.

Seizure-free. Interestingly, only five participants explicitly mentioned wanting to be seizure-free when asked what they hoped to achieve in self-managing their epilepsy. When participants did mention seizure freedom, it was in the context of wanting to maintain normalcy. "I don't want any more seizures…so I can get back to working part-time and back to doing what I want," explained a male participant. A female participant stated, "Even though the seizures aren't the bad part…I don't see them and I don't remember them, if I didn't have them I think my life would be a lot easier."

Other Themes

Two other themes that were not specifically related to the a priori research questions but were quite salient also emerged. These themes are displayed in Table 19.

Table 19

Other Themes

Themes	Frequency
Epilepsy is Different	$n = 14$
Lack of Resources and Skills to Seek out Information	$n = 17$

Epilepsy is different. Apparent in many participants' ($n = 14$) stories is the

uniqueness of epilepsy to these older adults. In many ways, epilepsy remains somewhat

of a mystery to them. "I don't know anyone else with epilepsy…. All my friends have

breast cancer, but no epilepsy," explained one female participant. Another participant

explicitly stated that he found epilepsy to be somewhat mysterious. "I don't really get it,

understand it…. I know when they did open heart surgery what they did, but I have a

hard time explaining this to people," he stated.

Epilepsy also seemed different to participants due to the stigma associated with it.

In fact, one participant did not even want the word epilepsy to be used during his

interview. "You can call it seizures," he said, citing that the word epilepsy sounded "too

weird." Other participants explained that, while they were very open with their other

health problems, they often desired to keep their epilepsy a secret. One male participant

explained that no one outside of his wife and a close neighbor knew of his epilepsy—and

the neighbor knew only because he witnessed the participant having a seizure once. "I tell

absolutely no one. I just don't want anyone to know that part of my business…. It would

be misunderstood," he explained.

As discussed previously, epilepsy is different in how care providers educate their

patients about it. According to the participants in this sample, much less formal education

is given to patients newly diagnosed with epilepsy when compared to that provided upon diagnosis of other chronic conditions.

Lack of resources and skills to seek out information. Many participants ($n = 17$) expressed a lack of ability and resources to seek out the information they desired. Many of these participants ($n = 11$) did not have computers, and the ones who did said they did not know how to use them to gather information. "I don't know where to even begin to find answers to the questions I have," explained a female participant. Participants also were often unable to interpret the information they (or their family members) found online. "My daughter brought over a pile of papers about epilepsy…but we had no idea what they said. It was all very scientific," stated a male participant. Furthermore, participants felt that they needed to talk to someone about their epilepsy, as opposed to only reading about it. "I need that connection…one-on-one to ask questions," explained a female participant.

Summary of Findings

In this chapter, research questions were answered by presenting themes that emerged during analysis. Three additional, non-research question-related themes also were discussed. Regarding research question one, the majority of participants were dissatisfied completely with the process through which they went to be diagnosed with epilepsy. This dissatisfaction stemmed chiefly from a delay in diagnosis and lack of adequate education and information at the time of diagnosis. Women more commonly experienced a delay in diagnosis than did men. Most participants reported being very surprised and unprepared for their diagnosis of epilepsy and did not realize that they, as older adults, were at relatively high risk for this disorder. The majority of the participants

also had misconceptions about the disease of epilepsy, its prognosis, and the treatment both at the time of diagnosis and at the time of their interviews. Most participants also reported a mismatch between their and their care providers' perceptions of the seriousness of being diagnosed with epilepsy. Regarding research question two, participants reported problems maintaining independence, managing medications, achieving goals, and remembering. Regarding research question three, participants reported the experience of both negative and positive life changes since being diagnosed with epilepsy. Negative changes included undesirable changes in lifestyle, perceived well-being, and physical and emotional health. Positive changes included desirable changes in relationships with family and friends, perspective, and spirituality. Regarding research question four, participants reported using strategies to manage epilepsy and its treatments, as well as those to manage the problems and life-changes that emerged in the discussion of question three. These strategies can be categorized as proactive or reactive. Finally, regarding research question five, participants expressed the outcomes that they hope to achieve in managing their epilepsy. These outcomes included being involved in treatment decisions, maintaining normalcy, being well-equipped to handle and explain their epilepsy, and being seizure-free.

Additional findings also emerged. The first included that epilepsy is different—participants' experiences with it are unique to those of other chronic conditions from which they suffer. In addition, participants perceived a pronounced stigma related to their epilepsy. Participants also expressed that they lacked the skills and resources to access the information they desired about their disorder.

Interactive Nature of Themes: A Participant Exemplar

None of the themes discussed previously exists or occurs in isolation. Rather, these themes are interactive and dependent on and resultant from one another. Figure 5 depicts this interactive nature of the themes.
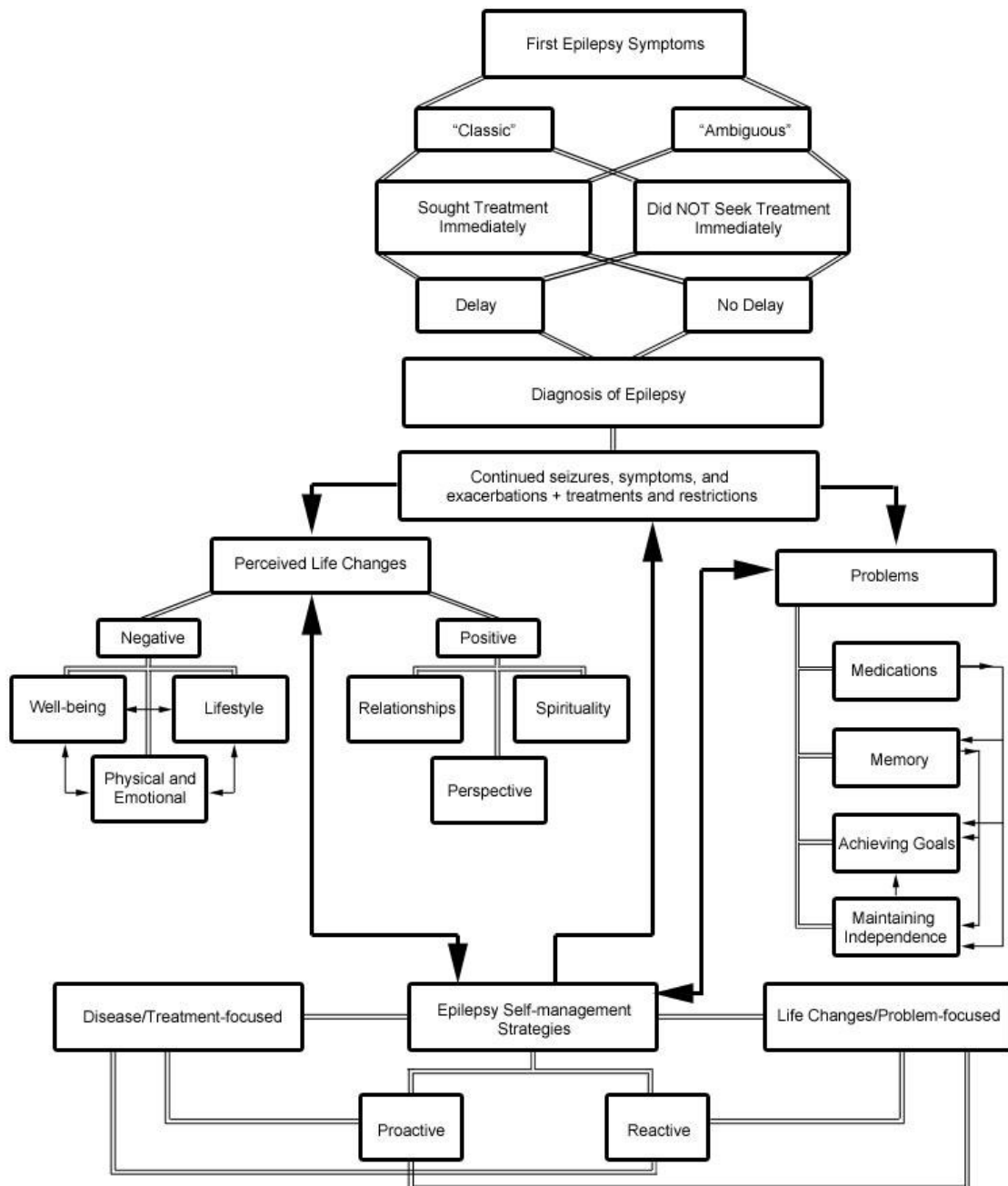

Figure 5. Schemata depicting the interaction of themes.

The most effective way to demonstrate the interactive nature of the themes that comprise epilepsy self-management for this population is via a participant exemplar (Sandelowski, 2010b). The following story provides a summary of the experiences of one of the participants from this study. This story serves to demonstrate, in a real-life case, how the themes described exist and interact for members of this population:

> Susan began experiencing odd behavior and memory problems when she was 72 years of age. She promptly mentioned these symptoms to her physician, who ordered blood work and an x-ray of her brain. When all of these results were normal, she was sent to be evaluated for Alzheimer's disease. She was diagnosed with Alzheimer's and began a medication regimen for it. Three months later, however, her symptoms had not improved. She re-visited her physician, who told her that her worsening symptoms were due to old age. She continued taking her Alzheimer's medications and continued having symptoms. Another six months later, she had a generalized seizure while in a water aerobics class. An emergency department physician confirmed that she had had a seizure and referred her to a neurologist, who ultimately diagnosed her with epilepsy. This diagnosis came over a year after her initial visit to her physician. Susan was very shocked to receive this diagnosis and could not imagine what caused her to develop it. Despite asking her neurologist what may have caused it, she was told that the cause was irrelevant and that medication would prevent future seizures. Susan was dissatisfied with this information but felt uneasy questioning her neurologist.

> Susan's neurologist prescribed an anti-epileptic medication and told her she should not drive until she was seizure free for six months. She was not told, however, that the symptoms that initially brought her to her physician—odd behavior and memory loss—were seizures and part of her epilepsy. Thus, when six months passed and she had had no generalized seizures, she resumed driving. However, her odd behavior and memory loss continued. Susan ultimately ran her car into a ditch during one of these episodes. It was only at this point that Susan became aware that her odd behavior and memory loss were seizures.

> Susan's medications were altered, and she began experiencing extreme fatigue as a result. She began sleeping until 11:00 a.m. every day and was forced to give up her volunteer activities. She no longer had the energy to cook Sunday meals for her extended family, either. Susan was not satisfied with this level of fatigue, and thus she sometimes reduced her medication dosage when she felt she needed to be more productive. She also began taking scheduled naps every day.

Susan's husband took on new roles at the time of her diagnosis. He became her chauffer and did much of the housework. Susan was not comfortable with these changes, and they made her feel depressed. She also experienced anger related to her inability to live her normal life.

Susan devised and used many strategies to manage her epilepsy. For instance, she paid extra for her pharmacy to organize her medications in dosage packets because her memory problems prevented her from consistently being able to take her medications correctly. Because she was uncomfortable being dependent on her husband for transportation, she began using a taxi. She managed to work out a reduced fare agreement with the taxi service. When she didn't feel well as a result of having a seizure or due to medication side effects, Susan responded accordingly by resting or cancelling commitments. For instance, because she could never predict her level of fatigue for a week, she refrained from making plans well in advance and chose to take part in activities that she could join at the last minute. She also found a back-up volunteer to fill in for her at church in case she was too fatigued to do her duties, thus allowing her to fulfill her commitments despite experiencing negative physical symptoms. Sometimes, though, Susan found herself trying to manage epilepsy-related problems after they had already occurred. For instance, Susan was scheduled to perform some music at the wedding of a friend's daughter. Susan had a bout of seizures the day before because she had cut down her medication in order to be alert for the wedding. Susan had not thought to schedule a back-up person for her performance. She missed the wedding and was unable to find another musician due to her general poor health (post-ictal fatigue) on that day. She feels that her lack of being able to perform at the wedding, as well as her lack of planning, negatively affected her friendship with the bride's mother.

Susan has read books about epilepsy, but desires more information about her condition that is presented in layman's terms. She does not have a computer and has been relying on her adult daughter to find articles for her about epilepsy, though she admits she has difficulty interpreting these articles. She does not know anyone with epilepsy and wishes to join a support group, but is unsure how to do so.

In this exemplar, the existence of themes that were presented in the findings previously is apparent. Susan underwent a difficult diagnosis process and was displeased with the timing of her diagnosis and the lack of information she received about her disorder at that time. She also had misconceptions about her disorder and did not recognize her main symptoms as being those of epilepsy, which ultimately led her to

being a victim of a car accident. She experienced several problems related to her disorder, including lack of independence and the experience of unpleasant physical and emotional symptoms. Susan, with her husband, devised proactive strategies to manage these problems. Susan did not use the same strategies every day, but rather the type of day she was having dictated which strategies she used. On a day during which she was experiencing problems with medication side effects, for instance, strategies to ameliorate them were used. These strategies were not needed every day, indicating that self-management is not a stagnant phenomenon, but *fluid and responsive to the needs of the person managing the disease*. She also used reactive strategies, which she felt led to negative outcomes. Susan desires more information about her disorder but does not possess the skill set to retrieve such information on her own. She feels isolated as a consequence of her epilepsy.

CHAPTER V

DISCUSSION

This chapter discusses the study methods, the findings, and the application of those findings to practice. To maintain clarity, findings associated with each research question are discussed separately, followed by a more general discussion of other key points. Recommendations for future research are made throughout the chapter. Finally, a summary of the chapter is provided.

Discussion of Methods

The discussion of methods is separated into three sections. First, lessons learned from the recruitment process are described. Second, a description of how the sample characteristics may have influenced the findings is presented. Third, key data collection strategies believed to help produce rich data are identified.

Recruitment Lessons

In the pilot study that preceded this study, self-referral was the only recruitment strategy utilized. Advertisements were placed in local neurology offices, and participants contacted the researcher if interested in taking part. While this strategy was successful in meeting recruitment goals for a small pilot study (five participants were recruited over a three-month period of time), it would not have been adequate in this study due to the requisite larger sample. Persons with chronic diseases can be difficult to recruit from in-office settings given the somewhat low frequency with which they visit their care providers. Once they are diagnosed, persons with chronic disease only may see their specialized care provider bi-annually or even annually, and problems and exacerbations often are managed without patients even physically attending the clinic—prescriptions or

tests are called in, for example (Lorig & Holman, 2003). Thus, patients often are simply not available for recruitment from the clinic setting.

For the current study, a recruitment strategy that would allow more access to potential participants was devised (see Chapter III). This strategy, in which potential participants were sent physician-signed letters informing them of the study and that they would be contacted via phone by a researcher in the coming days, proved very fruitful. Refusal rates were low (36%), and the strategy greatly assisted the researcher in purposively sampling, as she had a large pool of potential participants from which to draw. Such control over sample selection was not possible using the pilot study recruitment strategy. Because sampling in qualitative descriptive research is key in generating valid results and is based on emerging findings, a strategy similar to the one used in this study should be considered by researchers using similar methods.

The use of a letter informing potential participants of the study and indicating that they would soon be contacted by a researcher may have contributed to the low refusal rate in this study. While no data were collected in this study regarding participants' opinions about the ways in which they were recruited, many participants noted that they appreciated receiving the letter about the study, and all of the potential participants who called the researcher themselves regarding an interest in the study did so as a result of receiving the letter.

Influence of Sample Characteristics

The composition of sample in terms of gender, race, and age may have affected the findings of this study. Epilepsy affects both genders equally (Epilepsy Foundation, 2010), though the study sample was predominantly female (60%). However, the

distribution of males and females in the sample is reflective of a predominantly female population in the United States (51% female, 49% male), and the discrepancy between men and women is even more apparent in those over age 65 (United States Census Bureau, 2009). Further, the interpretive validity of the study is protected by the use of data-derived sampling and informational redundancy—both women and men were recruited until informational redundancy was met.

Epilepsy affects all racial groups equally (Epilepsy Foundation, 2010). A limitation of the current study is a lack of minority representation. All participants, except one African American, were Caucasian. The lack of minority participation was not due to refusal rates from minority participants. Rather, only one participant in the sampling pool was a minority, and this participant did take part in the study. The results of this study may not be fully generalizable to minorities.

Another limitation of this study is a lack of participants in *old* old age. The oldest participant in the study was 80 years of age. New-onset epilepsy does affect those over age 80 (Epilepsy Foundation, 2010), though not as commonly as younger older adults. While two potential participants older than age 80 (84 and 91 years, respectively) were contacted about participating in the study, both of them were excluded due to cognitive impairment. The findings of this study may not be fully generalizable to older adults with epilepsy who fall in a more advanced age range.

Key Data Collection Strategies

Data collection procedures used in this study were effective in generating a rich data set. The following strategies were helpful in producing this rich data:

- Instructing participants, during their initial recruitment phone call, to think about their experience with being diagnosed with epilepsy, as well as how their lives are different now that they have epilepsy, in the time prior to their interviews allowed participants to come to the interviews prepared and already thinking of which stories they wanted to tell.

- Informing participants that their confidentiality would be protected made participants feel more comfortable answering questions. While informing participants of the protection of their confidentiality is standard in any research study, the researcher felt that doing so explicitly allowed participants to be more open with their responses. In the initial several interviews, participants commonly asked the researcher if their physicians would be shown any of their interview statements, and sometimes showed concern about discussing medication adherence, for fear of their physicians being made aware of non-adherence. As a result, in subsequent interviews, the researcher spent more time discussing what protection of confidentiality meant because some participants seemed to believe that the researcher had been referring to confidentiality of interviews between her and their care providers. After participants understood that only the researcher and her co-investigators would see the data, they felt comfortable to talk freely about their experiences.

- Using story-telling assisted participants who had difficulties knowing where or how to begin. While most participants had no difficulty discussing their experiences, others struggled with knowing where to start.

The researcher asked these participants to try to express their feelings via telling a story—giving an example—about something they had experienced that conveyed what they were trying to express. This strategy worked very well.

Discussion of Findings

Research Question One

Key findings related to research question one—what are older adults' experiences with the process of being diagnosed with epilepsy?—emerged in this study. The majority of participants were dissatisfied with the process through which they went to become diagnosed with epilepsy, and this dissatisfaction largely stemmed from a delay in diagnosis and a lack of education and information received about the diagnosis and long-term management of the condition. Women in the sample had these dissatisfying experiences more often than the men. In addition, the majority of older adults in the sample were not aware of the high prevalence of epilepsy in people their age. They also failed to have a proper understanding, both at the time of diagnosis and persisting beyond that point, of the nature of the disease, its prognosis, and treatment. Finally, there was commonly a mismatch in the perceptions of participants and their providers in terms of the seriousness and overall life impact of the disease.

Dissatisfaction with diagnosis. During the pilot study that preceded the current study, an unexpected and robust finding was participants' dissatisfaction with their diagnosis processes. In fact, the researcher, or her committee, had not considered including a research question regarding participants' satisfaction with their diagnosis process until it became clear that it was a very salient issue for the pilot participants. The

literature review presented in Chapter II did not reveal any publications demonstrating this or the younger adult population's strong dissatisfaction with the diagnosis process. In the case of younger adults with epilepsy, it is not clear if this population has simply not been *asked*, during a formal research study, about their satisfaction with their diagnosis processes, or if they actually differ from older adults in this way.

Delay of diagnosis. The most common reason for dissatisfaction with the diagnosis process was an unacceptable delay in diagnosis. Females comprised the majority of participants who experienced such a delay. In reviewing the literature, one study that partially corroborated this finding was identified. Rowan and colleagues (2005) conducted a retrospective chart review of 159 (157 men and 2 women) older adult (age range 59–96 years) patients of Veterans Affair who experienced new-onset epilepsy late in life. They found that a delay in diagnosis was very common in the sample, with a mean length of time of 1.7 years from first seizure to diagnosis. Only 49 patients were diagnosed with the condition immediately when they presented to their healthcare providers.

Rowan and colleagues (2005) identified several factors that contributed to this delay. As was seen in the current study, many patients (about half) did not immediately report their symptoms to their healthcare providers because they did not recognize them as seizures. However, once patients *did* seek treatment, 70% of patients were not accurately diagnosed immediately. As was seen in the current study, many were misdiagnosed with other conditions, including Alzheimer's disease. In addition, 23% of patients with partial seizures were misdiagnosed as having transient ischemic attacks.

Patients who initially were misdiagnosed with these conditions then went on to receive inappropriate treatment for many months or years before being accurately diagnosed.

Rowan and colleagues (2005) also found that type of seizure symptoms (grand-mal versus partial or complex partial) was a significant factor in determining length of time to diagnosis. Half of patients exhibiting symptoms of grand-mal seizures (classic symptoms) were diagnosed immediately, while only 20% of 86 patients with complex partial seizures (ambiguous symptoms) were diagnosed immediately. Results of the current study are congruent with this finding, but only for the male participants. Male participants in the current study who demonstrated classic grand-mal seizure symptoms rarely experienced a delay in diagnosis, while female participants who reported a delay in diagnosis commonly presented with either grand-mal *or* complex partial seizure symptoms (50% in each group). These women also reported that their care providers were dismissive of their concerns about their symptoms, while no males in this sample had a similar experience. Rowan and colleagues (2005) did not report this finding in their male-dominant sample, either. In their study, there was no evidence that patients' symptoms were not taken seriously but rather that providers initiated incorrect diagnostic paths (Rowan et al., 2005).

While Rowan and colleagues (2005) reported some findings consistent with those resulting from this study, aspects of their investigation leave remaining gaps in knowledge. First, the charts of only two female patients were reviewed in the study. This lack of female representation is significant in light of the findings from the current study which suggest that women are more likely to experience a delay in diagnosis regardless of symptom presentation. Secondly, Rowan and colleagues' (2005) study, though

multi-site, was conducted solely within the Veterans Administration system. The majority of older adults do not receive care from this system but rather present to primary care providers in the community (Collins, Shapiro, & Ramsay, 2006). Furthermore, in the current study, many participants initially sought care in rural clinics. Finally, the findings from Rowan and colleagues' (2005) study are nearly a decade old (data were collected between 2001 and 2003). It is unclear if, in the last eight to ten years, the diagnosis process of older adults with new-onset epilepsy has changed.

The review of literature did not reveal any reports of younger adults experiencing such a delay in epilepsy diagnosis, though it appears that it is not uncommon in children with the disorder. Buelow and Shore (2006) interviewed 21 parents of children with epilepsy about their experiences with diagnosis of the condition. A correct epilepsy diagnosis often was delayed due to parents not seeking treatment and healthcare providers not recognizing children's symptoms as seizures. Children often were misdiagnosed with other conditions and thus received inappropriate treatment for varying amounts of time.

While no literature, apart from Rowan and colleagues' (2005) study, was found regarding older adults with epilepsy commonly experiencing a delay in diagnosis, it is not uncommon for older adults with other chronic conditions to experience a delay in diagnosis or to be misdiagnosed with other conditions. For example, older adults have been shown to be misdiagnosed with osteoarthritis when they are actually suffering from more acute, reversible causes of pain (Spiera, 1987). In more recent studies, investigators have found that Alzheimer's disease is over-diagnosed in the older adult population. White (2011) autopsied the brains of 426 older adults who had, before their deaths, been

diagnosed with and treated for Alzheimer's disease. Half of those brains autopsied failed to show signs of Alzheimer's. Some brains demonstrated evidence of various types of dementia, and some brains were normal. White (2011) noted that expense and decrements in quality of life are associated with such misdiagnoses and lack of appropriate treatment. Interestingly, two participants in this study and some in Rowan and colleagues' (2005) study (exact number not reported) were misdiagnosed initially with Alzheimer's disease when they presented to their care providers with seizure symptoms.

Older adults with Lewy Bodies disease, a type of dementia, often experience a great delay in diagnosis. In a survey of 935 caregivers of older adults with Lewy Bodies disease, 78% reported that their loved ones initially were misdiagnosed with Alzheimer's disease, Parkinson's disease, or psychiatric or mood disorders. Over half of those surveyed indicated that a correct diagnosis took over a year (Galvin, Duda, Kaufer, & Lippa, 2010). While it does share some commonalities with Alzheimer's and Parkinson's diseases in terms of initial presentation, Lewy Bodies disease causes unique symptoms—usually hallucinations—that set it apart from other diseases (Galvin et al., 2010). Yet, most older adults with this condition are misdiagnosed and receive inappropriate treatments.

A review of the literature did not yield any evidence that older adult women are, as they were in this study, more likely to experience a delay in diagnosis or misdiagnosis when presenting with chronic conditions. Strong evidence, though, demonstrates that women in general are more commonly incorrectly diagnosed when presenting with symptoms of heart disease, including myocardial infarctions. In a landmark study involving 10,000 participants, Healy (1991) found that women who presented with

cardiovascular symptoms were significantly less likely than were men to be referred for diagnostic procedures. Other investigators have found that this discrepancy is often due to the way in which many women present with cardiovascular disease, including acute myocardial infarctions. Women are significantly less likely than men to present with chest and left arm pain during a myocardial infarction. Their main symptoms are often more vague, less classic than those of men, and commonly include fatigue (Healy, 1991). In the current study, however, the women in the sample did not describe initial seizure symptoms that differed from those of the men in the sample. Women with both classic and ambiguous seizure symptoms were more likely to experience a delayed diagnosis than were men.

As was discussed in Chapter IV, both women and men living in rural areas were more likely to experience a delay in diagnosis. This finding is not surprising, given that it is known that older adults living in rural areas have fewer resources and are less likely than their city-dwelling counterparts to seek medical attention. They also tend to have fewer financial resources, which can prevent them from traveling to seek care (Bailey, 2009). Curious, however, is the finding that the women in this sample who experienced a delay in diagnosis were all well-educated and affluent, while none of the men who experienced a delay held a college degree and all had lower annual incomes.

The men in this sample experienced a delay in diagnosis only if they demonstrated ambiguous seizure symptoms, resided in a rural area, were less well-educated, and had a lower socioeconomic status. All of these characteristics seem reasonably contributory to their delay in diagnosis. Ambiguous seizure symptoms often are not recognized by primary care providers as seizure-related (Rowan et al., 2005),

those in rural areas have less access to health care (Bailey, 2009), and those of lower

education and socioeconomic status are less likely to utilize health care resources (United

States Department of Health and Human Services, 2003). The question, then, is why did

the women in this sample, who did not have characteristics that would pre-dispose them

to a delay in diagnosis, consistently report a delay in diagnosis? The answer to this

question is not clear, and a literature review revealed no investigations that have focused

on answering it.

   Lack of information. The second most common reason that participants were

totally or partially dissatisfied with their process of diagnosis was due to lack of

education and information given at the time of diagnosis and beyond. Women were more

likely to have this complaint than were the men. Most of the participants reported that

they expected to have some kind of formal education given to them about their epilepsy,

and this expectation was based on their experiences with other conditions such as stroke,

diabetes, and hypertension. While there is evidence that parents of children with epilepsy

have difficulty communicating with their children's healthcare providers about their

children's condition (Buelow, McNelis, Shore, & Austin, 2006), this finding is not

corroborated in the younger adult epilepsy literature. However, this finding is consistent

with Clark and colleagues' (2010) findings which indicate that care providers of adults

with epilepsy (neurologists and primary care providers) find their biggest challenge in

treating those with epilepsy to be lack of time available to spend with patients for the

purposes of educating them about their disorder. It appears, then, that older adults with

epilepsy may want and need more education about their disorder, but their care providers

do not have time to deliver it to them.

Misunderstanding of epilepsy. All participants were shocked at receiving an epilepsy diagnosis and reported that they were not aware that older adults were at risk for the condition. Epilepsy is not a publicly well-discussed disease. It is associated with stigma and is often viewed by the public as mysterious (Leppik et al., 2006). While other diseases that affect older adults—Alzheimer's, heart disease, and cancer—are well-advertised and discussed with older adults, such efforts with epilepsy have been undertaken only recently and are not aimed specifically at older adults. In 2008, the Epilepsy Foundation initiated Purple Day—a day on which, annually, events are held to raise awareness about the disease of epilepsy. The Purple Day campaign has been in existence only for three years, and thus may not have yet have been fully effective in spreading awareness to the older adults involved in this study.

Participants in this study also reported many misunderstandings about the disease of epilepsy, its prognosis, and available treatments. These misunderstandings likely stem from the lack of education delivered to patients at the time of diagnosis and may have great potential to affect outcomes. For example, some participants believed that their epilepsy was curable—that taking their medication eventually would eradicate the epilepsy and that they could stop taking their seizure medication when they stopped having seizures. Such misunderstandings could have devastating results for older adults with epilepsy, including seizure exacerbations, accidents, and injury to themselves and others.

Patient/provider perspectives. A key finding regarding older adults' diagnosis experiences is that they often felt that their care providers' perspectives on the seriousness of the disease of epilepsy, especially in how it would affect their daily lives,

was not well-matched with their actual post-diagnosis experiences. Participants felt

unprepared by their providers regarding the ways in which life would be different after

the diagnosis. This finding is somewhat consistent with that of McAuley and colleagues

(2010), who found that adults with epilepsy were most concerned about the *life issues*

caused by epilepsy and its associated treatments and restrictions, while practitioners

treating those patients were more concerned with *clinical issues*, such as medication

adherence. This mismatch in perceptions of patients and care providers also has been

shown to exist in Parkinson's disease—a disease that primarily affects older adults

(Stanley-Hermanns & Engebretson, 2010).

Implications and recommendations. Several practice implications and

recommendations for future research can be made based on the findings related to

research question one. First, time and effort must be invested to prevent the delay in

accurate diagnosis that was so pervasive in this sample and in the only other study that

could be found investigating this exact issue (Rowan et al., 2005). The delay in diagnosis

is not distressing only to older adults with epilepsy and their families, but lack of a timely

diagnosis can, and did in the cases of many of these participants, lead to months or years

of improper, unnecessary, and ineffective treatments and their associated costs, as well as

decrements in quality of life (White, 2011). It remains unclear, however, how widespread

the problem of delayed diagnosis is in this population currently, as well as how long the

delay usually exists. More research with a larger and more geographically and

racially diverse sample is needed in order to fully describe this problem. Such research

must be done utilizing different methods than those used in this study because the

prevalence of delayed epilepsy diagnosis and length of that delay need to be precisely

quantified. Once the problem of delayed diagnosis in this population has been described adequately, it can be solved only if factors contributory to it are identified.

Based on findings from this study and others (Rowan et al., 2005), primary care providers often do not recognize older adults' seizure symptoms as readily as they would in younger adults with epilepsy. It is known that older adults do indeed exhibit seizure symptoms that are distinct from those in younger adults and children. Seizure symptoms in older adults often present more subtly than in younger people and may include slight confusion, memory loss, or staring spells. Their post-ictal periods, however, are generally prolonged and characterized by more marked confusion than that which is seen in younger people. Older adults also often have co-morbidities, which can mask or seem to explain away the symptoms of seizures (Rowan et al., 2005; Rowan & Ramsay, 1997). The differences in seizure symptom presentation in older adults likely contribute to primary care providers' lack of recognition of these symptoms as potentially epilepsy-related. It is possible that an intervention with primary care providers, the providers to whom older adults most often present with seizure symptoms, is needed in order to educate them not only of the symptoms of seizures in older adults but also of the high prevalence of new-onset seizures in this population. While Locharernkul and colleagues (2010) assessed the knowledge of primary care providers and nurses regarding the *treatment* of persons (and not specifically older adults) with epilepsy, no literature documenting primary care providers' knowledge of and ability to recognize epilepsy symptoms in older adults could be found. Thus, future research should first focus on assessing the knowledge of these providers in terms of their recognition of seizure symptoms in older adults, as well as any misconceptions these providers may have

regarding the diagnosis of epilepsy in this population. Results from such an investigation could inform an intervention designed to improve providers' awareness of older adults' seizure symptom presentations and diagnostic steps that should be taken when those symptoms are seen in an older adult. For instance, epilepsy, once it is suspected, is not difficult or expensive to diagnose. A noninvasive outpatient test called an electroencephalogram can be used to make the diagnosis (Epilepsy Foundation, 2009). Thus, primary care providers could be made aware that when an older adult presents with new-onset memory loss or other symptoms that might be seizure-related, epilepsy should at least be ruled out as a potential cause. Of note is that the American Epilepsy Society and the Epilepsy Foundation have both tried to address primary care providers' lack of knowledge of seizure symptoms (for all ages) and have had difficulty gaining the interest of providers in participating due to the low frequency with which they see patients presenting with new-onset epilepsy (J. Buelow, personal communication, September 12, 2011). However, because these providers do not commonly see persons with epilepsy and, at least in the case of older adults, tend to misdiagnose this condition when it is presented, such an assessment and intervention is warranted.

Such an intervention would need to be tailored to providers depending on the areas in which they practice and such tailoring likely could be achieved via the use of online modules, each of which would be crafted to contain information about the needs of different types of primary care providers (those in rural versus more metropolitan areas, for example). This intervention also may help promote epilepsy awareness to older adults, as primary care providers might be more likely to discuss it with their patients if the providers were aware of its high prevalence in the population.

The findings of this study indicate that women may be more likely than men to experience a delay in diagnosis and that the delay experienced by these females often can be associated with the dismissiveness of primary care providers to whom these women present with their seizure symptoms. An investigation aimed at determining the breadth of this problem and contributory factors is needed. Because there was no apparent reason for the discrepancy seen between men and women in this sample in terms of delay of diagnosis, further qualitative inquiry with both women (those who have experienced a delayed diagnosis as well as those who have not) and care providers is appropriate to identify contributing factors.

Second, researchers must invest in determining how best to meet the educational needs of older adults who are newly diagnosed with epilepsy. Participants were very dissatisfied with the type and amount of education they received at the time of diagnosis, and this lack of education undoubtedly contributed to many participants' continued misunderstanding of their disease. While the findings of this study have highlighted some of the information participants want and need to know at the time of diagnosis, it remains unknown precisely what types of information they are receiving. Inquiry into what information is given routinely to older patients at the time of epilepsy diagnosis by their care providers would be worthwhile and likely would be achieved best by interviewing neurologists and their associated nursing staff regarding the education that is given to newly diagnosed older adults with epilepsy and to determine if it differs from that given to younger adults diagnosed with the condition. Such a study would serve as a type of needs assessment regarding education delivered to older adults at the time of diagnosis and would thus highlight areas of missing information or the inappropriate use of

education materials (dispensing brochures with medical jargon, as was described by participants in this study, for example).

Participants in this study indicated that they did not receive any formalized education about their disorder and that the lack of this education was surprising to them based on their experiences with other chronic conditions. Results from other studies, however, indicate that neurologists do not have time to deliver formalized education to their patients newly diagnosed with epilepsy. This issue is likely amenable to intervention via the use of advanced practice nurses (on-site or remotely) who could speak with older adult patients at the time of diagnosis or soon after in order to provide them with more structured, comprehensive education about their disorder. The development and testing of such an intervention in terms of its cost-effectiveness and ability to meet older adults' needs is warranted. This intervention would be combined with theory-based epilepsy self-management interventions designed for this population (discussed later in this chapter).

Participants also felt that neurologists down-played the seriousness of their disease in terms of how it ultimately would affect their lives. This problem may be related to the lack of education neurologists give their newly diagnosed older adult patients or could be a result of an actual misperception on the part of the providers. Because evidence suggests that patients and providers often have very different concerns regarding epilepsy (Clark et al., 2010), it is possible that neurologists may not even be aware of the ways in which epilepsy affects the lives of their patients. Researchers must inquire of neurologists how they perceive their patients' lives changing after an epilepsy

diagnosis and possibly intervene with them regarding how to prepare patients for these changes.

Research Question Two

Key findings related to research question two—what problems are experienced by older adults while self-managing epilepsy?—emerged in this study. Participants reported experiencing, post-diagnosis, problems maintaining independence, problems with medications and memory, and problems achieving goals.

Maintaining independence. Older adults in this study reported difficulties maintaining pre-diagnosis levels of independence. As is seen in the younger adult epilepsy literature (Krumholz, Fisher, Lesser, & Hauser, 1991; Unger & Buelow, 2009), several of the participants involved in this study, and particularly the youngest participants and those living in rural areas, found that their independence was negatively affected by their lack of ability to drive. This finding is not surprising as many older adults continue working past 65 years of age and thus must be able to drive to work themselves, especially in the event that their spouses also are employed. Even those who were not working, however, but lived alone or had an employed spouse found driving restrictions to be very disruptive to their normal lives. Martin and colleagues (2005) also found that a prime issue of importance to older adults with epilepsy was difficulties with transportation. Similar findings have emerged in studies investigating driving issues in older adults with Parkinson's disease (Uitti, 2009).

Unique to the current study is the finding that problems surrounding driving tended to attenuate with time for participants. For younger adults with epilepsy, there is evidence that issues related to driving occur in those newly diagnosed (Unger & Buelow,

2009) and those who are in the more chronic stages of the disease (Krumholz et al., 1991). Participants in this study felt that the development of a system to manage their transportation was effective in improving their independence problems related to driving. In addition to transportation-related issues, participants reported that their condition and its treatments interfered with their ability to live independently on a daily basis. This finding is related to participants' claims that epilepsy is a life-changing diagnosis, though their providers often do not alert them of or prepare them for these changes. While the researcher could locate no other published studies that corroborate this finding in the older adult population, Unger and Buelow (2009), in a study with newly diagnosed younger adults with epilepsy, found that participants commonly described the diagnosis as life-altering. However, the findings of this study are distinct from Unger and Buelow's (2009) in terms of how participants' independence was affected by epilepsy. Older adults reported much greater losses in independence than did the younger adults in Unger and Buelow's (2009) study. Several older adults in this study were forced to move out of their homes and into those of family members or into assisted living facilities because their epilepsy and its treatments made them incapable of managing a household. While Unger and Buelow's (2009) study involved only five participants, none of them reported such a drastic upheaval as a result of epilepsy.

Medications. Older adults reported several problems related to managing their medications. First, lack of ability to pay for seizure medications was a concern to many participants. While it is known that younger adults who are uninsured have difficulty accessing their seizure medications (Epilepsy Foundation, 2010), findings from only one other study, in which older adult participants were asked to write down their concerns

about epilepsy, have indicated that access to seizure medications is a major issue for older adults (Martin et al., 2005). Unique to these older adults is the type of health insurance they use—Medicare. Most older adults with epilepsy are retired or not working, cannot afford private insurance, and thus are forced to rely on Medicare for their healthcare needs, including prescriptions. A large portion of the sample found that Medicare and its donut hole left them unable to pay for their seizure medications. Financial concerns regarding medications were compounded for participants as a result of the existence of multiple co-morbidities. Unlike younger adults with epilepsy, older adults are not only paying for their anti-epileptic drugs, but also drugs for a variety of other conditions. Participants in this sample were more likely to pay for medications related to heart disease, diabetes, or pain and to forgo buying seizure medications when finances were limited—that older adults' epilepsy goes untreated due to financial limitations is thus a valid concern.

Participants also expressed difficulties with side effects of seizure medications, and these side effects contributed to both loss of independence and decisions made not to purchase epilepsy medications in favor of drugs for other conditions. Epilepsy medications are known for causing undesirable side effects in adults (Unger & Buelow, 2009), but participants in this sample reported that these side effects were much more pronounced when seizure medications were taken with medications for other conditions. Thus, a unique issue for this population is that of polypharmacy.

Finally, participants reported that they often had problems remembering to take their medication and attributed this problem to increasing memory problems since the onset of epilepsy (discussed later in this chapter), the number of medications prescribed

to them, and the frequency with which those medications and their dosages changed. In studies with younger adults with epilepsy (Jacoby, 1992; Unger & Buelow, 2009; Unsworth, 1999), medication management has been shown to be an extremely complex portion of epilepsy self-management. However, in none of these studies has memory loss been highlighted as a key reason for difficulties in managing medication. Such memory loss coupled with polypharmacy likely deems epilepsy medication management in older adults even *more* complex than that which has been reported in younger adults.

Memory. In addition to difficulties remembering to take seizure medications, participants also complained of general memory deficits since the onset of epilepsy. While McAuley and colleagues (2010) found that younger adults were concerned with general memory loss after the onset of epilepsy, the findings of this study are the only that can be found regarding the existence of a similar problem for older adults. Because McAuley and colleagues (2010) did not ask participants in their study to describe their memory loss, it is difficult to compare the memory loss experienced by younger adults with epilepsy with that of older adults with the condition. In this study, participants complained mostly of short-term memory loss since suffering from epilepsy. Interestingly, their scores, as a whole, on the Mini Mental Status Exam (Folstein et al., 1975) were most abnormal in the section of the tool that tests short-term verbal memory.

Achieving goals. Participants reported that epilepsy, in addition to medication side effects, memory problems, and other seizure-related symptoms, has made achieving personal goals, and specifically those associated with grandparenting, difficult to achieve. Younger adults with epilepsy have reported difficulties in maintaining normal parental roles (Buelow, 2001; Unger & Buelow, 2009), but no published studies reporting the

concern of older adults with epilepsy in relation to their ability to be grandparents could be found. Many of the participants in this study who voiced difficulty with grandparenting abilities cited safety of their grandchildren as the major concern. While Martin and colleagues (2005) found that older adults with epilepsy were concerned with safety issues, they did not report the exact types of safety issues that were concerning to their sample participants.

Implications and recommendations. Several implications for practice and recommendations for future research can be made based on the findings associated with research question two. First, based on the findings of this study and others (Martin et al., 2005), it must be recognized that driving restrictions are very problematic to older adults with epilepsy. Though members of this population are more often retired or unemployed when compared to younger adults with epilepsy, care providers of older adults with epilepsy must not assume that they will be unaffected by the driving restrictions that accompany an epilepsy diagnosis. In addition, because participants reported that their lack of independence related to driving restrictions improved over time due to the use of system-based strategies, it is important that such strategies be discussed and included in epilepsy self-management interventions, which are discussed later in this chapter.

Secondly, older adults with epilepsy may be at high risk for significant loss of independence, including upheaval from their personal dwellings. Such a transition can be incredibly stressful for older adults (Uitti, 2009), as well as their family caregivers (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). Neurologists and nurses interacting with older adults with epilepsy must be aware of these older persons' risk for loss of independence given that participants in this study did not feel prepared for this

change based on interactions with their neurologists. Epilepsy self-management interventions designed for this population (discussed later in this chapter) must be focused on preventing and managing this loss of independence.

Thirdly, current findings indicate that older adults with epilepsy commonly, for a variety of reasons, do not take the appropriate dosages of their anti-epileptic medications. Clinical outcomes (e.g., seizure frequency/severity, healthcare resource utilization, and safety) could be affected greatly by these medication errors. Results of this study highlight several barriers that prevent older adults with epilepsy from taking their medications as prescribed. Self-management interventions designed for this population (discussed later in this chapter) thus must include an assessment and intervention aspect related to identifying and overcoming these barriers.

Fourthly, older adults in this study reported problems with short-term memory loss following the onset of epilepsy. This memory loss was severe enough to interfere with their ability to live normally. Neuropsychological testing of these patients at the time of diagnosis and beyond may be needed to facilitate the diagnosis and treatment of epilepsy-related memory loss. None of the older adults in this sample reported having received any type of neuropsychological testing done since the time of their diagnosis.

Finally, neurologists and nurses working with older adults with epilepsy must be aware of the influence a diagnosis of epilepsy has on older adults' abilities to achieve their personal goals related to grandparenting. Again, participants expressed that they were unprepared by their neurologists regarding the potential for this problem. Self-management interventions designed for this population (discussed later in this

chapter) should include content regarding the achievement of personal goals in the context of an epilepsy diagnosis.

Research Question Three

In responding to research question three—how do older adults perceive that their lives have changed since being diagnosed with epilepsy?—participants reported experiencing mostly negative changes since their diagnosis of epilepsy, though some did report that positive changes had occurred in their lives since the diagnosis.

Negative changes. Participants in this study reported experiencing negative changes in lifestyle, perceived well-being, and physical and emotional status.

Lifestyle. Negative lifestyle changes included those to participants' social lives, relationships with family members and friends, the number of important commitments made, daily functional abilities, and ability to fulfill age-appropriate roles and responsibilities. No other published studies reporting similar results for older adults with epilepsy could be found. However, somewhat similar findings from studies involving younger adults with epilepsy do exist. Younger adults with epilepsy have been shown to perceive negative life changes in all of these areas (Buelow, 2001; Unger & Buelow, 2009). However, while negative changes in these areas of life appear common to both older and younger adults with epilepsy, the nature of these changes is not identical for both sets of groups. For example, while older adults reported a declining ability to independently maintain their homes (a negative change related to daily functional abilities), younger adults more often noted negative changes related to being productive at school or work (also a negative change related to daily functional abilities). Thus,

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while both older and younger adults with epilepsy experience negative lifestyle changes, that the general lifestyles of younger and older adults differ cannot be ignored.

Perceived well-being. Participants reported feeling less well as a result of their epilepsy. In other words, their perceived health was affected negatively by epilepsy and its treatments. While no other published evidence could be found to corroborate these findings in older adults with epilepsy, younger adults with epilepsy (Unger & Buelow, 2009) and older adults with other chronic neurological conditions such as Parkinson's disease also have reported a decline in their overall health due to the disease and its treatments (Gotham, Brown, & Marsden, 1986). In the current study, negative changes in perceived well-being were seen in participants with well- and poorly-controlled seizures, indicating that infrequent seizures or even seizure freedom does not guarantee that older adults with epilepsy will necessarily be feeling well or more well than older adults whose seizures are not as well-controlled. Similar findings resulted in a study with younger adults with intractable epilepsy (Buelow & Johnson, 2000).

Physical and emotional status. Participants reported experiencing unpleasant physical and emotional symptoms related to their epilepsy and its treatments. These symptoms likely contribute to their experience of decreased wellness (discussed previously). Unger and Buelow (2009), in a study of younger adults newly diagnosed with epilepsy, found that those in their sample experienced physical and emotional symptoms, similar to those reported by older adults in this study. The physical symptoms experienced by both older and younger adults with epilepsy (fatigue, for example) may have more of an effect on older adults than on their younger counterparts. As discussed previously, older adults with epilepsy experience more dramatic changes in levels of

independence than has been reported in younger adults. Physical limitations experienced by older adults with epilepsy may be more severe than those experienced by younger adults due to older adults' age-related physical changes and co-morbidities; these more severe physical symptoms may contribute to older adults' lack of ability to continue living as independently as they did prior to being affected by the disorder.

Positive changes. Participants did experience some positive changes as a result of being diagnosed with epilepsy, including those related to relationships with family and friends (becoming coming closer to family and friends during times of dependence), perspective (finding comfort in being diagnosed with epilepsy as opposed to other diseases that participants perceived as more harmful), and spirituality (feeling closer to their God during the difficult times associated with epilepsy). Buelow (2001) found that younger adults with epilepsy sometimes found that having epilepsy brought about positive changes in their self-image.

Implications and recommendations. It is clear that epilepsy has an overwhelmingly negative effect on the lives of older adults diagnosed with this condition. This is an important finding in light of participants' perceptions that their neurologists downplayed the seriousness of the disorder and did not convey that the disease of epilepsy could be so life-changing. Epilepsy self-management interventions designed for this population (discussed later in this chapter) must include strategies aimed at diminishing negatives changes experienced by older adults with epilepsy, while also maximizing their positive epilepsy-related experiences.

Research Question Four

In responding to research question four—what strategies do older adults utilize in self-managing epilepsy?—participants reported the use of disease/treatment-focused and life changes/problem-focused self-management strategies. That is, participants used strategies aimed not only at managing epilepsy symptoms and treatments but also the negative life changes and problems discussed regarding research questions two and three. These strategies were further categorized as proactive and reactive.

Disease/treatment-focused. All participants reported the use of strategies that were aimed at managing the disease of epilepsy (seizures and other symptoms, such as post-ictal fatigue and confusion) and its treatments (medication side effects, for example). While the use of these *types* of strategies was pervasive throughout the sample, the specific strategies used were diverse and depended on each individual older adult's context and circumstances. For example, one participant found that avoiding sleep deprivation was key in helping reduce the frequency of his seizures, while another participant reported that avoiding dehydration helped prevent seizures. Both of these participants took steps to avoid seizure triggers, but the strategies they used were very different given their specific contexts. Another example of the diversity in strategies used by the sample to attain a similar goal was seen in how they organized their medications. One participant reported that he had his wife organize all of his medications. Another older adult became friends with her pharmacist, who pre-packaged her medications (epilepsy and others) in such a way that all she had to do was open a pouch to take the correct pills each morning, afternoon, and so on. And another participant simply placed all of his morning medications in a bottle labeled "morning," and all of his evening

medications in a bottle labeled "night time." While all of these participants were taking measures to organize their medications, the ways in which they went about it were very different.

Life changes/problem-focused. All participants also reported the use of strategies aimed at managing the life changes and problems they experienced since being diagnosed with epilepsy. As was seen with seizure- and treatment-related strategies used by participants, differing strategies were used by participants to manage these issues. One participant managed medication side effects by self-titrating her seizure medication, while another participant achieved the same goal by scheduling and taking a three-hour nap every afternoon. The goal of both of these participants was to attenuate the side effect of fatigue caused by their seizure medications, but each behaved very differently to arrive at that goal.

Proactive versus reactive. The previously described management strategies could be further categorized consistent with Buelow's (2001) proactive versus reactive taxonomy. Both proactive (planned, systematic, and flexible) and reactive (unplanned and unpredictable) strategies were used by the majority of the sample in this study, while four participants used only reactive strategies. Participants consistently reported having unpleasant experiences when using reactive strategies, and much more pleasant and successful experiences when using proactive strategies. Participants who used only reactive strategies reported more and more significant epilepsy-associated problems and life changes than those who utilized some proactive strategies. Buelow (2001) had similar findings in her qualitative study involving younger adults with intractable epilepsy—those who used more reactive strategies actually demonstrated a lower quality

of life. All participants in Buelow's (2001) study suffered from intractable epilepsy, while the sample in the current study was comprised of those with varying degrees of seizure control. It is interesting that those in this study, regardless of seizure frequency, reported more desirable experiences when relying on proactive strategies.

In this study, participants reported that the prevalence of proactive strategies increased as they spent more time managing their disease. In addition, all four participants who did not report using proactive strategies had been recently diagnosed with epilepsy. Thus, it appears that there is a temporal component involved in the types of strategies (proactive versus reactive) used by older adults with epilepsy, with proactive strategies requiring more time and experience to develop.

Implications and recommendations. Important implications and recommendations for both practice and research can be made based on the findings related to research question four. First, these findings support the notion, which was alluded to in Chapter II, that there does not exist a homogenous list of self-management strategies which are "good" or "bad." Rather, older adults with epilepsy utilize a wide variety of unique strategies that are derived out of their particular contexts. There are commonalities, however, in what older adults hoped to achieve by using these various strategies—all were aimed at managing seizures/treatments or life changes/problems. Self-management interventions (discussed later in this chapter) must be developed with the context-bound nature of self-management in mind. Second, proactive strategies appear to be more effective than reactive strategies. However, more research is needed to quantify the relationship between type of strategy used (proactive versus reactive) and important outcomes. While Buelow's (2001) findings suggest that the use of proactive

strategies is associated with higher quality of life, these findings were rendered only from younger adults with intractable epilepsy. The relationship between types of epilepsy self-management strategies used and a variety of outcomes (quality of life and healthcare resource utilization, for example) needs to be quantitatively assessed in a larger sample of older adults with epilepsy. If findings from such a research study further support the notion that proactive strategies improve outcomes in this population, these findings could be used to inform the development of epilepsy self-management interventions that facilitate the development and use of proactive strategies. As will be discussed later, self-management interventions in older adults with epilepsy must focus on teaching problem-solving skills to those older adults, so that they may use those skills to devise and implement proactive management strategies.

Research Question Five

Participants in this study responding to research question five—what outcomes do older adults hope to achieve in self-managing their epilepsy?—shared the outcomes they hope to achieve in self-managing their epilepsy. These included wanting to be more involved in their care, maintaining normalcy, being well-equipped and, to a much lesser degree, achieving seizure freedom. Participants felt that their neurologists were not aware of their desires in terms of these outcomes.

Older adults also reported that their neurologists mostly are concerned with and usually only discuss seizure frequency and severity. As was described in Chapter II, seizure frequency and severity have been viewed, especially in medicine, as the prime outcomes of epilepsy management (Commission on Outcome Measurement in Epilepsy, 1998). However, findings from this study indicate, for older adults, that seizure freedom

is a desired outcome of management only when it allows a return to normal life. That is, participants in this sample were most interested in managing their epilepsy in such a way that would allow them to live normally, regardless of seizure frequency. This finding is congruent with the general chronic disease self-management literature review presented in Chapter II and Buelow's (2001) findings in a sample of younger adults with intractable epilepsy.

As was demonstrated in the literature review presented in Chapter II, those involved in epilepsy research have become aware of the need to improve the ways in which outcomes are defined and measured for those with epilepsy. The Managing Epilepsy Well Network (n.d.) has a taskforce devoted to this issue. Findings from the current study provided some initial insight into the outcomes important to older adults with epilepsy. Chiefly, older adults' desired epilepsy self-management outcomes appear to differ from those of their neurologists and are more related to maintaining a normal lifestyle in the context of having epilepsy. Seizure freedom is not a requisite for achieving this goal, as many participants reported they found seizures less disruptive to their lives than the amount of medication required to suppress them. Neurologists and nurses interacting with older adults with epilepsy must keep these outcomes in mind when devising ongoing treatment plans for older adults with epilepsy. In addition, because every person's version of a normal life is different, neurologists and nurses caring for older adults with epilepsy must be sure to ask what outcomes older adults are interested in achieving.

Current findings also can contribute to improving the measurement of outcomes important to older adults with epilepsy. As was discussed in Chapter II, an outcome of

epilepsy self-management most commonly measured in the nursing literature is that of quality of life. At present, there exist several quality-of-life measures specific for those with epilepsy, including the Impact of Epilepsy Scale (Jacoby, Baker, Smith, Dewey, & Chadwick, 1993), the Quality of Life Index—Epilepsy (Ferrans & Cohen, 1996), and the Quality of Life in Epilepsy—31 (Cramer et al., 1998).

A critique of each of these existing measures in light of this study's findings highlights the need for the development of an outcome assessment tool for this population. None of these three tools were developed based on research with older adults, and none were based on research regarding patients' desired outcomes. In addition, the Impact of Epilepsy Scale (Jacoby et al., 1993), though epilepsy-specific and sensitive to measuring perceived changes in the concepts it measures, lacks evidence of reliability and validity and a theoretical basis. Both the Quality of Life Index—Epilepsy (Ferrans & Cohen, 1996) and Quality of Life in Epilepsy—31 (Cramer et al., 1998) are useful tools in assessing quality of life in adults with epilepsy. Both have evidence of reliability and validity, a strong theoretical basis, and are epilepsy-specific. However, neither of these tools measure perceived *changes* in quality of life since being diagnosed with epilepsy. The goal in administering an outcome assessment tool to members of this population is to determine the effect that epilepsy has had on their outcomes. Tools that do not include this change component, thus, are less helpful in determining how epilepsy has affected the person's outcomes.

Instruments that measure changes in outcomes caused by chronic diseases do exist. Bakas, Champion, Perkins, Farran, and Williams (2006) designed and psychometrically tested the Bakas Caregiving Outcomes Scale, the purpose of which is to

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measure change in stroke caregivers' adaptational outcomes. This instrument has evidence of reliability and validity and has been used in a variety of caregiver populations (Bakas et al., 2006). Findings from the current study could inform the development of such an intervention for older adults with epilepsy by guiding the development of pertinent instrument items.

Finally, self-management interventions (discussed in the next section) that are devised for this population must be aimed at affecting outcomes other than seizure frequency and severity.

Other Findings

Other findings that were not related directly to the a priori research questions also emerged and are discussed here.

Epilepsy is different. Participants in this study expressed that epilepsy is, in several ways, a different type of disease. To the older adults in this sample, epilepsy remained a mysterious disease about which they felt much stigma. Very few of the participants felt comfortable describing what epilepsy is, and most of them knew no other people with epilepsy. The stigma and mystery associated with epilepsy has been well documented (Epilepsy Foundation, 2010), but the findings from the current study provide new information about the uniqueness of epilepsy, at least from the viewpoint of older adults. All of the older adults involved in this study had at least one other co-morbidity. Thus, they were familiar with other chronic diseases, including the diagnosis and treatment that accompany them. Many participants expressed how differently their diagnosis and treatment of epilepsy was handled by healthcare providers when compared to other chronic diseases from which they currently or had suffered.

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They often were surprised with the lack of information given to them about their epilepsy when compared to that of diseases such as hypertension and stroke.

Lack of resources and skills to seek out information. While the participants in this study had many questions concerning their epilepsy, they reported a lack of resources and skills to seek out that information. They reported being uncomfortable with using the Internet and overwhelmed with scientific literature they found in libraries. They often relied on younger family members to retrieve Internet-based information for them about their epilepsy but commonly found that they could not interpret it accurately.

Implications and recommendations. The stigma and mystery surrounding epilepsy are likely to continue as long as epilepsy is treated as a different kind of disease. Because epilepsy is seen as a specialized condition, neurologists and nurses may not feel comfortable discussing it at length with their patients. In order to assist older adults with epilepsy at the time of diagnosis and beyond, those involved in their care must have a thorough understanding of epilepsy, its treatments, and how this disease can affect the lives of these patients.

Those providing care to older adults with epilepsy, as well as those designing self-management interventions for this population, must be aware of the limitations in both access to and skills in using online resources reported by participants in this sample. The ways in which this finding may affect intervention development are discussed later in this chapter.

Overall Findings

Apart from the distinct themes that emerged as findings in the current study, overall characteristics of the major findings are worthy of discussion. In this section, the

system-embedded and process-like nature of epilepsy self-management in older adults is discussed. Next, ways in which the findings from the current study can influence intervention development are reviewed.

Systems. The literature review presented in Chapter II introduced and supported the notion that chronic disease self-management, including epilepsy self-management, is a system-embedded phenomenon. That is, any person self-managing a chronic condition does so within his or her own unique system. The results of this study lend further support to the system-bound nature of epilepsy self-management in older adults.

In the case of all participants in this study, there was evidence that their self-management was system-based. That is, participants did not report managing their epilepsy in complete isolation. Rather, even for those who lived alone and were extremely isolated socially, other people were involved in their epilepsy management. For example, one female participant lived alone, did not drive, and often was unable to afford her medications. She found that forming a relationship with a local pharmacy allowed her to get her medications when needed. "The main pharmacist just gave me a charge account there…and when I need them he brings them to me, even if it's just one at a time and I can't pay. They won't let me go without," she explained. Even participants who used no proactive strategies were practicing management within a system—they were surrounded by people (family and friends) who facilitated their reactive behavior. One female participant explained, "I think my husband is in denial…so I've kind of been too. That's just how we've handled it, even though it's not for the best." Participants spoke explicitly of devising their own systems, often with other people, to manage all aspects of their condition. Participant quotes included throughout Chapter IV provide

examples of participants managing epilepsy by creating systems for handling

transportation, medications, side effects, seizures, physical and emotional symptoms, and

other problems and life changes. As discussed previously, the range of self-management

strategies used by participants in this study is large, and, while pre-planned, proactive

strategies appear to yield better outcomes than unplanned, reactive ones, no list of best or

worst strategies can be extracted from the data. Appropriate self-management strategies

must, rather, be devised individually based on older adults' available systems and their

particular contexts.

Researchers conducting studies involving other chronic disease populations also

have uncovered the system-based nature of self-management. Moore (2009), in her

ongoing research with cardiac rehabilitation patients, has found that these persons'

self-management as it relates to weekly exercise is influenced greatly by the family, or

system as it is referred to by Moore, in which those persons live and exist. Accordingly,

Moore and her colleagues (2009), as part of a National Institutes of Health-funded study

(P30 NR010676), are in the process of devising and testing a self-management

intervention that involves the entire family, or system, in which persons in

post-myocardial infarction cardiac rehabilitation exist. Participants will design their own

self-management action plans with others in their family or system, and action plans are

devised with the needs and desires of the entire family or system in mind (Moore, 2009).

Moore (2009) reports that the preliminary findings of the ongoing study are promising in

terms of those participants undergoing the system-oriented self-management intervention

exercising more often and more consistently than those receiving the individual

intervention. Similar interventions (discussed later in this section) may be effective in improving outcomes in older adults with epilepsy.

Process. As explained in Chapter II, self-management is a process. Despite researchers often measuring self-management as an outcome, it is a process that leads to outcomes. Not surprisingly, epilepsy self-management in older adults emerged, in this study, as a process. All of the aspects of epilepsy self-management that were described in the findings appear to be highly interactive (see Figure 5). As was found in Unger and Buelow's (2009) concept analysis of epilepsy self-management in younger adults newly diagnosed with the condition, this process is not stagnant but fluctuates as often as daily depending on the older adult's circumstances. In the case of the older adults with epilepsy in this study, the personally important outcomes to which their self-management leads include being involved in the treatment of their epilepsy and maintaining normalcy. These outcomes can be attained with or without seizure freedom. This finding is significant, as the literature largely promotes seizure frequency and severity as the two main goals of epilepsy management (Buelow & Johnson, 2000). In order to ensure that older adults with epilepsy and their neurologists are working collaboratively in managing these older adults' epilepsy, it is imperative that the desired outcomes of *both* groups be made explicit.

Implications and recommendations. As will be discussed in more detail later in this section, interventions that are designed for older adults self-managing epilepsy must be uniquely tailored to each older adult's context. Secondly, Figure 5 depicting the self-management process of older adults with epilepsy needs to be tested to confirm the proposed relationships and to determine, more clearly, the impact of the process on

self-management outcomes. Such testing could be done qualitatively using a grounded theory method, quantitatively using a correlational design, or via mixed methods. Such a study would render a better developed model of epilepsy self-management in older adults, and this model could be used to guide the development of self-management interventions.

Intervention development. The findings from the current study can inform the development of a variety of interventions, some of which can be aimed at improving older adults' experiences with epilepsy diagnosis (previously discussed), and also those that can be aimed at improving their epilepsy self-management outcomes.

As was discussed in Chapter II, there is currently a paucity of effective epilepsy self-management interventions, and those that do exist have not been tailored to the needs of older adults. Findings from this study, and specifically those related to problems and negative life changes experienced by older adults with epilepsy, can be used to provide such tailoring to self-management interventions. These findings can guide researchers regarding the areas for which older adults with epilepsy should be assessed for problems. The interventions those older adults receive would be tailored based on their current or potential areas of difficulty.

In the chronic disease literature, there is evidence that self-efficacy theory-based interventions are most effective at improving outcomes, though they have not been shown to affect all outcomes, and their effects attenuate with time. Based on the findings from this study and those of Moore's (2009), a self-efficacy *and* systems-based epilepsy self-management intervention should be developed for older adults with epilepsy.

The literature review in Chapter II supports the notion that self-management is problem-based (Lorig & Holman, 2003), and the findings from this study indicate that proactive self-management strategies are more effective at rendering positive outcomes. The participants in this study who used proactive strategies were engaging in problem-solving when they planned and implemented proactive strategies. Problem-solving ability is a component of self-efficacy that is amenable to intervention (Lorig & Holman, 2003), and thus self-management interventions developed for this population must have a problem-solving component that will prepare them to engage in proactive self-management strategies, even in the early stages of their diagnosis. Such an intervention would not provide older adults with epilepsy with straight education or a list of strategies to use. Rather, the focus of the intervention should be on preparing these older adults to manage, via the use of proactive strategies, their epilepsy/treatments and problems/life changes they experience.

While problem-based interventions have been shown to affect self-management outcomes, and the findings of this study suggest that problem-solving ability is important in epilepsy self-management in older adults, prior self-management interventions (see Chapter II) based on self-efficacy theory have failed to affect outcomes over an extended period of time. Here, it is proposed that the addition of a systems component to a self-efficacy-based epilepsy self-management intervention would render that intervention more effective. Prior to the implementation of an epilepsy self-management intervention for an older adult with epilepsy, that person's specific context should be assessed so that the intervention can be tailored to his or her available systems (Moore, 2009). Problem-solving also should be taught in the context of the system that the older adult

with epilepsy will be using to self-manage his or her epilepsy. Given that many of these older adults utilize systems with spouses, other family members, or friends, the intervention may need to be implemented with these significant others as well. It is also possible that the intervener would need to assist the older adult with epilepsy in identifying his or her available systems. The goal of the intervention would be to improve the problem-solving ability of the older adult with epilepsy so that he or she can implement proactive management strategies, within a system unique to him or her, and achieve his or her personal self-management outcomes.

As mentioned previously, older adults in this study felt uncomfortable using the Internet and preferred to interact with another person when learning about their condition. The most recently developed epilepsy self-management intervention, WebEase, is only available online (DiIorio et al., 2009). While this intervention has demonstrated promising results in a small sample of those with epilepsy, it may not be applicable to older adults who lack the skills or equipment to use it. This is especially true for older adults living in rural areas.

All of the participants in this study, however, had telephones. Interventions delivered via telephone have been shown to be effective. Bakas and colleagues (2009) implemented a telephone-based intervention aimed at improving the outcomes of caregivers of stroke survivors. The eight-week intervention involved telephone calls from a nurse who assessed caregiver needs and provided an intervention tailored to those caregivers' specific needs. This intervention was effective—caregivers who received the intervention had better outcomes than those in the attention control group who received a brochure on caregiving and phone calls from nurses but no tailored intervention

(Bakas et al., 2009). A prime advantage of a telephone intervention is that it is low-cost and does not require participants to travel for the intervention, which would be a particular problem for older adults with epilepsy. In the case of older adults with epilepsy, because family members or friends are likely to be part of the system upon which the older adult will rely in self-managing his or her epilepsy, an initial home visit by the advanced practice nurse implementing the intervention may be necessary. The remainder of the intervention could be carried out via telephone.

Recommendations for Future Research

In this chapter, several recommendations for future research have been made. Researchers must now focus their efforts on conducting:

- A quantitative research study aimed at describing the current delay in diagnosis in a larger, more diverse sample of older adults with epilepsy;

- A needs assessment regarding primary care providers' knowledge of symptom presentation in older adults with epilepsy, as well as their perceptions of the impact of the disease on patients' lives;

- A quantitative research study aimed at describing the relationships between types of self-management strategies used (proactive versus reactive) and self-management outcomes in a larger, more diverse sample of older adults with epilepsy;

- A qualitative, quantitative, or mixed methods study testing of the conceptual framework presented in this study (see Figure 5);

- The development of an instrument designed to measure changes in self-management outcomes important to older adults with epilepsy; and

- Based on the research in the current study, intervention development and testing studies aimed at improving older adults' experiences being diagnosed with epilepsy and their epilepsy self-management outcomes.

Summary

In this chapter, the methods used in the study and the major findings have been discussed. Implications for practice have been identified and recommendations for future research have been made.

APPENDIX A

SUMMARY OF STATE OF THE SCIENCE OF CHRONIC DISEASE AND
EPILEPSY SELF-MANAGEMENT LITERATURES

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
How is self-management conceptually defined?	No single definition exists. Historically portrayed as a behavioral concept—what people do constitutes their self-management. Occurs in multiple domains. Not synonymous with compliance. More recently portrayed as a process that is context-dependent and often involves an entire family.	Portrayed as a behavioral concept that occurs in the domains of medications, seizures, safety, physical and emotional comfort, and functional status. Most recent definitions portray it as context-dependent. Portrayed as particularly complex.	Epilepsy researchers are just beginning to acknowledge the context-dependent nature of epilepsy self-management. Epilepsy self-management has not yet been conceptualized as including the entire family in which the person with epilepsy exists.

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
How is self-management operationally defined?	Medication and treatment compliance. Engagement in behaviors.	Medication and treatment compliance. Engagement in behaviors. Often measured via Epilepsy Self-Management Scale.	Because self-management is a process, it does not lend itself to direct measurement. Measuring self-management as compliance is at odds with the conceptual definition of self-management. Measuring self-management as engagement in behaviors does not recognize the fluid and context-bound nature of the concept and is too limiting. Researchers should strive to characterize self-management rather than directly measure it.

<div align="right">Table continues</div>

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
What are the outcomes of self-management?	Disease status and severity (progression of disease, number of exacerbations). Health status and quality of life. Healthcare resource utilization.	Seizure frequency and severity. Health status and quality of life. Healthcare resource utilization (rarely).	The disease status and severity outcomes are derived from the medical model, whereas health status and quality of life outcomes are congruent with the nursing model. Researchers must consider how developmental factors (age, for example) and length of time since diagnosis affect pertinent outcomes.

Table continues

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
What affects and influences self-management?	Contextual factors: age, gender, socioeconomic status, disease severity. Internal factors: knowledge and beliefs, self-efficacy, self-regulation. External factors: access to healthcare and social support	Contextual factors: Age, gender, and socioeconomic status assumed to influence epilepsy self-management as in general chronic disease, but not tested in epilepsy; some evidence that seizure severity influences self-management. Internal factors: knowledge, beliefs and self-efficacy. External factors: Social support has been shown to be related to self-management in one study.	In general chronic disease, the most evidence suggests that self-efficacy affects self-management, including self-management outcomes. The relationship between self-efficacy and epilepsy self-management has not been tested, though self-efficacy appears in most epilepsy self-management models.

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
How effective are self-management interventions?	True self-management interventions are superior to pure education. Theory-based self-management interventions are superior. In the arthritis and asthma populations, evidence suggests that self-management interventions affect outcomes, though these changes attenuate with time. Generic self-management interventions can improve outcomes, though these changes attenuate with time.	Too few high-quality studies testing epilepsy self-management interventions have been implemented to allow for conclusions to be drawn about the effect of such interventions. A new intervention, WebEase, has been shown to slightly affect outcomes in a small sample of those with epilepsy.	In general chronic disease, conclusions that can be made regarding the effectiveness of self-management-enhancing interventions are limited by the small number of high-quality studies that have been executed, measurement of outcomes only in the short-term, and use of varying measurements for outcomes. The literature regarding the effectiveness of epilepsy self-management interventions is so underdeveloped that ways in which epilepsy self-management outcomes can be improved via intervention cannot be described.

Literature Review Questions	General Chronic Disease Literature	Epilepsy Literature	Comments
What is known about self-management in older adults?	The presence of chronic disease negatively affects older adults' lives and results in increased numbers of subjective unhealthy days. Older adults utilize some self-management strategies more often than younger adults. Self-management interventions delivered to older adults with hypertension and diabetes have been shown to improve outcomes.	Older adults with epilepsy experience decrements in quality of life. No research has been conducted regarding the epilepsy self-management of older adults.	Unique characteristics of older adults have the potential to complicate their epilepsy self-management.

APPENDIX B

IRB APPROVAL OF STUDY

![Indiana University logo]

INDIANA UNIVERSITY
OFFICE OF RESEARCH ADMINISTRATION

To: JANICE M BUELOW NURSING
From: IU Human Subjects Office
Office of Research Administration – Indiana University
Date: April 08, 2011
RE: NOTICE OF EXPEDITED APPROVAL
Protocol Title: Epilepsy Self-Management in Older Adults: A Qualitative Study
Protocol #: 1102004788 |
Funding Agency/Sponsor: NATIONAL INSTITUTES OF HEALTH
IRB: IRB-01, IRB00000220
Expiration Date: April 07, 2012
The above-referenced protocol was reviewed by the Institutional Review Board (IRB-01). The protocol meets the requirements for expedited review pursuant to §46.110, Category (6) (7) . The protocol is approved for a period of April 08, 2011 through April 07, 2012. This approval does not replace any departmental or other approvals that may be required. If you submitted and/or are required to provide participants with an informed consent document, study information sheet, or other documentation, a copy
of the enclosed approved stamped document is enclosed and must be used.
As the principal investigator (or faculty sponsor in the case of a student protocol) of this study, you assume the following responsibilities:
1. **CONTINUING REVIEW:** Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval *before* the expiration date. If continued approval is not received by the expiration date, the study will automatically expire, requiring all research activities, including enrollment of new subjects, interaction and intervention with current participants, and analysis of identified
data to cease.
2. **AMENDMENTS:** Any proposed changes to the research study must be reported to the IRB prior to implementation. Only after approval has been granted by the IRB can these changes be implemented. An amendment form can be obtained at:
http://researchadmin.iu.edu/HumanSubjects/hs_forms.html.
3. **UNANTICIPATED PROBLEMS AND NONCOMPLIANCE:** Unanticipated problems and noncompliance must reported to the IRB according to the policy described in the Unanticipated Problems and Noncompliance SOP, which can be found at
http://researchadmin.iu.edu/HumanSubjects/hs_policies.html. NOTE: If the study

involves gene therapy and an event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).

4. **ADVERTISEMENTS:** Only IRB-approved advertisements may be used to recruit participants for the study. If you submitted an advertisement with your study submission, an approved stamped copy is provided with the approval. To request approval of an advertisement in the future, please submit an amendment, explaining the mode of communication and information to be contained in the advertisement.

5. **COMPLETION:** Prompt notification must be made to the IRB when the study is completed (i.e. there is no further subject enrollment, no further interaction or intervention with current participants, including follow-up, and no .further analysis of identified data). To notify the IRB of study closure, please obtain a close-out form at http://researchadmin.iu.edu/HumanSubjects/hs_forms.html.

6. **LEAVING THE INSTITUTION:** The IRB must be notified of the disposition of the study when the principal investigator (or faculty sponsor in the case of a student project) leaves the institution.

7. **VULNERABLE POPULATION:** Please note that there are special requirements for the inclusion of prisoners in research. You may not enroll or otherwise include an individual who is or becomes a prisoner while enrolled in the research. For additional information on the requirements for including prisoners in research, please refer to http://researchadmin.iu.edu/HumanSubjects/hs_policies.html.

APPENDIX C

ADVERTISEMENT USED IN PILOT STUDY

Study # 1102004788

Are you age <u>60 or older</u>? Have you been diagnosed with <u>epilepsy (seizures)</u>? If so, you may be eligible to take part in an
<u>Epilepsy Self-Management Study</u>

Researchers at the Indiana University School of Nursing will be conducting a study beginning in spring 2011 exploring the self-management experiences of older adults diagnosed with epilepsy (seizures).

<u>What is the study about?</u>
Managing epilepsy can be a complex and difficult process.
The purpose of this study is to find out how older adults who have been diagnosed with epilepsy manage this disease on a daily basis. We hope to gain information that will allow us to help older adults with any problems they face in managing this disease.

<u>What does the study involve?</u>
About an hour of your time
Answering questions about your experiences with having and self-managing epilepsy as an older adult
You will receive a $20 Wal-Mart gift card as a token of appreciation for your time

<u>How do I participate?</u>
If you would like to be contacted by a researcher for more information about taking part in the study, **please call Wendy Miller at 812-797-4646.**

**Please contact Wendy Miller, MSN, RN, CCRN, PhD Student at
<u>(812) 797-4646</u> with any questions.
Principal Investigator: Janice Buelow, PhD, RN
Indiana University School of Nursing (IUPUI campus)
1111 Middle Drive
Indianapolis, IN 46202**

RECRUITMENT LETTER

A Research Study: Epilepsy Self-Management in Older Adults
Conducted by Janice Buelow, PhD, RN and Wendy R. Miller, MSN, RN, CCRN
Indiana University School of Nursing

Dear Patient,

Managing your epilepsy can be a difficult and complex process. As your neurologist, I am writing to tell you about a study for older adults with epilepsy.

The purpose of this study is to learn more about how older adults diagnosed with epilepsy late in life manage their disease on a daily basis and how having epilepsy affects their lives. The study involves a one-time, face-to-face interview with co-investigator Wendy Miller. You will be asked a series of questions about how you manage your epilepsy. As well, if you have a family member who assists you in managing your epilepsy, you may invite him or her to participate in a separate interview.

What does the study involve?
About an hour of your time
Answering questions about your experiences with having and self-managing epilepsy as an older adult

You will receive a $20 Wal-Mart gift card as a token of appreciation for your time

In the next few weeks, a nurse from Indiana University will call you to see if you are interested and eligible to take part in the study. **If you know you do not want to take part in the study, call Wendy Miller at 812-797-4646 and let her know and she will not contact you again.**

Taking part in this study is completely up to you. Your care will not be affected at all by your decision.

Sincerely,

INFORMED CONSENT

INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR

Epilepsy Self-Management in Older Adults: A Qualitative Study

You are invited to participate in a research study of self-management in epilepsy. You were selected as a possible subject because you are an adult aged 60 years or older who has been diagnosed with epilepsy. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Janice Buelow, PhD, RN and Wendy Miller, MSN, RN, CCRN of Indiana University School of Nursing.

STUDY PURPOSE:

The purpose of this study is to find out how older adults with epilepsy manage this disease on a daily basis. We are interested in what kinds of experiences older adults with epilepsy have while managing their disease and how epilepsy affects their lives. Because older adults often have a family member or friend who helps them manage their disease, we are also interested in what kinds of experiences those family members or friends have in helping older adults manage their epilepsy.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 20 older adults who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

You will receive a phone call from or meet with an investigator (Wendy Miller) to arrange an interview. You will meet with the investigator for one audio-recorded interview that will last about 45 minutes. Before the interview begins, you will complete the Mini-Mental Status Exam. This exam involves answering simple questions and following simple commands. Those older adults who have a family member or friend ("significant other") taking part in the study will also complete the Dyadic Relationship Scale. Completing this scale involves answering questions about your relationship with your family member or friend ("significant other") who assists you with self-management of your epilepsy. These take about five minutes each to complete. During the interview, you will be asked questions about how you manage your epilepsy and how epilepsy has changed your life. Interviews will take place in a private location of your choice. All interviews will take place over approximately 5 months, and your interview will take place when it is most convenient for you following your agreement to be part of the

study. Once your interview has been completed, your participation in the study is complete.

RISKS OF TAKING PART IN THE STUDY:

While on the study, the risks are:

-Feeling uncomfortable answering the interview questions.
-Possible loss of confidentiality. The risk of loss of confidentiality is slight.
-Feeling uncomfortable being audio-recorded.

In order to prevent these above risks from happening, several steps will be taken. If at any time you feel uncomfortable answering a question on the questionnaire(s) or during the interview, you may tell the investigator that you feel uncomfortable with the question and do not care to answer it. Also, you can choose to stop the interview at any time or take a break from the interview if you begin to feel uncomfortable. Regarding the protection of your confidentiality, the following measures will be taken to make sure your confidentiality is protected: only two investigators (Wendy Miller and Janice Buelow) will have access to the audio-recorded interviews, audio recorded interviews will be destroyed as soon as the recordings are transcribed, transcriptions of interviews will not contain your name, all information we receive from you will be kept in a locked cabinet in a private location accessible only to investigators Wendy Miller and Janice Buelow, any private information that is stored on a computer will be stored on a single computer accessible only to these investigators and will be protected by a password, and the study results that are shared or published will be presented without your name or any other information that might make it possible for someone to identify you.

BENEFITS OF TAKING PART IN THE STUDY:

The benefits to participation that are reasonable to expect are that the knowledge gained from your participation will help the investigators gain a better understanding about how epilepsy affects the lives of older adults, how older adults manage epilepsy, and the specific problems faced by older adults managing epilepsy. Learning about how older adults self-manage epilepsy and the problems they face when doing so will allow investigators to create tools and programs to help other older adults managing epilepsy. Participating in the study will provide no direct, immediate benefits to you.

ALTERNATIVES TO TAKING PART IN THE STUDY:

Instead of being in the study, you have these options: Not taking part in the study.

CONFIDENTIALITY:

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and in computer databases in which the results are stored.

Only two investigators will have access to the audio-taped interviews. The tapes will not be used for educational purposes, and will be destroyed once the interview is completely transcribed by the researcher—most likely within 1 month of the interview.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IU Institutional Review Board or its designees, the Bloomington Hospital Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP) may need to access your medical and/or research records.

COSTS:

There are no costs associated with participation in this study.

PAYMENT:

You will receive a $20 Wal-Mart gift card as a token of appreciation for your time.

CONTACTS FOR QUESTIONS OR PROBLEMS:

For questions about the study or a research-related injury, contact the researcher Janice Buelow at 317-274-9639 or 1-800-506-7796. After business hours, please call 317-274-9639 or 1-800-506-7796.

In the event of an emergency, you may contact Janice Buelow at 317-274-9639 or 1-800-506-7796.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects office at 812-856-4242 or 800-696-2949 or by email @ irb01@iupui.edu

You may also call the Bloomington Hospital Institutional Review Board at 812-353-2847.

VOLUNTARY NATURE OF STUDY:

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with your neurologist or other health care providers. Your participation may be terminated by the investigator without regard to your consent in the following circumstances: If it is determined that you do not represent the population of interest in the study. For example, if you do not meet the inclusion criterion of being age 60 years or older.

SUBJECT'S CONSENT:

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject's Printed Name: _____

Subject's Signature: _____ **Date**:_____
(must be dated by the subject)

Printed Name of Person Obtaining Consent:_____

Signature of Person Obtaining Consent: _____ **Date**:_____

MINI MENTAL STATUS EXAM

Attention

A) Ask the individual to begin with 100 and count backwards by 7. Stop after 5 subtractions. Score the correct subtractions.

93	☐	☐
86	☐	☐
79	☐	☐
72	☐	☐
65	☐	☐
		Total:_____

B) Ask the individual to spell the word "WORLD" backwards. The score is the number of letters in correct position.

D	☐	☐
L	☐	☐
R	☐	☐
O	☐	☐
W	☐	☐
		Total:_____

Delayed Verbal Recall

Ask the individual to recall the 3 words you previously asked him/her to remember.

Ball	☐	☐
Flag	☐	☐
Tree	☐	☐
		Total: _____

Naming
Show the individual a wristwatch and ask him/her what it is. Repeat for pencil.

Watch	☐	☐
Pencil	☐	☐

Repetition

Ask the individual to repeat the following:

"No if, ands, or buts"	☐	☐

3-Stage Command
Give the individual a plain piece of paper and say, "Take the paper in your hand, fold it in half, and put it on the floor."

Takes	☐	☐
Folds	☐	☐
Puts	☐	☐

Reading

Hold up the card reading: "Close your eyes" so the individual can see it clearly.
Ask him/her to read it and do what it says. Score correctly only if the individual actually closes his/her eyes.   ☐   ☐

Writing

Give the individual a piece of paper and ask him/her to write a sentence. It is to be written spontaneously. It must contain a subject and verb and be sensible.
☐   ☐

Copying

Give the individual a piece of paper and ask him/her to copy a design of two intersecting shapes. One point is awarded for correctly copying the shapes. All angles on both figures must be present, and the figures must have one overlapping angle.

        ☐   ☐

Total Score:_____

DEMOGRAPHIC DATA COLLECTION FORM

OLDER ADULTS
Study ID Number:_____
Age:_____
Gender:_____
Type of epilepsy:_____
Cause of epilepsy:_____
Number of seizures per month:_____
Work Status: Unemployed   Employed Full-Time   Employed Part-Time   Retired
Living Situation: Alone With Another Person   Alone but Visited Regularly
Assistive Significant Other?   Yes   No
Length of time person has known assistive significant other:_____
Nature of relationship with significant other:_____
Level of education (number of years):_____
Other co-morbidities:_____
Number of medications taken (including AEDs):_____
Length of time since epilepsy diagnosis:_____
Household income: less than $20,000 $21,000–$40,000 $41,000–$60,000
        $61,000–$100,000   greater than $100,000

REFERENCES

Alderson, M., Starr, L., Gow, S., & Moreland, J. (1999). The program for rheumatic independent self-management: A pilot evaluation. *Clinical Rheumatology, 18*(4), 283–292.

Anderson, R., Freedland, K., Clouse, R., & Lustman, P. (2001). The prevalence of comorbid depression in adults with diabetes: A meta-analysis. *Diabetes Care, 24*(6), 1069–1078.

Armbrister, K. (2008). Self-management: Improving heart failure outcomes. *The Nurse Practitioner: The American Journal of Primary Health Care, 33*(11), 20–28.

Ayres, L., Kavanaugh, K., & Knafl, K. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research, 13*(6), 871–883.

Bailey, J. M. (2009). The top 10 rural issues for health care reform. *Center for Rural Affairs, 2*(1), 1–8.

Bakas, T., Austin, J. K., Okonkwo, K. F., Lewis, R. R., & Chadwick, L. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first six months after discharge. *Journal of Neuroscience Nursing, 34*(5), 242–251.

Bakas, T., Champion, V., Perkins, S., Farran, C., & Williams, L. (2006). Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. *Nursing Research, 55*(5), 346–355.

Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009). Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK). *Topics in Stroke Rehabilitation, 16*(2), 105–121.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*.

    Englewood Cliffs, NJ: Prentice Hall.

Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY:

    W. H. Freeman.

Barlow, J., Sturt, J., & Hearnshaw, H. (2002). Self-management interventions for people

    with chronic conditions in primary care: Examples from arthritis, asthma and

    diabetes. *Health Education Journal, 61*(4), 365–378.

Barlow, J., Turner, A., Swabyl, L., Gilchristl, M., Wright, C., & Doherty, M. (2008). An

    8-yr follow-up of Arthritis Self-Management Programme participants.

    Rheumatology, 48(2), 128–133.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002).

    Self-management approaches for people with chronic conditions: A review. *Patient*

    Education and Counseling, 48(2), 177–187.

Begley, C. E., Shegog, R., Iyagba, B., Chen, V., Dubinsky, S., Newmark, M., . . .

    Friedman, D. (2010). Socioeconomic status and self-management in epilepsy:

    Comparison of diverse clinical populations in Houston, TX. *Epilepsy & Behavior,*

    19(3), 232–238.

Berg, J., Dunbar-Jacob, J., & Sereika, S. (1997). An evaluation of a self-management

    program for adults with asthma. *Clinical Nursing Research, 6*(2), 225.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient

    self-management of chronic disease in primary care. *Journal of the American*

    Medical Association, *288*(19), 2469–2475.

Boss, G., & Seegmiller, J. (1981). Age-related physiological changes and their clinical
significance. *Western Journal of Medicine, 135*(6), 434–440.

Boult, C., Altmann, M., & Gilbertson, D. (1996). Decreasing disability in the 21st
century: The future effects of controlling six chronic conditions. *American Journal
of Public Health, 86*(10), 1388–1393.

Bourbeau, J., & van der Palen, J. (2009). Promoting effective self-management
programmes to improve COPD [Editorial]. *European Respiratory Journal, 33*(3),
461–463.

Brodie, M. J., & Kwan, P. (2005). Epilepsy in elderly people. *British Medical Journal*,
331(7528), 1317–1322.

Brody, B., Williams, R., Thomas, R., Kaplan, R., Chu, M., & Brown, S. (1999).
Age-related macular degeneration: A randomized clinical trial of a
self-management intervention. *Annals of Behavioral Medicine, 21*(4), 322–329.

Buelow, J., & Shore, C. (2006). Childhood epilepsy: Failures along the path to diagnosis
and treatment. *Epilepsy & Behavior, 9*(3), 440–447.

Buelow, J., & Smith, M. (2004). Medication management by the person with epilepsy:
Perception versus reality. *Epilepsy & Behavior, 5*(3), 401–406.

Buelow, J. M. (2001). Epilepsy management issues and techniques. *Journal of
Neuroscience Nursing, 33*(5), 260–269.

Buelow, J. M., & Johnson, J. (2000). Self-management of epilepsy: A review of the
concept and its outcomes. *Disease Management & Health Outcomes, 8*(6),
327–336.

Buelow, J. M., McNelis, A., Shore, C. P., & Austin, J. K. (2006). Stressors of parents of children with epilepsy and intellectual disability. *Journal of Neuroscience Nursing, 38*(3), 147–154.

Buetow, S., Goodyear-Smith, F., & Coster, G. (2001). Coping strategies in the self-management of chronic heart failure. *Family Practice, 18*(2), 117–122.

Buszewicz, M., Rait, G., Griffin, M., Nazareth, I., Patel, A., Atkinson, A., . . . Haines, A. (2006). Self management of arthritis in primary care: Randomised controlled trial. *British Medical Journal, 333*(7574), 879.

Callahan, C., Unverzagt, F., Hui, S., Perkins, A., & Hendrie, H. (2002). Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Medical Care, 40*(9), 771–781.

Caplin, D., & Creer, T. (2001). A self-management program for adults with asthma: Maintenance and relapse of skills. *Journal of Asthma, 38*(4), 343–356.

Center for Managing Chronic Disease. (2010). *Key informants' perspectives on managing epilepsy.* Ann Arbor, MI: Author.

Center for the Advancement of Health. (2002). *Essential elements of self-management interventions*. Washington, DC: Author.

Centers for Disease Control and Prevention. (2000). Health-related quality of life among adults with arthritis. *Morbidity and Mortality Weekly Report, 49*(17), 366–269.

Centers for Disease Control and Prevention. (2001). *Key findings in chronic disease*. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2009). *Chronic disease incidence, prevalence, and costs*. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2010a). *Improving and extending quality of life in older Americans*. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2010b). *Framework for epilepsy prevention and control*. Retrieved from http://www.cdc.gov

Centers for Disease Control and Prevention. (2010c). *Intervention programs*. Retrieved from http://www.cdc.gov

Charron-Prochownik, D., Zgibor, J., & Peyrot, M. (2007). The diabetes self-management assessment report tool (D-SMART): Process evaluation and patient satisfaction. *Diabetes Education, 33*(5), 833–835.

Chodosh, J., Morton, S. C., Mjoica, W., Maglione, M., Suttorp, M., Hilton, L., . . . Shekelle, P. (2005). Meta-analysis: Chronic disease self-management programs for older adults. *Annals of Internal Medicine, 143*(6), 427–438.

Clark, N. (2003). Management of chronic disease by patients. *Annual Review of Public Health, 24*(1), 289–313. doi: 10.1146/annurev.publhealth.24.100901.141021

Clark, N., Gong, M., & Kaciroti, N. (2001). A model of self-regulation for control of chronic disease. *Health Education and Behavior, 28*(6), 769–782.

Clark, N. M., Janz, N. K., Dodge, J. A., Schork, M. A., Wheeler, J., Liang, J., . . . Santinga, J. (1997). Self-management of heart disease by older adults: Assessment of an intervention based on social cognitive theory. *Research on Aging, 19*(3), 362–382.

Clark, N. M., Stoll, S., Sweetman, M., Youatt, E. J., Derry, R., & Gorelick, A. (2010). Fostering epilepsy self-management: The perspectives of professionals. *Epilepsy and Behavior, 19*(3), 225–231.

Collins, N. S., Shapiro, R. A., & Ramsay, R. E. (2006). Elders with epilepsy. *The Medical Clinics of North America, 90*(5), 945–966.

Commission on Outcome Measurement in Epilepsy. (1998). Commission on Outcome Measurement in Epilepsy, 1994–1997: Final report. *Epilepsia, 39*(2), 213–231.

Corbin, J., & Strauss, A. (1988). *Unending work and care: Managing chronic illness at home*. San Francisco, CA: Jossey-Bass.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). London, UK: Sage.

Coster, S., & Norman, I. (2009). Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. *International Journal of Nursing Studies, 46*(4), 508–528.

Cramer, J. A., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meador, K., & Hermann, B. (1998). Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia, 39*(1), 81–88.

Crystal, S., Johnson, R. W., & Harman, J. (2000). Out of pocket health care costs among older Americans. *Journal of Gerontology, 55*(1), 51–62.

Diaz, H., & Herring, P. (2006). Type 2 diabetes as a portal for older adult community and university collaboration: One county's experience. *Public Health Report, 121*(4), 479–482.

DiIorio, C. (1997). Epilepsy self-management. In D. Gochman (Ed.), *Handbook of health and behavioral research: Provider determinants* (pp. 213–230). New York, NY: Plenum.

DiIorio, C. (2009, December). *Theoretical aspects of self-management*. Poster presented at the American Epilepsy Society Annual Meeting, Boston, MA.

DiIorio, C., Escoffery, C., McCarty, F., Yeager, K., Henry, T., Koganti, A., . . . Wexler, B. (2009). Evaluation of WebEase: An epilepsy self-management Web site. *Health Education Research, 24*(2), 185–197.

DiIorio, C., Faherty, B., & Manteuffel, B. (1992). Self-efficacy and social support in self-management of epilepsy. *Western Journal of Nursing Research, 14*(3), 292–303.

DiIorio, C., Faherty, B., & Manteuffel, B. (1994). Epilepsy self-management: Partial replication and extension. *Research in Nursing & Health 17*(3), 167–174.

DiIorio, C., Hennessy, M., & Manteuffel, B. (1996). Epilepsy self-management: A test of a theoretical model. *Nursing Research, 45*(4), 211–217.

DiIorio, C., & Henry, M. (1995). Self-management in persons with epilepsy. *Journal of Neuroscience Nursing, 27*(6), 338–343.

DiIorio, C., Shafer, P., Letz, R., Henry, T., Schomer, D., & Yeager, K. (2004). Project EASE: A study to test a psychosocial model of epilepsy medication management. *Epilepsy & Behavior, 5*(6), 926–936.

Epilepsy Foundation. (2009). *Facts and statistics*. Retrieved from http://www.epilepsyfoundation.org

Epilepsy Foundation. (2010). *Epilepsy in the elderly*. Retrieved from http://www.epilepsyfoundation.org/

Faught, E. (1999). Epidemiology and drug treatment of epilepsy in elderly people. *Drugs and Aging, 15*(4), 255–269.

Faught, E., Duh, M. S., Weiner, J. R., Guerin, A., & Cunnington, M. C. (2008). Nonadherence to antiepileptic drugs and increased mortality: Findings from the RANSOM Study. *Neurology, 71*(120), 1572.

Feely, M. (1999). Drug treatment of epilepsy. *British Medical Journal, 318*(7176), 106.

Ferrans, C., & Cohen, F. (1996). Quality of life: Persons with epilepsy and the general population. *Epilepsia, 34*(6), 25.

Ferrans, C., & Powers, M. (1985). Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science, 8*(1), 15–24.

Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189–198.

Fuller, G. (2000). Falls in the elderly. *American Family Physician, 61*(7), 2159–2168.

Funnel, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes, 22*(3), 123–127.

Gallo, B. (2006). Epilepsy in the elderly. *Epilepsy Foundation, 68*(1), 83–86.

Galvin, J. E., Duda, J. E., Kaufer, D. I., & Lippa, C. F. (2010). Lewy Body dementia: Caregiver burden and unmet needs. *Alzheimer Disease and Associated Disorders, 24*(2), 177–181.

George, M., Campbell, J., & Rand, C. (2009). Self-management of acute asthma among low-income urban adults. *The Journal of Asthma, 46*(6), 618–624. doi: 10.1080/02770900903029788

Gibson, P. G., Coughlan, J., Wilson, A. J., Abramson, M., Bauman, A., Hensley, M., & Walters, E. (2002). Self-management education and regular practitioner review for adults with asthma. *Cochrane Database of Systematic Reviews, 2.* doi: 10.1002/14651858

Gilliam, F., Kuzniecky, R., Faught, E., Black, L., Carpenter, G., & Schrodt, R. (1997). Patient-validated content of epilepsy specific quality-of-life measurement. *Epilepsia, 38*(6), 233.

Gordon, C., & Galloway, T. (2008). *Review of findings on Chronic Disease Self-Management Program (CDSMP) outcomes: Physical, emotional & health-related quality of life, health care utilization and costs*. Retrieved from http://health.utah.gov/arthritis

Gotham, A. M., Brown, R. G., & Marsden, C. D. (1986). Depression in Parkinson's disease: A quantitative and qualitative analysis. *Journal of Neurology, Neurosurgery, and Psychiatry, 49*(4), 381–389.

Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self- and family management of chronic conditions. *Nursing Outlook, 54*(5), 278–286.

Healy, B. (1991). The Yentl Syndrome. *New England Journal of Medicine, 325*(4), 274–276.

Hesdorffer D. C., Logroscino G., Benn, E., Katri, N., Cascino, G., & Hauser, W. (2011). Estimating risk for developing epilepsy: A population-based study in Rochester, Minnesota. *Neurology, 76*(1), 23–27.

Holman, H., & Lorig, K. (2004). Patient self-management: A key to effectiveness and efficiency in care of chronic disease. *Public Health Reports, 119*(3), 239–243.

Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288.

Jaarsma, T., Stromberg, A., Martensson, J., & Dracup, K. (2003). Development and testing of the European Heart Failure Self-Care Behaviour Scale. *The European Journal of Heart Failure, 5*(3), 363–370.

Jacoby, A. (1992). Epilepsy and the quality of everyday life: Findings from a study of people with well-controlled epilepsy. *Social Science and Medicine, 34*(6), 657–666.

Jacoby, A., Baker, G., Smith, D., Dewey, M., & Chadwick, D. (1993). Measuring the impact of epilepsy: The development of a novel scale. *Epilepsy Research, 16*(1), 83–88.

Janson, S. L., McGrath, K., Covington, J. K., Cheng, S., & Boushey, H. A. (2009). Individualized asthma self-management improves medication adherence and markers of asthma control. *Journal of Allergy and Clinical Immunology, 123*(4), 840–846.

Janz, N., Clark, N., Dodge, J. A., Schork, M., Mosca, L., & Fingerlin, T. (1999). The impact of a disease-management program on the symptom experience of older women with heart disease. *Women's Health, 30*(2), 1–24.

Joyce, G. F., Emmett, B., Keeler, B. S., & Goldman, D. P. (2005). The lifetime burden of chronic disease among the elderly [2005 Web-Exclusive Supplement 2]. *Health Affairs, 10*(24). doi: 10.1377/hlthaff.W5.R18

Karceski, S. C. (2005). Advances in managing epilepsy. *Patient Care, 39*(2), 29–36.

Katz, P., Yelin, E., Eisner, M., & Blanc, P. (2002). Perceived control of asthma and quality of life among adults with asthma. *Annals of Allergy, Asthma and Immunology, 89*(3), 251–258.

Kobau, R., & DiIorio, C. (2003). Epilepsy self-management: A comparison of self-efficacy and outcome expectancy for medication adherence and lifestyle behaviors among people with epilepsy. *Epilepsy & Behavior, 4*(3), 217–225.

Kovar, P., Allegrante, J., MacKenzie, C., Peterson, M., Gutin, B., & Charlson, M. (1992). Supervised fitness walking in patients with osteoarthritis of the knee: A randomized, controlled trial. *Annals of Internal Medicine, 116*(7), 529–534.

Krauss, G., & Crone, N. (2001). Side-effects of anti-epileptic drugs. *Epilepsia*, *22*(2), 13.

Kruger, J., Helmick, C. G., Callahan, L., & Haddix, A. (1998). Cost-effectiveness of the arthritis self-help course. *Archives of Internal Medicine, 158*(11), 1245–1249.

Krumholz, A. (2009). Driving issues in epilepsy: Past, present, and future. *Epilepsy Currents, 9*(2), 31–34.

Krumholz, A., Fisher, R. S., Lesser, R. P., & Hauser, W. A. (1991). Driving and epilepsy: A review and reappraisal. *Journal of the American Medical Association, 265*(5), 622–626.

Laccheo, I., Ablah, E., Heinrichs, R., Sadler, T., Baade, L., & Liow, K. (2008). Assessment of quality of life among the elderly with epilepsy. *Epilepsy and Behavior, 12*(2), 257.

Lawlor, D. A., Patel, R., & Ebrahim, S. (2003). Association between falls in elderly

    women and chronic diseases and drug use: Cross-sectional study. *British Medical*

    Journal, 327(7417), 712–717.

Leppik, I. (1988). Compliance during treatment of epilepsy. *Epilepsia*, *29*(2), S79–S84.

Leppik, I. (2001). Treatment of epilepsy in the elderly. *Epilepsy Currents, 1*(2), 46–47.

Leppik, I., Kelly, K., DeLorenzo, R., Mathern, G., White, H., Patrylo, P., &

    DeToledo-Morrell, L. (2006). Basic research in epilepsy and aging. *Epilepsy*

    Research, 68(S1), S21–S37.

Lewis, L. (2007). Round-table: Promoting self-management of diabetes. *American*

    Journal of Nursing, 107(6), 65–69.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Locharernkul, C. Suwaroporn, S., Krongthong, W., Limarun, C., & Arnamwong, A.

    (2010). A study of knowledge and attitude improvement on epilepsy among Thai

    physicians and nurses. *Journal of the Medical Association of Thailand, 93*(8),

    875–884.

Lorig, K. (2003). Self-management education: More than a nice extra. *Medical Care,*

    41(6), 699–701.

Lorig, K., Feigenbaum, P., Regan, C., Ung, E., & Holman, H. (1986). A comparison of

    lay-taught arthritis self-management courses. *Journal of Rheumatology, 13*(4),

    763–767.

Lorig, K., González, V., Laurent, D., Morgan, L., & Laris, B. (1998). Arthritis

    self-management program variations: 3 studies. *Arthritis Care Research, 11*(6),

    448–454.

Lorig, K., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1–7.

Lorig, K., Laurin, J., & Holman, H. (1984). Arthritis self-management: A study of the effectiveness of patient education for the elderly. *Gerontologist, 24*(5), 455–457.

Lorig, K., Lubeck, D., Kraines R. G., Seleznick, M., & Holman, H. R. (1985). Outcomes of self-help education for patients with arthritis. *Arthritis and Rheumatology, 28*(6), 680–685.

Lorig, K., Mazonson, P., & Holman, H. (1993). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis and Rheumatology, 36*(4), 439–446.

Lorig, K., Ritter, P., & González, V. (2003). Hispanic chronic disease self-management. A randomized community-based outcome trial. *Nursing Research, 52*(6), 361–369.

Lorig, K., Ritter, P., Laurent, D., & Fries, J. (2004). Long-term randomized controlled trials of tailored-print and small-group arthritis self-management interventions. *Medical Care, 43*(4), 346–354.

Lorig, K., Ritter, P., Stewart, A., Sobel, D., Brown, B., Bandura, A., . . . Holman, H. (2001). Chronic disease self-management program. 2-year health status and health care utilization outcomes. *Medical Care, 39*(11), 1217–1223.

Lowry, K. P., Dudley, T., Oddone, E. Z., & Bosworth, H. B. (2005). Intentional and unintentional nonadherence to antihypertensive medication. *The Annals of Pharmacotherapy, 39*(7), 1998–1203.

Lyon, B. (2005). Getting back on track: Nursing's autonomous scope of practice. *Clinical Nurse Specialist, 19*(1), 28–33.

Malow, B. (2004). Sleep deprivation and epilepsy. *Epilepsy Currents, 4*(5), 193–195.

Managing Epilepsy Well Network. (n.d.). MEW Network at a glance. Retrieved from http://www.sph.emory.edu/ManagingEpilepsyWell

Mancuso, C., Rincon, M., McCulloch, C., & Charlson, M. (2001). Self-efficacy, depressive symptoms, and patients' expectations predict outcomes in asthma. *Medical Care, 39*(12), 1326–1338.

Marks, R., Allegrante, J., & Lorig, K. (2005a). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing disability: Implications for health education practice (Part I). *Health Promotion Practice, 6*(37), 37–43.

Marks, R., Allegrante, J., & Lorig, K. (2005b). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing disability: Implications for health education practice (Part II). *Health Promotion Practice, 6*(148), 148–156.

Martin, M., Beebe, J., & Lopez, L. (2010). A qualitative exploration of asthma self-management beliefs and practices in Puerto Rican families. *Journal of Health Care for the Poor and Underserved, 21*(2), 464–474.

Martin, M., Catrambone, C., Kee, R., Evans, A., Sharp, L., Lyttle, C., . . . The Chicago

    Initiative to Raise Asthma Health Equity Investigative Team. (2009). Improving

    asthma self-efficacy: Developing and testing a pilot community-based asthma

    intervention for African American adults. *The Journal of Allergy and Clinical*

    Immunology, 123(1), 153–159.

Martin, R., Griffith, R., Faught, E., Gilliam, F., Mackey, M., & Vogtle, L. (2005).

    Cognitive functioning in community dwelling older adults with chronic partial

    epilepsy. *Epilepsia, 46*(2), 298–303.

Martin, R., Vogtle, L., Gilliam, F., & Faught, E. (2003). Health-related quality of life in

    senior adults with epilepsy: What we know from randomized clinical trials and

    suggestions for future research. *Epilepsy & Behavior, 6*(4), 626–634.

Martin, R., Vogtle, L., Gilliam, F., & Faught, E. (2005). What are the concerns of older

    adults living with epilepsy? *Epilepsy & Behavior, 7*(4), 297–300.

Mason, J. (2002). Qualitative interviewing: Asking, listening and interpreting. In T. May

    (Ed.), *Qualitative research in action* (pp. 225–241). London, England: Sage.

Maxwell, J. (1992). Understanding and validity in qualitative research. *Harvard*

    Educational Review, 62(3), 279–300.

Mazzuca, S., Moorman, N., Wheeler, M., Norton, J., Finebert, N., Vinicor, F., . . .

    Clark, C. (1986). The diabetes education study: A controlled trial of the effects of

    diabetes patient education. *Diabetes Care, 9*(1), 1–10.

McAuley, J., Elliott, J., Patankar, S., Hart, S., Long, L., Moore, J., & Shneker, B. (2010).

    Comparing patients' and practitioners' views on epilepsy concerns: A call to

    address memory concern. *Epilepsy & Behavior, 19*(4), 580–583.

McAuley, J., McFadden, L., Elliott, J., & Shneker, B. (2008). An evaluation of

    self-management behaviors and medication adherence in patients with epilepsy.

    Epilepsy and Behavior, 13(4), 637–641.

McGowan, P., & Green, L. (1995). Arthritis self-management in native populations of

    British Columbia: An application of health promotion and participatory research

    principles in chronic disease control. *Canadian Journal of Aging, 14*(Supp. 1),

    201–212.

McSweeney. J., O'Sullivan, P., Cleves, M., Lefler, L., Cody, M., Moser, D., . . .

    Zaho, W. (2010). Racial differences in women's prodromal and acute myocardial

    infarction symptoms. *American Journal of Critical Care, 19*(1), 63–73.

Miles, M., & Huberman, A. (1994). *Qualitative data analysis: A source book of new*

    methods. Beverly Hills, CA: Sage.

Miller, W. (2010). Qualitative research findings as evidence: Utility in nursing practice.

    Clinical Nurse Specialist, 24(4), 191–193.

Miller, W., & Buelow, J. (2010, December). *Epilepsy self-management in older adults: A*

    pilot study. Poster presented at the American Epilepsy Society Annual Meeting,

    San Antonio, TX.

Mitrushina, M., & Satz, P. (2006). Reliability and validity of the Mini-Mental State Exam

    in neurologically intact elderly. *Journal of Clinical Psychology, 47*(4), 537–543.

Miura, T., Kojima, R., Mizutani, M., Shiga, Y., Takatsu, F., & Suzuki, Y. (2001). Effect

    of digoxin non-compliance on hospitalization and mortality in patients with heart

    failure in long-term therapy: A prospective cohort study. *European Journal of*

    Clinical Pharmacology, 57(1), 77–83.

Moons, P., Budts, W., & DeGeest, S. (2006). Critique on the conceptualisation of quality of life: A review and evaluation of different conceptual approaches. *International Journal of Nursing Studies, 43*(7), 891–901.

Moore, S. (2009, December). *Self-management: A systems approach* [Discussion of research project NINR P30 NR010676]. Presentation at the Indiana University School of Nursing Center for Enhancing Quality of Life, Indianapolis, IN.

Morrow, A., Haidet, P., Skinner, J., & Naik, A. (2008). Integrating diabetes self-management with the health goals of older adults: A qualitative exploration. *Patient Education and Counseling, 72*(3), 418–423.

Moskowitz, J. M., Henneman, T. A., & Young-Holt, B. (2002). California 2000 HIV/AIDS knowledge, attitudes, beliefs and behaviors (KABB) survey: Methods and results [Pamphlet]. Berkeley, CA: University of California, Berkeley.

Naughton, C., Bennet, K., & Feely, F. (2006). Prevalence of chronic disease in the elderly based on a national pharmacy database. *Age and Ageing, 35*(6), 633–636.

Newman, M. (1986). *Health as expanding consciousness*. St. Louis, MO: Mosby.

Nightingale, F. (1859/1969). *Notes on nursing: What it is and what it is not*. New York, NY: Dover.

Osborne R., Wilson T., Lorig K., & McColl, G. (2007). Does self-management lead to sustainable health benefits in people with arthritis? A 2-year transition study of 452 Australians. *Journal of Rheumatology, 34*(5), 1–6.

Paradowski, B., & Zagrajek, M. (2005). Epilepsy in middle-aged and elderly people: A three-year observation. *Epileptic Disorders, 7*(2), 91–95.

Partnership for Solutions. (2002). *Chronic conditions: Making the case for ongoing care*. Baltimore, MD: The Johns Hopkins University.

Patton, M. (2001). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Perucca, E., Berlowitz, D., & Birnbaum, A. (2006). Pharmacological and clinical aspects of antiepileptic drug use in the elderly. *Epilepsy Research, 68*(1), 49–63.

Powell, L. H., Calvin, J. E., Richardson, D., Janssen, I., Mendes de Leon, C., Flynn, K. J., . . . Avery, E. for the HART Investigators. (2010). Self-management counseling in patients with heart failure: The heart failure adherence and retention randomized behavioral trial. *Journal of the American Medical Association, 304*(12), 1331–1338.

Ramsay, R., Rowan, A. J., & Pryor, F. (2004). Special considerations in treating the elderly patient with epilepsy. *Neurology, 62*(2), S24–S29.

Reimsma, R., Kirwan, J., Taal, E., & Rasker, J. J. (2002). Patient education for adults with rheumatoid arthritis. *Cochrane Database of Systematic Reviews, 2003*(2), doi: 10.1002/14651858.CD003688

Rodgers, B., & Cowles, K. (1993). The qualitative research audit trail: A complex collection of documentation. *Research in Nursing and Health, 16*(3), 219–226.

Rolfe, G. (2004). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing, 53*(3), 304–310.

Rowan, A. J., Ramsay, R., Collins, J., Pryor, F., Boardman, K., Uthman, B., . . . The VA

    Cooperative Study 428 Group. (2005). New onset geriatric epilepsy: A randomized

    study of gabapentin, lamotrigine, and carbamazepine. *Neurology, 4*(11),

    1868–1873.

Rowan, A. J., & Ramsay, R. E. (1997). *Epilepsy in the elderly*. New York, NY:

    Butterworth-Heinemann.

Ruggiero, R., Glasgow, R., & Dryfoos, J. (1997). Diabetes self-management:

    Self-reported recommendations and patterns in a large population. *Diabetes Care,*

    20(4), 568–576.

Ryan, P., & Sawin, K. (2009). The individual and family self-management theory:

    Background and perspectives on context, process, and outcomes. *Nursing Outlook,*

    57(4), 217–225.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative

    research revisited. *Advances in Nursing Science, 16*(2), 1–8.

Sandelowski, M. (1994). The use of quotes in qualitative research. *Research in Nursing*

    and Health, 17(6), 479–482.

Sandelowski, M. (1995a). Qualitative analysis: What it is and how to begin. *Research in*

    Nursing and Health, 18(4), 371–375.

Sandelowski, M. (1995b). Sample size in qualitative research. *Research in Nursing and*

    Health, 18(2), 179–183.

Sandelowski, M. (1996). One is the liveliest number: The case orientation of qualitative

    research. *Research in Nursing and Health, 19*(6), 525–529.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23*(3), 334–340.

Sandelowski, M. (2001). Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing and Health, 24*(3), 230–240.

Sandelowski, M. (2010a, June). *Qualitative research.* Workshop presented at the University of North Carolina Qualitative Analysis I Workshop. Chapel Hill, NC.

Sandelowski, M. (2010b). What's in a name? Qualitative description revisited. *Research in Nursing and Health, 33*(1), 77–84.

Sawicki, P. T. (1999). A structured teaching and self-management program for patients receiving oral anticoagulation: A randomized controlled trial. *Journal of the American Medical Association, 281*(2), 145–150.

Schneider, J., & Conrad, P. (1983). *Having epilepsy: The experience and control of illness*. Philadelphia, PA: Temple University Press.

Shaw, E., Stokes, T., Camosso-Stefinovic, J., Baker, R., Baker, G., & Jacoby, A. (2009). Self-management education for adults with epilepsy. *Cochrane Database of Systematic Reviews 2010*(10), doi: 10.1002/14651858.CD004723.pub3

Shegog, R., Bartholomew, L. K., Parcel, G. S., Sockrider, M. M., Masse, L., & Abramson, S. L. (2001). Impact of a computer-assisted education program on factors related to asthma self-management behavior. *Journal of the American Medical Informatics Association, 8*(1), 49–56.

Shope, J. T. (1996). Educating patients and families to manage a seizure disorder successfully. In N. Santilli (Ed.), *Managing Seizure Disorders* (pp. 123–134). Philadelphia, PA: Lippincott-Raven.

Shultz, J., Corbett, C., & Allen, C. (2009). Slavic women's understanding of diabetes dietary self-management and reported dietary behaviors. *Journal of Immigrant and Minority Health, 11*(5), 400–405.

Speer, E., Reddy, S., Lommel, T., Fischer, J., Heather, S., Park, S., & Johnson, M. (2008). Diabetes self-management behaviors and A1C improved following a community-based intervention in older adults in Georgia senior centers. *Journal of Nutrition for the Elderly, 27*(1–2), 179–200.

Spiera, H. (1987). Osteoarthritis as a misdiagnosis in elderly patients. *Geriatrics, 42*(11), 37–42.

Stanley-Hermanns, M., & Engebretson, J. (2010). Sailing the stormy seas: The illness experience of persons with Parkinson's disease. *The Qualitative Report, 15*(2), 340–369.

Sweeney, J., Rosano, C., Berman, R., & Luna, B. (2001). Inhibitory control of attention declines more than working memory during normal aging. *Neurobiology of Aging, 22*(1), 39–47.

Swendeman, D., Ingram, B., & Rotheram-Borus, M. J. (2009). Common elements in self-management of HIV and other chronic illnesses: An integrative framework. *AIDS Care, 21*(10), 1321–1334.

Taylor, J., Rea, H., McNaughton, S., Smith, L., Muldar, J., Asher, M., . . . Stewart, A. (1991). A tool for measuring the asthma self-competency of families. *Journal of Psychosomatic Research, 35*(4–5), 483–491.

Thomas, L. (1981). On the science and technology of medicine. In P. Lee, N. Brown, &

    I. Red (Eds.), *The nation's health* (pp. 485–492). San Francisco, CA: Boyd &

    Fraser.

Thornhill, K., Lyons, A., Nouwen, A., & Lip, G. (2008). Experiences of living with

    congestive heart failure: A qualitative study. *British Journal of Health Psychology,*

    13(1), 155–175.

Uitti, R. J. (2009). Parkinson's disease and issues related to driving. *Parkinsonism*

    Related Disorders, 15(S3), S122–S125.

Unger, W., & Buelow, J. (2009). Hybrid concept analysis of adults newly diagnosed with

    epilepsy. *Epilepsy & Behavior, 14*(1), 89–95.

United States Census Bureau. (2009). United States population statistics. Retrieved from

    http://www.census.gov

United States Department of Health and Human Services. (2003). National healthcare

    disparities report. Retrieved from http://archive.ahrq.gov

Unsworth, C. (1999). Living with epilepsy: Safety during home, leisure, and work

    activities. *Australian Occupational Therapy Journal, 46*(3), 89–98.

van Genugten, L., van Empelen, P., Flink, I., & Oenema, A. (2010). Systematic

    development of a self-regulation weight-management intervention for overweight

    adults. *BMC Public Health, 10*(1), 649.

Wagner, E., Austin, B., & von Korff, M. (1996). Organizing care for patients with

    chronic illness. *Milbank Quarterly, 74*(4), 511–544.

Waterhouse, E., & Towne, A. (2005). Seizures in the elderly: Nuances in presentation

    and treatment. *Cleveland Clinic Journal of Medicine, 72*(3), S26.

Webel, A., & Holzemer, W. (2009). Positive self-management program for women living with HIV: A descriptive analysis. *Journal of the Association of Nurses in AIDS Care, 20*(6), 458–467.

White, L. (2011, April). *Alzheimer's disease may be easily misdiagnosed*. Workshop presented at the American Academy of Neurology Meeting, Honolulu, HI.

Whitley, H. P., Fermo, J. D., Ragucci, K., & Chumney, E. C. (2006). Assessment of patient knowledge of diabetic goals, self-reported medication adherence, and goal attainment. *Pharmacy Practice, 4*(4), 183–190.

Yeager, K., DiIorio, C., Shafer, P., McCarty, F., Letz, R., Henry, T., & Schomer, D. (2005). The complexity of treatments for persons with epilepsy. *Epilepsy and Behavior, 7*(4), 679–686.

Yohannes, A. M., Roomi, J., Baldwin, R. C., & Connolly, M. J. (1998). Depression in elderly outpatients with disabling chronic obstructive pulmonary disease. *Journal of Clinical Nursing, 17*(5), 34–42.

Yusuff, K. B., Olubunmi, O., & Bonatson, Y. J. (2008). Adherence to anti-diabetic drug therapy and self-management practices among type-2 diabetics in Nigeria. *Pharmacy World & Science, 30*(6), 876–883.

CURRICULUM VITAE

Wendy Renee Miller

EDUCATION

Institution	Major	Degree Awarded	Date
Indiana University	Nursing	BSN	2003
Indiana University	Adult Health Clinical Nurse Specialist	MSN	2007
Indiana University	Clinical Nursing Science	PhD	2011

LICENSURE

License	Expiration Date
Registered Nurse	10/31/2013

CERTIFICATIONS

- Certified Critical Care Registered Nurse (CCRN)
- Advanced Cardiac Life Support (ACLS)

HONORS AND AWARDS

Award	Year
National Research Service Award (F31)—National Institutes of Health	2010–2013
American Epilepsy Society Nurse Researcher Award	2010
American Epilepsy Society Top 10% Abstract Award	2010
NIH T32 Pre-Doctoral Research Fellowship	2008–2010
Research Incentive Fellowship—Indiana University	2008–2010
Academic Achievement Award—Indiana University	2008, 2009, 2010, 2011
Region 8 Faculty Workforce Development Scholarship	2006
BSN Graduate with Highest Distinction	2003
Elizabeth Grossman Award for highest graduation GPA in nursing on all Indiana University campuses	2003

PROFESSIONAL SOCIETIES

American Association of Critical Care Nurses
American Epilepsy Society
American Psychiatric Nurses Association
Gerontological Association of America
Indiana State Nurses Association
Midwestern Nursing Research Society
National Association of Clinical Nurse Specialists (including local Indiana chapter)
Sigma Theta Tau

FUNDED GRANTS

National Institutes of Health National Research Service Award (1F31NR012114-01). 2010.
National Institutes of Health National Research Service Award (1F31NR012114-02). 2011.

PUBLICATIONS

Fulton, J., Otte, J., & Miller, W. (2011). *Concept analysis of quality of life: A meta-analysis.* Manuscript submitted for publication.

Miller, W., & Buelow, J. (2011). Psychometric Testing of Self-Efficacy for Partnership Scale: An example of instrument development. *Clinical Nurse Specialist, 25*(1), 11–14.

Buelow, J., Dean, P., Gilbert, K., Miller, W., and Pleuger, M. (2010). Epilepsy. In *American Association of Neuroscience Nursing Core Curriculum* (5th ed.).

Habermann, B., Miller, W., McLennon, S., Chen, H., Rafail, L., & Wojcieszek, J. (2010). Couples living with Parkinson's disease: Needs and concerns at advanced to end stage. *Movement Disorders, 25*(Supp. 3), S694.

Miller, W. (2010). Qualitative Research findings as evidence: Utility in nursing practice. *Clinical Nurse Specialist*, *24*(4), 191–193.

Unger*, W., & Buelow, J. (2009). Hybrid concept analysis of self-management in adults newly diagnosed with epilepsy. *Epilepsy & Behavior, 14*(1), 89–95.

Unger*, W. (2008, May). Findings from a hybrid concept analysis of patients newly-diagnosed with epilepsy [Abstract]. *Clinical Nurse Specialist, 22*(2), 107.

Unger*, W. (2008). Use of the clinical reasoning model for the development of interventions for mechanical tissue tension-induced pain [Abstract]. *National Association of Clinical Nurse Specialists Journal, 21*(2), 109.

*Maiden name

PRESENTATIONS

Miller, W. (2011, October). *Epilepsy self-management in older adults: A qualitative study*. Poster presented at the Sigma Theta Tau International Conference, Grapevine, TX.

Habermann, B., Chen, H., Miller, W., & McLennon, S. (2011, August). *Couples living with advanced Parkinson's disease (PD) or multiple sclerosis (MS): Needs, concerns and decision making at end of life*. Poster presented at the NINR Science of Compassion Conference, Bethesda, MD.

Miller, W. (2010, December). *Epilepsy self-management in older adults: A pilot study*. Poster presented at the American Epilepsy Society Annual Meeting, San Antonio, TX.

Miller, W. (2010, April). *Psychometric testing of a Self-Efficacy for Care Partnership Scale and a Family Care Needs Scale for parents of children with epilepsy and intellectual disabilities*. Poster presented at the Midwestern Research Nursing Society Annual Meeting, Kansas City, MO.

Unger*, W. (2008, May). *Findings from a hybrid concept analysis of patients newly-diagnosed with epilepsy*. Student abstract presented at the National Association of Clinical Nurse Specialists Annual Meeting, Atlanta, GA.

Unger*, W. (2007, May). *Use of the clinical reasoning model for the development of interventions for mechanical tissue tension-induced pain*. Poster presented at the National Association of Clinical Nurse Specialists Annual Meeting, Phoenix, AZ.

*Maiden name

SPEAKING ENGAGEMENTS

Year	Organization	Engagement
2011	Indiana University Health System	Delivered presentation at the Iowa Advanced Practice Institute regarding appraisal of the evidence.
2010	Indiana University Bloomington	Delivered critical care content to undergraduate nursing students in a Health Alterations course.

| 2010 | Indiana University–Purdue University Indianapolis | Served as a content expert for the concept of self-management and delivered lecture to Master's nursing students in a Scientific Basis for Nursing Practice course. |

EMPLOYMENT

Year(s)	Institution	Job Description
2006–Present	Indiana University School of Nursing	Adjunct faculty, with the following teaching assignments: • H361 (didactic) • H362 (clinical) • S470 (didactic) • S471 (clinical) • H354 (clinical) • H365 (didactic)
2004–2007	Bloomington Hospital Bloomington, IN	Staff/Charge Nurse/Primary Preceptor in the following units: • Cardiovascular ICU • Medical-Surgical ICU • Cath Lab recovery
2003–2004	Methodist Hospital Indianapolis, IN	Staff Nurse in a level one neurological trauma center

SERVICE

Year(s)	Organization	Activities
2010–Present	Neuroscience Nursing Foundation	Grant Reviewer
2010–Present	Clinical Nurse Specialist—*The Journal of Advanced Nursing Practice*	Manuscript Reviewer
2010–Present	*Journal of Neuroscience Nursing*	Manuscript Reviewer
2008–Present	American Epilepsy Society	Committee Member/Abstract Reviewer