The Pennsylvania State University
The Graduate School
School of Nursing

LIFE PATTERNS OF FAMILY CAREGIVERS OF PATIENTS WITH
AMYOTROPHIC LATERAL SCLEROSIS

A Dissertation in
Nursing
by
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Submitted in Partial Fulfillment
of the Requirements
for the Degree of

Doctor of Philosophy
August 2012
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ABSTRACT

**Background:** Amyotrophic lateral sclerosis (ALS) is a progressive, degenerative motor neuron disease that is associated with the loss of upper and lower motor neurons. ALS is a terminal disease that represents an expected death trajectory that impacts greatly on patients as well as the family caregivers who provide the majority of their care. While providing this critically important care, family caregivers face significant threats to their own health, including psychological, physical, and financial distress. Despite the strain placed on these family caregivers, little research efforts have been directed at this caregiving phenomenon. Therefore, the purpose of this research study was to advance understanding of the experience of family caregivers who care for a patient with amyotrophic lateral sclerosis through a unitary transformative lens for the advancement of nursing science. To accomplish this purpose, two aims were established for this research study. Aim 1 was to document the life patterns of family caregivers of ALS patients exhibited through the nurse researcher/ALS family caregiver process of health as expanding consciousness (HEC). Aim 2 was to integrate the life patterns of individual family caregivers of ALS patients into a thematic pattern of the whole representing the ALS caregiving experience across all caregiving families.

**Methods:** The theory of health as expanding consciousness (Newman, 1979, 1986, 1994) is the theoretical framework for the study and basis for the research protocol. The researcher engaged in a nurse researcher/ALS family caregiver process with a purposive sample of eight family caregivers who care for a loved one with ALS. The researcher and families together facilitated pattern recognition, insights, and
transformations to discover and describe the everyday world of providing care to an ALS family member. Sixteen audio-taped and transcribed open-ended interviews were analyzed using hermeneutic dialectics. Data collection spanned three months and utilizing researcher as instrument life patterns of health as expanding consciousness emerged as the family caregivers lived day to day providing care to their family member with ALS.

**Results:** Nine patterns of the whole across all ALS family caregivers emerged from the data. These patterns of the whole were: (a) suspicions emerge but ALS diagnosis is delayed, (b) support that helps the caregiver, (c) support can make caregiving more difficult, (d) looking toward the future, (e) adaptations from ALS, (f) obstacles to the caregiving role, (g) caregiver respite, (h) focus of others, and (i) strategies aiding the caregiving role. The nurse researcher/ALS family caregiver process that was revealed in this research study was: (a) establishing a time and place for the nurse researcher and ALS caregiver to form a relationship, (b) developing a bond with each ALS caregiver, (c) creating an atmosphere which allows the caregiver and nurse complete freedom to express themselves openly, (d) offering a sense of timelessness for insights about the ALS caregiving experience, and (e) transformation as the nurse researcher and ALS family caregiver came together to find meaning in the chaotic experience of family caregiving for an ALS patient.

**Conclusion:** This research study examined the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient within the theoretical framework of Newman’s health as expanding consciousness (HEC). The researcher formed a caring relationship with each family caregiver and made a concerted effort to be fully present in
the moment during all interactions with each ALS family caregiver. The caring relationship initiated by the nurse researcher blossomed into a partnership in which both nurse and ALS family caregivers experienced pattern recognition, insight, and transformation.

This research provided new insights into the life patterns of ALS family caregivers as well as demonstrated the importance of understanding the meaning of this unique caregiving experience. The insights revealed through this research study disclosed important implications for nursing research and practice while adding to the empirical support of health as expanding consciousness (HEC) and the potential for expansion of this nursing theory and method.
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ACKNOWLEDGEMENTS

I wish to acknowledge and thank the following people who have been so instrumental to my success throughout my doctoral journey. First, I would like to thank and express my eternal love and gratitude to my husband, Andrew Vavreck and my two children, Alex and Cecilia Vavreck. This has been a long journey that all four of us have traveled together and their support, encouragement, and love has made it possible for me to reach this point in time. Also, the support of my parents, Russel and Donna Shipley along with the guiding spiritual presence of my grandmother, Cecilia Lansberry has provided me with an enveloping field of love and encouragement throughout this journey. Also the never-ending encouragement from treasured friends Larissa Youngberg and Laurel Neitling has kept me going through the many ups and downs of graduate school. Finally, my cohort of doctoral students, Pamela Spigelmyer and Kimberly Fenstermacher has provided guidance and encouragement from our first doctoral class together throughout our entire doctoral experience; we have been our own cheerleaders for each other from the start.

Janice Penrod has been my advisor and mentor since I started my doctoral program. She introduced me to nursing research and provided me with guidance and support as I struggled in my efforts to narrow my research ideas into a cohesive direction for research. Without the research experience gained through being a research assistant on her study in the ALS clinic, I would not be where I am today in my research career. I owe her immensely for her support and scholarly counsel throughout this PhD journey.

Susan Loeb has provided scholarly guidance throughout the development of my dissertation and mentored me in the research analysis process through her prison study
work. She has also been an endless source of support throughout my doctoral studies and research presentations and there is no better encouragement for me than seeing her beautiful smile encouraging me through any research presentation. I am forever grateful to have had her guidance and friendship throughout this journey,

Sharon Falkenstern first introduced me to Margaret Newman in 2009 by taking me to Memphis to meet with Dr. Newman and the HEC research group. Sharon has been encouraging of my research efforts from the start and has guided me through the analysis process in such a supportive manner that I cannot imagine ever enjoying a research project as much as I have thoroughly enjoyed working side by side with her. She has my eternal gratitude for guiding my HEC study through graciously sharing her expertise so freely with me.

Fred Schied was my professor in my very first semester of doctoral work at Penn State. He instilled a love of adult learning that I utilize currently in my teaching at Slippery Rock University. His encouragement to constantly meet the learning needs of each adult learner I teach is something I try to achieve with every interaction in my classes.

I wish to thank Dr. Zachary Simmons and Susan Walsh, RN for their support in this research endeavor. Their endorsement and encouragement made the recruitment of all the ALS family caregivers possible. I am humbled after being in their ALS clinic for over two years, because their care and dedication, along with the entire ALS healthcare team showed me what a difference healthcare providers can make in the lives of ALS patients and their family caregivers.
Most of all, I thank the ALS family caregivers who graciously shared their lives, insights, stories, and time with me. They will forever have my undying gratitude and admiration.
Chapter 1
Introduction to the Study

Overview

Approximately 6000 people in the U.S. are diagnosed with amyotrophic lateral sclerosis (ALS) each year with as many as 30,000 Americans having the disease at any one point in time (ALS Association, 2010). Incidence rates are estimated at 1.2-2/100,000 and prevalence is generally reported at about 6/100,000 population (Z. Simmons, personal communication, February, 2010). Sixty percent in the ALS database are men and 93% are White (ALS Association, 2010). Also, most people with ALS develop the disease between ages 40 and 70, with 55 being the mean age of diagnosis (ALS Association, 2009). The average time from symptom onset to diagnosis of the disease is estimated to be more than 12 months (ALS Association, 2010; Chio, 1999). Approximately 50% of ALS patients survive for 30 months after the onset of their symptoms (Radunovic, Mitsumoto, & Leigh, 2007). The 5-year survival rates can range from 9%-40% and 10-year survival rates can be from 8% to 16% (Simmons, 2005). The care of these patients falls largely on the shoulders of informal, family caregivers and this caregiving impacts the mental and physical well being of these carers dramatically, yet little research efforts have been directed at family caregivers of ALS patients.

It is my intent as a nurse researcher to examine the everyday world and associated meaning of caregiving for a family member with ALS. This chapter introduces the phenomenon of interest, the nursing exploration of Margaret Newman’s health as expanding consciousness (HEC) with family caregivers of patients with ALS. The conceptual framework, including discussion of three paradigmatic perspectives in nursing
and overview of Margaret Newman’s health as expanding consciousness provide a context for the research question and theoretical definitions provided. Lastly, this chapter will address the significance of this nursing research as well as summary of the chapter.

**Statement of the Problem**

**Overview of ALS.** Amyotrophic lateral sclerosis is a progressive, degenerative motor neuron disease that is associated with the loss of upper and lower motor neurons (Naganska & Matyja, 2011) and is commonly called Lou Gehrig disease (Fletcher, 2004). This neurodegenerative disease involves the loss of motor neurons in the (a) cerebral cortex, (b) brainstem, and (c) the spinal cord (Shook, 2009), which affects the person’s ability to move, swallow, and ultimately, breathe. “A-myo-trophic” is a Greek word, which consists of: “A” meaning no; “myo” meaning muscle and “trophic” representing nourishment or “No muscle nourishment.” This is important because in ALS the muscles do not receive nourishment, which causes them to atrophy, or waste away. “Lateral” refers to the area in the spinal cord where the sections of nerve cells that control muscles are found. As this lateral section deteriorates, it forms hardened areas or “sclerosis” which prevents the motor neurons from sending impulses to muscle fibers that are responsible for muscle movement. When these muscles can not receive the motor neuron messages that they need to function, the muscles atrophy and lead to the hallmark symptoms of ALS: muscle weakness in the arms and legs; swallowing, speech and breathing difficulties (ALS Association, 2009).

Even though the duration of this debilitating illness varies among patients, the outcome is very clear. ALS is a terminal diagnosis and represents an expected death trajectory, or a steady decline in health status over time with an inevitable slide towards
death (Field & Cassel, 1997) that impacts greatly on patients as well as the family caregivers who provide the majority of their care (Penrod & Hupcey, 2010).

**Overview of ALS caregiving.** The care of people with a terminal illness can strain the most highly adjusted family unit (Cummins, 2001; Doka, 2000; Fletcher, 2004; Sawatzky & Fowler, 2003) and caring for a patient living with ALS is often associated with a particularly demanding caregiving experience (Williams, Donnelly, Holmlund, & Battaglia, 2008). Caregiving time varies with the progression of the ALS disease but as the disease progresses, the caregiving intensity increases as well (Hecht et al., 2003).

This caregiving largely occurs in the community with family members taking most of the responsibility for care of the patients (Aoun, Kristjanson, Currow, & Hudson, 2004), which means that these ALS family caregivers end up providing increasingly supportive care that often extends over years of declining capacity for their loved one. In addition, because most ALS patients are still living at home within weeks or days of their death, these family caregivers are involved in their care up to or shortly prior to their death (Mitsumoto, 2002).

With ALS, most patients eventually have to quit work due to increasingly debilitating physical or mental abilities, which causes them to require considerable support from both outside and inside the home until they lose most of their independence. At this point in time, the reality of care that is home-based must be faced (Mitsumoto, 2002). This home care is most commonly provided by family caregivers (i.e. spouses, children, or live in companions) and the focus early on is on maintaining the patient’s ability for independence in performing self-care. This caregiver role eventually changes to assisting the patient in performing activities of daily living (ADLs), which commonly
include eating, bathing, and walking. Family caregivers are required to learn new cooking and food preparation skills as the patient develops problems with swallowing and chewing (Carr-Davis, Blakely-Adams, & Corinblit, 2007). In addition, as mobility becomes a concern, the family caregiver needs to assist the patient in repositioning him or herself to prevent the formation of decubitus ulcers as well as to promote comfort (Mendoza & Rafter, 2002).

As the ALS disease progresses, family caregivers assume more complex caregiving roles and a need for round the clock care often develops toward the end of the illness trajectory (MDA-ALS, 2008). The caregiver has to adapt to changes in the patients’ speech (Carr-Davis, Blakely-Adams, & Corinblit, 2007), often serving as the main interpreter for the patient, or learn how to operate new assistive communication devices (ACD). The role of operating complicated equipment is not limited to ACDs, in addition, (a) Percutaneous Endoscopic Gastrostomy (PEG) tubes for nutritional needs, (b) ventilation equipment, (c) bi-level positive airways pressure (BIPAP) machines, and (d) suction devices all add strain to the ALS caregiving experience (Mitsumoto, 2002).

For many ALS caregivers, homes need to be transformed into hospital-like settings; this change often stresses the entire family system in that household. If the patient has been the primary breadwinner for that family, financial concerns and anxiety levels may be high (Rabkin, Wagner, & Del Bene, 2000). As care levels increase, family privacy is often lost and the family caregiver will experience frequent mental and physical exhaustion. All of these factors create considerable stress on the caregiver and patient alike. Mitsumoto (2002) asserts that this stress can be so great that patients may actually start to wish they were dead, and family caregivers may wish that the patient
were dead as well. These feelings can lead to guilt-ridden behavior and feelings of hostility by both patients and family caregivers.

In addition, research with ALS caregivers has shown a more pronounced effect of ALS on the quality of life (QOL) of family caregivers than on the ALS patients themselves (Bromberg & Forshew, 1998). The Quality of Life Research Unit, University of Toronto (2010) has defined quality of life as: “The degree to which a person enjoys the important possibilities of his/her life. Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors.” The three major life domains identified are (a) Being, (b) Belonging, and (c) Becoming. The Being domain includes (a) physical (i.e. hygiene, exercise, personal health), (b) psychological (i.e. cognition, feels, psychological health), and (c) spiritual (i.e. personal values and spiritual beliefs). The Belonging domain is concerned with an individual’s fit with the surrounding environment. Lastly, the Becoming domain contains purposeful activities that a person does to obtain their own individual goals, wishes or desires.

Vignola et al. (2008) have identified anxiety as a factor impacting QOL that plays heavily in the lives of family caregivers and posit it is a common ingredient in the psychological constellation of caregiver symptoms, starting at the time of the ALS diagnosis and increasing as the illness progresses. Anxiety has a powerful negative impact on these caregivers QOL because as anxiety increases after the initial diagnosis of the disease, the caregiver’s satisfaction with life markedly decreases, impacting their overall perception of QOL. Williams, Donnelly, Holmlund, & Battaglia (2008) assert ALS places unique demands on the family caregivers’ QOL because as the ALS disease
advances, family caregivers have less and less time to adapt and adjust to the multitude of psychological, physical, and emotional changes that are present in the patients as well as the caregivers themselves. The family caregiver’s QOL is also negatively impacted by (a) the increasing strain on resources (i.e. financial, emotional, physical) (Clark, & Standard, 1996), and (b) the ongoing need to adapt to the disease. Taken together, these demands can result in caregiver burden and depression (Gauthier et al., 2007). Woolley and Ringel (1997) examined ALS caregivers in terms of physical and mental well-being and found that as the ALS disease progressed, the ALS caregiver’s perception of their own physical and mental health declined as well. Action (2002) confirmed these findings and contends that ALS caregiving places increased risk for physical as well as emotional illness for family caregivers.

The phenomenon of caregiving is multidimensional (Yamashita, 1998), resulting in a dramatic burden that is placed upon the shoulders of ALS family caregivers. Despite the strain placed on these family caregivers, little research efforts have been directed at this caregiving phenomenon. Therefore, it is the intent of this nurse researcher to examine the everyday world and associated meaning of the caregiving role of ALS patients. To accomplish this goal this nurse researcher will examine the phenomenon of ALS caregiving through the paradigmatic lens of the unitary transformative paradigm. Margaret Newman’s theory of health as expanding consciousness (HEC) will frame the primary research of this study and through this paradigmatic lens, the ALS caregiver’s unique qualities can be revealed in that moment in time, while the interaction between person and environment exhibits the manifestation of wholeness. As the nurse researcher participates in this encounter, her presence can promote personal choice and the unveiling
of truth (Newman, 1994). This research study represents a unique approach in studying the phenomenon of ALS family caregiving because ALS family caregiving has never been examined previously from the unitary transformative paradigm, nor from Margaret Newman’s Theory of health as expanding consciousness (HEC), which will be utilized as both the theoretical framework as well as methodology.

**Purpose of the Study**

The purpose of this study is to advance understanding of the experience of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative lens for the advancement of nursing science.

Aim 1: Document the life patterns of family caregivers of ALS patients exhibited through the nurse researcher/ALS family caregiver process of health as expanding consciousness (HEC).

Aim 2: Integrate the life patterns of individual family caregivers of ALS patients into a thematic pattern of the whole representing the ALS caregiving experience across all caregiving families.

**Conceptual Framework**

The term conceptual framework is used interchangeably with conceptual model, system or scheme to denote global ideas about groups, individuals, and situations that are appealing to science (Fawcett, 1980). These global ideas are further broken down into concepts, which enable an individual to form a mental picture of some phenomenon of interest. Concepts can be very abstract in nature, such as hopelessness or resilience, or very concrete, as in floor or chair. Concepts can then be linked together to form propositions, which show their relation to each other. Nye and Berardo (1966, p. 64)
define a conceptual model as “a set of concepts and those assumptions that integrate them into a meaningful configuration.” Conceptual frameworks therefore enable specific phenomena to be identified by discerning relevant concepts as well as detailing the relationships among them.

Fawcett (1980) asserts the concepts making up a conceptual framework are very abstract and commonly cannot be seen directly in the real world. In addition, she contends the assumptions that link concepts together are abstract generalizations that cannot be immediately empirically tested. A conceptual framework provides scientists with a perspective that enables them to see and speculate about phenomena of interest. Through the identification of relationships and description of a phenomenon of interest, conceptual frameworks provide a first step in the development of a theoretical foundation needed for scientific endeavors (Burr, 1973).

Conceptual frameworks have been heavily used in nursing science to describe a phenomena of interest to nursing and usually incorporate the four essential nursing concepts of person, environment, health and nursing (Yura & Torres, 1975). Conceptual frameworks are rooted in a researcher’s own philosophical and scientific orientation (Fawcett, 1980). In other words, conceptual frameworks embrace the worldview or paradigmatic perspective of the researcher utilizing it and throughout its evolution, nursing science has embraced many conceptual frameworks representing the varied paradigmatic perspectives present within the discipline of nursing.

**Paradigmatic Perspectives**

Nursing science has evolved through paradigm shifts that have impacted the practice of nursing. A paradigm is defined by Guba (1990, p. 17) as “a basic set of
beliefs that guides action, whether of the everyday garden variety or action taken in connection with a disciplined inquiry.” Patton (1978, p. 203) defines a paradigm in terms that are consistent with Kuhn’s (1970) as “a worldview, a general perspective, a way of breaking down the complexity of the real world. As such, paradigms are deeply embedded in the socialization of adherents and practitioners: paradigms tell them what is important, legitimate and reasonable.” Kuhn (1970) proposes that a paradigm is “a discipline’s specific method of solving a puzzle, of viewing human experience, and of structuring reality.” Lauden (1977, p. 97) used the term “research tradition” in the place of paradigm and defined it as a set of assumptions about the basic kinds of entities in the world, assumptions about how these entities interact, assumptions about the proper methods to use for constructing and testing theories about these entities.” Morgan (1983, p. 377) stresses the importance of these assumptions and asserts assumptions make “messes researchable.” In other words, researchers choose their own assumptions and then base their research studies on these assumptions, which enable the manner for achieving what the researcher values. Through these worldviews, or paradigms, a research can choose the values, truths and perspectives to guide and frame their research efforts (Munhall, 2007).

**Nursing paradigm history.** Throughout history, many different paradigms have been used in guiding the actions of different professions (Guba, 1990). For nursing science, we are interested in those paradigms that guide disciplined inquiry and historically throughout nursing science’s development different nursing paradigms have been embraced due to the recognition of the need for knowledge that is specific to nursing (Newman, 1972). However, in spite of the progressive visions of Florence
Nightingale on not only nursing but also nursing research, nursing historically embraced a “practice-oriented or doing” culture that Watson (1981) asserts hindered its intellectual and scientific development.

Historically, until the 1950’s the term nursing science was seldom used in the nursing literature (Watson, 1981). In fact, Abdellah (1969, p. 390) writes of an occurrence in 1949 where a nurse researcher submitted a journal article only to have it returned because the journal stated “nurses do not do research…research has no place in nursing.” At this time and during the 1950’s and 1960’s, the focus of patient care was based on a medical model, which espoused the perception of the patient as being in good or bad health and needing varying amounts of nursing help to attain “maximum health or well-being” (Newman, 1994, p. 12). However, as new approaches to understanding human and physical phenomena evolved from other fields (i.e. adaptation, ecological views, and systems perspectives) nursing scholars started to question the aligning of nursing to the medical model as a rationale for nursing practice (Munhall, 2007). In addition, it was during this historical period of the 1950’s and 1960’s that nursing was beginning to infiltrate the university setting and as nursing education became aligned with higher education, nursing expectations and standards began to change (Watson, 1981), however slowly. Nursing educators discerned that baccalaureate and graduate nursing required its own theoretical nursing research focus to prepare nursing students, to further nursing practice as well as to advance nursing’s scientific knowledge base (Watson, 1981). No longer could the male dominated medical model solely influence nursing’s professional practice and educational development and as a result, the need for nursing to establish its own distinct scientific body of knowledge became evident
(Munhall, 2007). With the publication in 1952 of *Nursing Research*, the focus of nursing in establishing its own body of research was begun (Newman, 1972).

In addition, the spoken language used by nursing began to change, which demonstrated a shift from the medical, causal model to a distinct holistic nursing model (Munhall, 2007). This shift represented a new way in which nursing viewed phenomena, which was more interactive in nature. In the early 1970’s when Martha Rogers introduced her unitary view of person-environment, where there was an absence of boundaries between a person and the environment while emphasizing the mutual simultaneous interaction between the two (Rogers, 1970). In 1991, Newman, Sime, and Corcoran-Perry proposed an overarching statement meant to clarify the paradigmatic shifts in nursing. They asserted that the focus of the discipline of nursing is focused on “caring in the human health experience” (p. 3). Further, Newman, Sime, and Corcoran-Perry assert three paradigmatic perspectives in nursing are positioned within the focus of the discipline and titled these three paradigms as: (a) the particulate-deterministic, (b) interactive-integrative, and (c) unitary-transformative paradigms. This schema reflects two components that are instrumental to the paradigmatic perspectives: entity and process of change (Picard & Jones, 2005).

**Particulate-deterministic paradigm.** In this paradigm, the entity component (particulate) is a viewed as being measurable, controllable, manipulated and predictable. The process of change component (deterministic) is regarded as a linear process that is causal in nature. From an ontological perspective, (i.e. what is the nature of reality), reality exists “out there” and is determined by many natural laws (Guba, 1990). Knowledge is traditionally summarized in context-free generalizations, many times in the
form of cause-effect laws. From an epistemological (i.e. nature of the relationship between researcher and researched) stance, the researcher adopts a distinct, non-
interactive position. Values and any biases or confounding factors are immediately
excluded so that they cannot influence results. Methodologically, or how the researcher
goes about the acquisition of knowledge, hypotheses or questions are formed in
propositional form in advance and are empirically tested under carefully controlled
research conditions (Guba, 1990). Knowledge must be verified before being accepted
and the identification of antecedents is necessary for prediction or control to occur.
Paradigmatic perspectives originating from this paradigm include: (a) positivism, (b)
objectivism, (c) rationalism, and (d) reductionism (Picard & Jones, 2005). From this
paradigmatic perspective, caring in the health human experience could be examined
through the concepts that comprise the phenomenon of caring. Caring could be broken
down into measurable, definable characteristics. In addition, health could be isolated into
the characteristics representative of healthy versus non-healthy (Newman, 1995).
Similarly, caring could be analyzed as a therapeutic intervention impacting a person’s
health in relation to responses that are measurable (Morse, Solberg, Neander, Bottorff, &

Interactive-integrative paradigm. The interactive-integrative paradigm is an
extension of the particulate-deterministic paradigm (Newman, 1995). Within the
interactive-integrative paradigm, the researcher is still an outside observer with the
desire, but not the ability, to control variables present (Newman, 2008). This paradigm
stems from the particulate-deterministic paradigm (Newman, 1995) and the entity
component (interactive) views phenomenon as being multidimensional and contextual in
nature. The process of change element (integrative) is characterized by multiple antecedents and probabilistic relationships, which result in bringing about changes in a phenomenon. This paradigm still involves prediction and control, but includes subjective data to better understand a phenomenon (Newman, Sime, & Concoran-Perry, 1991). Ontologically, this paradigm embraces the view that reality exists but can never be completely understood because it is piloted by natural laws that are only partially understood (Guba, 1990). Epistemologically, the researcher seeks an objective view of the subjective experience and findings are considered to be “probably true” in nature (J. Penrod, personal communication, September 2007). Methodologically, natural settings including qualitative inquiries are employed, but adherence to the concepts of validity, reliability and generalizability are still embraced (Guba, 1990). These differences from the particulate-deterministic paradigm demonstrate a shift towards a more holistic view with the realization that reality can be an interpretation that is close to the meaning of the truth as well as its subjective interactive perspective of inquiry. It does not totally embrace holism (Picard & Jones, 2005), however, because it still carries out the analysis of the person in a particularistic manner through (a) the analysis of a person as being made of up of parts, (b) reducing those parts to measurable beings, (c) manipulating and controlling the parts, and (d) extending to the whole based on knowledge of the parts. This paradigm is consistent with post-positivism, but it also shows an ontological shift towards value placed on multiple ways of knowing or reality.

**Unitary-transformative paradigm.** The unitary-transformative paradigm represents a distinctly unique perspective that did not extend or emerge from the previous two paradigms (Newman, 1995). A phenomenon (entity component) is viewed as “a
unitary, self-organizing field embedded in a larger self-organizing field. It is identified by pattern and by interaction with the larger whole” (Newman, Sime, & Corcoran-Perry, 1991, p. 4). The process of change is unidirectional and unpredictable; always moving through stages of organization and disorganization to higher levels of more complex organization (Newman, 1994). Ontologically, multiple realities exist through multifarious mental constructions that are socially and experientially based (Guba, 1990). In other words, truth is what that individual says it is at that moment in time. Epistemologically, the researcher no longer is an observer, but rather a participant in the evolving pattern of the whole. The researcher and researched work together to co-create findings which reflect reality (Newman, 2008). Methodologically, individual interpretations are brought forth and refined hermeneutically and then contrasted/compared dialectically (Guba, 1990). Collaborative interaction is embraced because practical knowledge is of primary concern (J. Penrod, personal communication, September 2007). In other words, not only does the researcher obtain information about the participant’s experience, but the researcher actually experiences it together with the participant (i.e. ALS family caregiver). Newman (1994, p. 82) asserts this paradigm represents a radical shift in nursing paradigms and embraces “the view of the human being as a unitary phenomenon unfolding in an undivided universe.” Parts or variables cannot be separated into isolated entities. Unique to this perspective, nurse researchers utilizing this paradigm discard the notion of prediction or control as being essential to nursing science. This is necessary because pattern is regarded as being the “identifying characteristic of a person’s wholeness” (Picard & Jones, 2005). Through this paradigmatic lens, a person’s unique qualities are revealed at that moment in time, and
the interaction between person and environment exhibits the manifestation of wholeness. Control or prediction must be abandoned because the uniqueness of that person is revealed in that moment in time and the manifestation of wholeness is revealed through the interaction between the person and his/her environment. The nurse researcher engages in this interaction with the person and through his/her intentional presence fosters the uncovering of truth as well as personal choice (Newman, 1994). Lastly, knowledge is derived through recognition of patterns and reflects not only the phenomenon studied, but the viewer as well. Change emerges as a transformation of the total pattern (Newman, 1995). Examples of nursing research from this paradigmatic perspective would include study caring in the human health experience as a unitary-transformative process of mutuality as well as creative unfolding (Newman, 1995). Specifically, Falkenstern, Gueldner, & Newman (2009) examined families with a child with special healthcare needs utilizing not only the unitary transformative paradigm, but the health as expanding consciousness (HEC) conceptual framework and method.

**Introduction to Health as Expanding Consciousness**

Margaret Newman’s life experiences preceding her nursing career, especially when caregiving for her mother who had ALS, laid the foundation for her theory of health as expanding consciousness (HEC) (Newman, 1997). Her theory evolved from Martha Rogers’ theory of unitary human beings (Rogers, 1970) and describes “life as a process of expanding consciousness” (Newman, 2005, p. 4). It was developed on the following assumptions (Newman, 1997, p. 22): (a) health encompasses conditions known as disease, (b) disease can be considered a manifestation of the underlying pattern of the person, (c) the pattern of the person that manifests itself as disease is primary and exists
prior to structural or functional changes, and lastly (d) health is the expansion of consciousness.

Newman’s major premise is that health is expanding consciousness (Newman, 2008). Health is not viewed separately from disease, but encompasses disease as a pattern of the whole (Newman, 1986, 1994, 1995, 1997, 2005). “Health encompasses disease and non-disease and is a manifestation of the underlying pattern of person-environment” (Newman, 1994, p. 11). The HEC model presents health and illness as a manifestation of a life process. For example, a person is not less whole when they are sick or ill. Unlike a medical model of illness, the HEC theory encourages nurses to concentrate on meaning and power of an illness or disease as an evolving process of the whole for that person instead of focusing on the helplessness or incurability of a disease (Jones, 2006).

This definition of health meant the abandonment of the medical model paradigm of health, which regards viewing patients as being constructed of separate parts and trying to “fix” what is wrong with them, and instead embraces a new paradigm of health. This paradigm of health, which Newman asserts is essential to nursing research (Newman, 1994), embraces the view of an individual as an emerging pattern of the whole.

Assumptions of HEC revolve around pattern and wholeness (Newman, 1979, 1986, 1994). Pattern “describes relationships, both within the person as well as with other people and environment. The pattern is a portrayal of the undivided wholeness of all that there is” (Picard & Jones, 2005, p. 5). Consciousness, which is the pattern of the whole that distinguishes each person from another, co-exists with the universe. An
understanding of pattern is elementary to the understanding of health. Throughout a human’s life, from birth to death, a pattern is manifested that makes that person unique. For example, every person’s genetic structure contains unique patterns that direct our physical and behavior make-up. An example of this would be with voice patterns and how each person’s voice patterns are discernable alone even if a visual image of that person is not present. These two are among many patterns inherent to each human that identifies us as unique and our ability to understand this unitary nature of humans is enhanced as patterns are identified and understood (Newman, 1994).

Newman (1994) describes humans as conscious beings who have the capacity for insight as well as awareness. Therefore, as human beings, we are capable of (a) recognizing patterns, (b) gaining insights into our own experiences, and (c) continuously evolving to expand our own consciousness. The process of daily life gravitates towards higher levels of consciousness. This process can be sometimes smooth, satisfying or harmonious; or it can be sometimes arduous or disharmonious, as in a diseased state. A sick person is not a separate entity with a separate disease. Instead, we are all open energy systems that continuously interact and evolve with each other. A pattern that is revealed in illness does not end with that person, but is part of a greater whole. For example, Newman (1994) asserts the pattern of the whole as containing an individual who is an open system that interacts with a family as an open system interacting with a community, which is also an open system.

The patterns that people feel, see, or hear depict relationships. They don’t involve merely quantifiable entities, but are concerned with how a person relates with others and the environment. In other words, patterns connect and show relationships. All patterns
involve rhythm, movement, and diversity. Patterns are constantly moving and interacting with the parts changing in relation to each other (Newman, 1994, 2008).

Newman’s initial concepts focused on movement, time, space and consciousness (Newman, 1979). The following relationships between the concepts are presented (George, 2001, p. 521): (a) Time and space have a relationship that is complementary; (b) Through movement, space and time become a reality; (c) Movement is the reflection of consciousness; (d) Time is a function of movement; and (e) Time is a measurement of consciousness. In addition, when reviewing the HEC theoretical framework, Marchione (1993, p. 6) maintained Newman’s implicit assumptions include the following characteristics about human beings: (a) humans are open energy systems that are in a continuous state of connectedness with the environment (a universe of open systems); (b) humans are unabating in the evolution of their own patterns of the whole (health); (c) Humans are able to think abstractly; (d) humans are affective, cognitive and intuitive; and (e) humans are more than the sum of their individual parts.

Pattern recognition centers on what is meaningful in the lives of the participants or simply stated, meaning characterizes or makes up one’s pattern. Through this process of pattern recognition, meaningful events and individuals are reflected upon as life patterns emerge. It is through periods of disorganization such as those represented by disease or illness, that opportunities for new life choices may become identified (Prigogine, 1976). Through the interaction with a caring nurse researcher utilizing HEC, a person can recognize opportunities for direction or action. Nurse researchers who embrace Newman’s HEC theoretical perspective focus on the patterns unfolding in a person’s life and concentrate on the quality and connectedness of relationships while
recognizing the reciprocal pattern of the individual and the environment (Newman, 1995).

**Proposed Research Study**

For this research study, the family caregiver of an ALS patient is the focus for the application of the HEC theory. In order to achieve pattern recognition done with the family caregiver, the nurse researcher must be totally open to the experience. The nurse researcher must also engage in an authentic, true and uninhibited relationship with the family caregiver. To this nurse researcher, being authentic means being genuine as well as the “true you” which represents one’s own strengths, values, beliefs, needs, motives, and sense of justice. These qualities enable a person with a model that can guide that person through any human interaction. Through this relational process, the relationship becomes mutual where in the family caregiver and the nurse’s patterns of consciousness interconnect, resulting in a new pattern of the whole (Figure 1.1). Newman (1994) refers to participants in a study as “clients”. For this research study, this nurse researcher will not be using this terminology of “client”, but instead refer to all participants as ALS family caregivers. As they come to know the pattern of the whole, the nurse researcher and ALS family caregiver can experience pattern recognition, transformation and the expansion of consciousness (Newman, 1994).
Newman (1994) asserts nursing research should concentrate on phenomenon that are a reality of nursing practice. Merely producing research data as an outcome for a study is not enough. She says nursing research portrays the “emancipatory process of pattern recognition” (p.92) and defines this as research as praxis. Munhall (2007, p. 132) states praxis is the critical reflection on the “ends and the means of activity for the purpose of transformation and is a means of consciousness raising in which theory and action become one.” Linchfield (2005) contends praxis relies on the premise that research, theory, and practice are one process and through this praxis, both researcher and participant travel through new ways within each of their own respective life worlds. Through her own research, Linchfield identified four themes as being interrelated in
praxis: (a) partnership, (b) dialogue, (c) pattern recognition, and (d) health and its meaning. Within this proposed research study, the nursing interaction with ALS family caregivers will be a partnership. Within the confines of this partnership, dialogue will ensue encircling the interaction between the nurse researcher and family caregivers, while providing insights about how situations, events, or people are interconnected. As the process unfolds, the nurse researcher can identify patterns and through this sharing of pattern recognition, the family caregivers can gain insights into their own caregiving experience and how they might move forward in life accompanied by new ways of thinking about the ALS caregiving experience. Through the co-creation of meaning, the nurse researcher and family caregivers will move together to find order within the chaos of caring for an ALS patient. Health, as defined by Newman (1994) can have new meaning for not only the family caregivers but for the nurse researcher as well. This health, according to Newman (1994, 2005, 2008) is the expansion of consciousness.

**Chosen Conceptual Framework**

Health as expanding consciousness (HEC) is an example of a nursing theory where the theorist, Margaret Newman, developed a unique research method that is congruent with the theory (Newman, 1994). HEC is a nursing theory that is meant for nursing research as well as practice. For this research study, this nurse researcher will utilize the theory of health as expanding consciousness as both the theoretical framework for the study as well the research method based on the following reasons. First, this theory embraces the Unitary Transformative paradigm and represents a distinctly unique perspective, where nursing is embraced as a unitary process of mutuality and creative unfolding between nurse and ALS family caregiver is present (Newman, 1991). This
theoretical framework is very distinguishable from theories utilizing the particulate-deterministic paradigm (i.e. positivistic) or the interactive-integrative paradigm (i.e. postpositivistic) because phenomenon is viewed as a unitary, self-organizing field embedded in a larger self-organizing field (Newman, 1991). It is identified by “pattern and by interaction with the larger whole” and through this pattern recognition, knowledge is gained, which reflects not only the participants but the phenomenon as well (Newman, Sime, & Corcoran-Perry, 1991, p. 4). Ontologically, it posits that reality is a mental construction, socially based where there are multiple realities and many interpretations possible. Epistemologically, the researcher is not an observer, but rather co-creates with the family caregiver a new pattern of the whole (i.e. findings), which emerges through hermeneutic, dialectic dialogue within this process (methodology). Lastly, mutual meaning can be derived as the nurse and ALS family caregiver join together as one to experience new insights together (Newman, 1991).

Health as Expanding Consciousness Research Method

As a research methodology, HEC uses a six-step method for inquiry (Newman, 1994). The first step, a taped interview, starts with a simple open-ended statement, which is modifiable to be appropriate for the research focus. Next the interview is transcribed. Following the transcription, the nurse researcher develops a narrative by selecting key statements that are deemed to be most important to the participants (i.e. ALS family caregivers) and arranges these key data segments into chronological order to highlight the most noteworthy events. This narrative is then transformed into a diagram or pattern analysis, which is a graphical representation of significant relationships depicting the narrative in sequential pattern configurations. Patterns of the whole will emerge,
consisting of segments of the ALS family caregiver’s relationships over time (Newman, 1994).

Follow-up, through a second interview is conducted where the diagram (pattern analysis) is shared with the ALS family caregiver. This mutual viewing provides the caregiver with the ability to confirm, clarify, or revise the story. Also, if the nurse researcher has doubts about any parts of the story, this gives him or her the opportunity to clarify it. The family caregiver may express that pattern recognition is happening and the caregiver and nurse can mutually reflect on the ALS family caregiver’s life pattern (Newman, 1994).

The last step is application of the theory and this occurs after the interviews are completed. The nurse then completes a more intense analysis of the data in conjunction with the HEC theory. The nature of the sequential patterns of interaction are evaluated in terms of quality and complexity and pattern similarities can be then designated through themes and stated in propositional form (Newman, 1994).

**Research Question**

For the purpose of this study, the research question posed is: What are the life patterns of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative paradigmatic lens?

**Theoretical Definitions**

The following section provides a summary of definition of terms for the purpose of this research study. Definitions for (a) environment, (b) health, (c) life pattern, (d) paradigm, (e) patterns of the whole, (f) person, (g) praxis, and (h) nurse researcher/ALS
family caregiver process are derived from Newman’s theory of health as expanding consciousness (1994).

**Environment.** The environment is an energy field that is in constant interaction with a person’s energy field. It is made up of energy fields of all living and non-living objects outside of the person.

**Health.** Health is a unitary transformative experience that is uni-directional and evolves over time. It is unique for every human, family and community and is manifested in the interaction between a person and the environment. Health and illness are not mutually exclusive, but rather a unitary process. Health, as defined by Newman (1994), is expanding consciousness (Newman, 1995).

**Life pattern.** Life patterns are a configuration of patterns that occur over an individual’s life course that are a result of person-environment interactions. They are unique to every person and each is enclosed within the pattern of the whole.

**Paradigm.** A point of view from which a field of study is conceptualized, including the assumptions that are inherent in that view and the basis upon which knowledge claims are accepted. According to Newman (1994) the three paradigms present in nursing literature are (a) particulate-deterministic, (b) interactive-integrative, and (c) unitary–transformative paradigms.

**Patterns of the whole.** Patterns of the whole are “primary, underlying, indivisible patterns which include the context of the identified focus” (Newman, 1994, p. 10). It can be pictured graphically as an ever increasing sphere of energy that has as it’s core the individual, surrounded by a larger energy sphere of the family, encased by an even larger energy field of community, and ultimately an energy pattern of the universe
as it’s largest energy circle. This pattern of the whole reflects the phenomenon of nursing practice.

**Person.** A person is a unitary human being or energy field that is in constant mutual interaction with the environment.

**Praxis.** Praxis is the unity of nursing research and nursing theory into one process. It is formed through the mutual partnership and dialogue with another, and the ensuing pattern recognition that occurs through that co-creation of meaning with a nurse researcher and participant (i.e. ALS family caregiver).

**Nurse researcher/ALS family caregiver process.** This is a mutually evolving process that results from the interaction between a nurse researcher and an ALS family caregiver and the environment. The goal of this process is for the nurse researcher to aid the ALS family caregiver in understanding their unique life patterns. Expansion of consciousness is possible through recognizing patterns, adding insights, increasing the potential for action and transforming decisions for both the ALS family caregiver and the nurse researcher. The nurse research as well as the ALS family caregiver can be mutually changed and transformed.

**Significance of Study to Nursing**

This research study is significant to nursing because it addresses a gap in nursing literature about the phenomenon of being a family member caring for a loved one with ALS. Research examining ALS family caregiving is warranted due to the intense physical and emotional impact this complicated caregiving role has on the family members who assume it. These family caregivers provide increasingly supportive care that can extend over years of declining capacity for their loved one. Further, since most
ALS patients are still living at home within weeks or days of their death, these family caregivers are actively involved in their care up to and shortly prior to their death (Aoun, 2004). This caregiving exacts a dramatic burden on the family caregivers and places them at increased risk for physical and emotional illness. In addition, the need for round the clock care that accompanies the final stages of ALS negatively impacts the caregiver’s quality of life, creates high levels of anxiety and increased financial stress on the family unit.

This is the first research study that has used a unitary transformative paradigmatic lens to focus on the describing life patterns of family caregivers who support and care for ALS family members. Through this paradigmatic lens, a person’s unique qualities are revealed at that moment in time, and the interaction between person and environment exhibits the manifestation of wholeness. It is also the first research study to examine ALS family caregiving utilizing health as expanding consciousness as the theoretical framework/research method. This study is unique because through collaborative interaction between the nurse researcher and ALS family caregiver, not only does the nurse researcher learn about the ALS family caregiver’s experiences, but actually experiences it together with the family caregiver as co-creation of meaning occurs. Through pattern recognition, which centers on what is meaningful in the life of the caregiver, meaningful events/individuals are reflected upon together by the nurse researcher and ALS family caregiver and through this interaction life patterns emerge. This intentional presence of the nurse researcher fosters the uncovering of truth as well as personal choice of the ALS family caregivers and enables life patterns to emerge. These life patterns of the ALS family caregivers represent research findings that are co-created
together to reveal opportunities for direction or action. Through this relational process, the nurse researcher and ALS family caregiver’s patterns of consciousness interconnect, resulting in a new pattern of the whole.

Nurse educators can utilize these research findings to aid nursing students of all levels (i.e. undergraduate, graduate, and continuing professionals), to view the family caregiver in a more holistic manner through the nurse researcher/ALS family caregiver interactions present. By focusing on the family as a whole, not solely on a disease or medical condition present, can alter the nursing focus of care. Nursing students and nurse researchers may be encouraged to try health as expanding consciousness and the research as praxis it represents after seeing this research study example of the HEC theory and research method. It is important for clinical nurses to maintain not only professional clinical competencies, but also focus on how they relate to or communicate with family members. By examining these research findings, nurses can view the family as a whole to uncover caregiver life patterns, stimulate pattern recognition, elucidate caregiver choices, and support action potential (Newman, 1994).

Findings from this research will also contribute to the advancement of nursing research, practice, and theory. Uncovering the unique life patterns of ALS family caregivers will show the application of Newman’s theory of health as expanding consciousness to this family caregiving phenomenon. This research can also expand the body of literature that supports the application of Newman theory of health as expanding consciousness. If nursing is to continue to develop as its own discipline, it must have its own body of knowledge. According to Meleis (1997) much of what exists currently in nursing literature has been borrowed from other scientific disciplines. This research
study represents knowledge that is uniquely nursing that can be applied to nursing research, practice and nursing theory development that is situated in the unitary-transformative paradigm. Thus, this study contributes nursing knowledge that can advance nursing science.

**Chapter Summary**

This first chapter has provided an overview of the ALS illness along with an overview of the ALS caregiving experience. The purpose of this study is to advance understanding of the experience of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative lens for the advancement of nursing science. Margaret Newman’s HEC model will provide both the theoretical framework as well as the research method to examine the research question of: What are the life patterns of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative lens? This research study, with its unitary transformative paradigmatic focus will examine the complexity of human experiences of health in relationship with nursing and the environment of caring for a loved one with amyotrophic lateral sclerosis.
Chapter Two

Review of the Literature

Introduction

This chapter provides a review of literature integral to the study of family caregivers of patients with amyotrophic lateral sclerosis (ALS). An overview of literature relevant to the disease of amyotrophic lateral sclerosis, family caregiving, and ALS caregiving will be examined. Lastly, overviews of three relevant nursing theories that could guide a study of ALS caregiving are provided with special examination of health as expanding consciousness (Newman, 1979, 1986, 1994) as the theoretical framework chosen to guide this research.

Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS) is the most common neuromuscular disease in adults of any age (Forshew & Hulihan, 2007) and is presented as a progressive degenerative disorder with unknown etiology (Silani et al, 2011; Vitale & Genge, 2007). Motor neuron diseases are distinguished by atrophy (i.e. wasting away of muscle) and progressive weakness of muscles. There are multiple types of motor neuron diseases. The first type, primary lateral sclerosis (PLS), is characterized by damage in the upper motor neurons, which emanate from the spinal column. If only lower motor neurons are involved, PMA or progressive muscular atrophy is diagnosed (Naganska & Matyja, 2011). When the lower motor neurons, which originate in the spinal column, are injured, spinal muscular atrophy or progressive muscular atrophy is diagnosed.

Diagnosis of ALS. Amyotrophic lateral sclerosis is diagnosed by having both upper and lower motor neurons damaged. Once these motor neurons die, they cannot
transmit nerve impulses to the muscles, which results in the muscle weakness that is representative of the ALS disease (ALS Association, 2010). According to the World Federation of Neurology (WFN), in order to have a diagnosis of ALS the following three criteria must be met: (a) confirmation of upper motor neuron findings, (b) evidence of lower motor neuron findings, and (c) evidence of progression within and beyond the site of onset (Naganska & Matyja, 2011). Muscles such as those that move the eyes or the external sphincters that maintain stool in the bowel and urine in the bladder are rarely involved in ALS. Other muscles not affected (Forshew & Hulihan, 2007) are those involved in (a) internal organs (heart, kidneys, or liver), (b) sexual functions, and (c) senses (smell, taste, sight, hearing, and touch).

Currently there is no single diagnosis test for ALS (Mitumoto & Rabkin, 2007; Naganska, & Matyja, 2011; Radunovic, 2007) and diagnosis is most commonly achieved through a physical examination and series of diagnosis tests. This process usually involves the elimination of other diseases that mimic ALS before a definitive diagnosis can be accomplished (ALS Association, 2008; ALS Association, 2010) and diagnosis in early stages, because it is so difficult to diagnose, may take 9-11 months after symptoms start before a definitive diagnosis can occur (Mitumoto & Rabkin, 2007). The following tests are usually included in the diagnosis process: (a) electro-diagnostic tests including electromyography (EMG) and nerve conduction velocity (NCV), (b) spinal tap, (c) urine and blood tests including high resolution serum protein electrophoresis, parathyroid and thyroid hormone levels and 24 hour urine collection for heavy metals, (d) muscle and/or nerve biopsy, (e) myelogram of the cervical spine, (f) x-rays, including magnetic resonance imaging (MRI), and (g) thorough neurological examination (ALS Association,
Diagnostic criteria also require the patient to have signs of impairment in more than 1 of 4 body regions, evidence of both upper and lower motor neuron degeneration, and progressive spread within or between body regions (Mitsumoto & Rabkin, 2007). There are other neurological diseases that have some of the same symptoms of ALS and for this reason, the ALS Association (2010) states that when an individual is diagnosed with ALS, he or she should seek a second opinion from an ALS expert, which they assert is someone who diagnoses as well as treats many ALS patients and has expertise in the medical specialty of ALS.

ALS was initially diagnosed by the French neurologist, Jean Martin Charcot in the late 1800’s and is still recognized by the name, “Charcot’s Disease” in many European countries (ALS Association, 2007).

Lou Gehrig and His Relationship to ALS. Relatively little research was dedicated to this disease until the 1940’s when Lou Gehrig, a well known and widely respected professional baseball player for the New York Yankees was diagnosed with the disease (Forshew & Hulihan, 2007). Although Lou Gehrig is recognized historically as one of baseball’s greatest players, his parents did not want him to play baseball. He grew up in very humble surroundings due the poverty of his German immigrant family (Abady, 2006). Lou was one of four children, but he was the only one who survived infancy (Schwartz, 2007). He lived in Manhattan on the Upper East Side in poverty because his father was frequently ill and his mother worked as a cook. He started playing baseball in high school and it was only when a talent scout observed him playing that Lou was offered a scholarship to play college football (Stevens, 2010). Gehrig started to play for the New York Yankees in 1923 and played in every single game, never missing one, for
14 years (Abady, 2006). That accomplishment netted him a record of playing more than 2130 games (Schwartz, 2007), a record that stood for 50 years. When Lou was only 35 years old he started having problems running around the bases as well as experienced difficulty with swinging the bat, and he recognized that something was physically wrong with him. He was diagnosed with ALS within two months of the onset of symptoms (ALS Association, 2010). On May 2, 1939, Gehrig voluntarily took himself out of the baseball lineup because he realized that he would no longer be able to play baseball (Tope, 2010). On July 4, 1939 (Adler, 1997), the Yankees held a special service honoring his accomplishments and it was during his memorable speech at this ceremony that he uttered his most famous saying about what his baseball career meant to him. “Fans, for the past two weeks you have been reading about the bad break that I got, yet today I consider myself to be the luckiest man on the face of the earth” (Schwartz, 2007). Over 61,000 fans and team members were present for this emotional event. He stayed with the Yankees serving as a team captain and on December 8, 1939 was inducted into the Baseball Hall of Fame (Abady, 2006). Only two other baseball players, Babe Ruth and Hank Aaron would ever drive in more runs than Gehrig. Nicknamed “the Pride of the Yankees,” Lou Gehrig died at his home on June 2, 1941, exactly 16 years to the day after starting as the first baseman for the New York Yankees (Stevens, 2010).

According to the ALS Association (2010), without Lou Gehrig’s popularity and experience with ALS, millions of Americans would never have heard of the ALS disease and his name recognition has driven support for ALS treatment and research that otherwise might not have been possible. This is very important because every 90 minutes
someone in the United States is diagnosed with ALS, and every 90 minutes another
person will lose his or her battle against this disease (ALS Association, 2010).

**ALS Disease.** The age of onset of ALS is between the ages of 40-70, with a peak
age of 55 (Forshew & Hulihan, 2007). Even though the average life expectancy is 3 to 5
years from the onset of diagnosis, ALS life expectancy is variable (ALS Association,
approximately 50% of ALS patients survive for 30 months after the onset of their
symptoms. Simmons (2005) asserts the 5-year survival rates can range from 9%-40%
and 10-year survival rates can be from 8% to 16% in the absence of long-term
mechanical ventilation (LTMV). With LTMV survival can be 15 years or more (Hayashi
& Oppenheimer, 2003). Even though the duration of this debilitating trajectory varies
among ALS patients, the outcome is certain. ALS is a terminal disease. Its impact is felt
greatly not only by patients diagnosed with the disease, but also on the family caregivers
who are responsible for providing the majority of their care (Mitsumoto & Rabkin, 2007).

**Types of ALS.** For 90%-95% of ALS patients, the disease comes out of
nowhere. These patients develop the disease without having any family history of the
disease. This is called sporadic ALS and is the most common form of the disease (ALS
Association, 2010; Forshew & Hulihan, 2007). Any given male has a one in 1,000
chance of getting ALS and any female has a one in 1,200 chance (ALS Association,
2009). The lifetime risk of sporadic ALS is 1:400 (Johnston et al., 2006) and only 5% of
sporadic ALS patients have onset of symptoms before the age of 30 (Silvani et al., 2011).

Approximately 5%-7% of ALS is familial, which means some other member of
that family has had ALS (Carlesi et al., 2011; Silani et al, 2011). Familial ALS (FALS)
is caused by a defect or mutation in a gene and is inherited in an autosomal dominant manner. This means the chance of a FALS patient passing this gene onto an offspring is 50%. Inheriting this gene however, does not guarantee that the child will develop ALS later in life (ALS Association, 2010).

Sporadic ALS presents differently in men and women. Men have a greater percentage of onset in the spinal area, while women have a higher chance of bulbar (face, mouth and throat muscles) presentation. Gender appears to have no clear impact on survival (McCombe & Henderson, 2010). This could possibly due to different exposures to environmental or exogenous (occurring outside the body) toxins, differences between male and female nervous systems, or difference between male and female ability to repair cell damage.

**SOD1 gene.** One gene has been associated with approximately 20% of familial ALS cases (ALS Association, 2010). It is named superoxide dismutase 1, or SOD1, and is located on chromosome 21. It was formerly called the amyotrophic lateral sclerosis 1 (adult) gene (Weizmann Institute of Science, 2012). The main function of normal SOD1 is to detoxify or clean free radicals that are byproducts of cellular metabolism. When abnormal SOD1 was identified in 1993, it was presumed that it led to a decrease in protein function that would cause an increase of toxic free radicals. However, recent theory suggest the problems is not a loss of function, but instead the addition of a new or toxic function, which has yet to be identified fully (Forshew & Hulihan, 2007). There are rare incidents of locations on chromosomes 2 and 15 in which the faulty gene is inherited by both parents for ALS to develop. These rare cases of familial ALS, commonly called juvenile ALS, are associated with an early onset of ALS combined with a long duration
of the disease (Forshew & Hulihan, 2007). However, there are more than 100 mutations in this SOD1 gene associated with ALS (ALS Association, 2009). It is important to recognize that regardless of the etiology, the presentation of familial or sporadic ALS is the same. It is only the known presence of a family history of ALS that distinguishes between the two.

**Limb and bulbar presentations of ALS.** Both the presenting symptoms and course of the illness vary significantly among patients. Limb weakness is the initial symptoms for 65% of ALS patients (Cwik, 2006; Gordon, 2011). Some typical early symptoms include: (a) difficulty walking, (b) tripping, (c) foot drop, (d) hand weakness, (e) dropping objects, (f) shoulder weakness, (g) difficulty buttoning shirts, and (h) turning a key (Gordon, 2011; Rowland, Mitsumoto, & De Vivo, 2005). These common fine motor activities can be easily dismissed by patients and can lead to delays in seeking medical evaluation for many, which can also delay the diagnosis of the disease (ALS Association, 2010; Silani et al, 2011).

Between 20% to 30% of ALS patients present with bulbar dysfunction (ALS Association, 2009; Kuhnlein et al., 2008). Bulbar ALS is the type in which onset symptoms are in the facial muscles, speech, and swallowing (ALS Association, 2010). The term bulbar refers to the motor neurons located in the bulb region of the brain stem, which control the muscles of speaking, swallowing, or chewing (Forshew & Hulihan, 2007). Almost all ALS patients demonstrate bulbar involvement in later stages of ALS (Kuhnlein et al., 2008).
Management of ALS

Assessment of the disease progression is very difficult (Radunovic, Mitsumoto, & Leigh, 2007). Several different functional scales, imaging techniques, and neurophysical tests have been developed, but none have sufficient diagnostic or prognostic certainty associated with them (Mitsumoto, Ulug, & Pullman, 2005; Winhammar, Rowe, Henderson, & Kiernan, 2005). The most useful clinical measures remain the forced vital capacity (FVC) (Czaplinski & Yen, 2006) and the revised ALS functional rating scale (Kaufmann, Levy, Thompson, et al., 2005).

Respiratory management of ALS. Because most ALS patients die of progressive respiratory failure, the assessment as well as management of respiratory function is crucial (Lechtzin, 2006; Singh et al, 2011). Forced vital capacity (FVC) is the most commonly utilized measure to assess respiratory function in ALS patients (Simmons, 2005; Singh et al., 2011). Shorter survival times have been associated with lower FVC in ALS patients (Stambler, Charatan, Cedarbaurn, et al., 1998). Although it remains unclear whether noninvasive positive pressure ventilation (NIPPV) can actually slow the rate of FVC decline over time (Simmons, 2005), it has been shown to have many benefits, especially when utilized for four or more hours consecutively in a 24-hour time frame. NIPPV is usually provided by a bi-level positive pressure device (BIPAP) because continuous positive pressure (CPAP) ventilation has not be shown to be beneficial to ALS patients (Radunovic, Mitsumoto, & Leigh, 2007). Simmons (2005) asserts that because there is an association with respiratory symptoms when the FVC reaches 50% or less, BIPAP is usually started at this point. BIPAP can be tolerated fairly well among ALS patients, but when problems arise, they are usually due to patients being
unable to tolerate the sensation of the facemask or the airflow in the nose or pharynx (Lechtzin, 2006). This is especially true (Bourke, Bullock, Williams, Shaw, & Gibson, 2003; Gruis, Brown, Schoennemann, Zebarah, & Feldman, 2005) in patients with bulbar presentation of ALS. With these ALS patients, BIPAP can be effective until severe problems with secretions and inability to cough emerge.

**Long-term ventilation.** BIPAP will not sustain life indefinitely in ALS patients and ultimately these patients and their families need to decide whether they desire a tracheostomy and long-term ventilation in order to survive (Simmons, 2005). Use of long-term ventilation in the United States is very low. The ALS CARE database (Bradley, Anderson, Bromberg, et al., 2001) state only 3.2% of ALS patients with a FVC less than 40% utilize long-term ventilation. The utilization of long-term ventilation by an ALS patient represents a dramatically different, more complex level of care (Rousseau, Pietra, Blaya, & Catala, 2011) than NIPPV, or BIPAP utilization, and must be considered carefully by patient and caregiver alike.

Long-term ventilation can substantially prolong life. In fact in one study by Hayashi and Oppenheimer (2003), of the 70 ALS patients receiving long-term ventilation enrolled in their study, 33, or 47% survived longer than five years, but these patients also lost their ability to speak. Long-term ventilation is also very expensive with an average cost of $153,120.00 per year, which is not covered by insurance (Simmons, 2005). Fousseau, Pietra, Blaya, and Catala (2011) found that although ALS patients who choose to have their lives extended via a tracheotomy and mechanical ventilation can have quality of life that is unaffected, the presence of the tracheotomy leads to total dependence on caregivers who must deal with the care on a 24/7 basis, which can create a
very heavy burden on family caregivers. Lastly, Simmons maintains the use of long-term ventilation poses a significant challenge to family caregivers because it requires the caregivers to spend less time away from the home, poses considerable financial strain, and increases stress in dealing with multiple nurses, insurers, and suppliers. In fact 47% of caregivers caring for a long-term ALS ventilator patient maintain that their own health had suffered while 42% stated having the ALS patient at home was a major burden (Moss, Casey, & Stocking, 1993) from the caregiving involved. Caregiver resentment was present and 30% of caregivers caring for these ventilated patients rated their own quality of life lower than that of the ventilated ALS patients they were caring for (Kaub-Wittemer, Von Steinbuchel, & Wasner, 2003). Death in these long-term ventilated ALS patients comes from either a decision to stop the ventilatory support or from complications that arise from something other than respiratory status, such as infection (Lechtzin, 2006).

**Dysphagia.** Dysphagia, or difficulty swallowing, impacts the ability to take in enough food resulting in malnutrition and dehydration (Kasarskis et al., 1996; Simmons, 2005) as well as increased choking, and pulmonary aspiration risks. Among studies in ALS patients with bulbar presentation, 93% have dysarthria, or difficult or unclear articulation of speech; 86% have dysphagia and 64% exhibit tongue fasciculation (Chen & Garrett, 2005). Tongue weakness frequently limits the ALS patient’s ability to move food around in the mouth, which may cause frequent choking or coughing episodes. Meal times often become very labored and long. Malnutrition, dehydration and weight loss often follow. In one study, 16.4% of ALS patients were found to be malnourished
and this malnourishment causes a 7.7% increased risk of death (Desport, Preux, & Truong, 1999).

Management of dysphagia is initially controlled by changes in the consistency of the patients’ food with thicker liquids and recommendations of eating more frequent, smaller meals (Simmons, 2005). Solid foods should be moist and soft for the patient to eat. The use of a straw along with a chin-tuck maneuver is recommended for liquid intake. When these measures prove ineffective, the placement of a gastrostomy feeding tube (also called percutaneous endoscopic gastrostomy, or PEG tube) is recommended.

**PEG tubes.** The benefits of a PEG tube are many. First, the nutritional status of most ALS patients is dramatically increased (Mazzini, Corra, & Zaccala, 1995) and quality of life (QOL) is enhanced, however Simmons (2005) points out that careful measurements with ALS patients concerning QOL have yet to be carried out. Nutritional status is very important to ALS patients because they may actually burn more calories than they did pre-diagnosis because they need to use more muscles to perform routine activities, like eating, than before (ALS Association, 2008). The muscles of the body also store energy that the body needs to use quickly and when the muscles become atrophied and wasted in ALS patients, they cannot store as much energy. Insertion of a PEG tube can ensure that adequate nutrition occurs while reducing meal times (Mitsumoto & Rabkin, 2007), which can be often frustrating for the patient and difficult for the caregiver to witness. The tube feedings provide all the nutrition needed and can often restore weight loss (Carr-Davis, Blakely-Adams, & Corinblit, 2007). Many ALS patients can still maintain eating some oral foods, as long as choking is not a risk, while receiving their tube feedings via a PEG tube (ALS Association, 2010). The PEG tube
also provides a safe way to give medication (Radunovic, Mitomoto, & Leigh, 2007).

There are three ways of inserting a PEG tube: surgically, endoscopically, or radiologically. Surgical placement requires the patient to undergo general anesthesia, so in most ALS patients, endoscopic placement is preferred (Z. Simmons, personal communication, June, 2010).

**Dysarthria.** Because bulbar presentation in ALS usually involves a combination of both upper and lower motor neuron dysfunction, dysarthria early signs include: (a) harsh, hoarse or strained voice, (b) breathy speech patterns with short phrases, (c) hypernasality, (d) decreased range of pitch and loudness, (e) imprecise consonants, or (f) inappropriate pauses in speech (Kuhnlein et al., 2008). Because the tongue acts as the main articulator of speech, slurring can appear as one of the primary symptoms of impaired tongue function in ALS and as the ALS disease progresses, patients have increasing difficulty and ultimately many fail to produce accurate speech (Tomik & Guiloff, 2008). Slow speech rate is a prominent characteristic of dysarthria in ALS patients (Ball, Willis, Beukelman, & Pattee, 2001; Weismer, Laures, Jeng, Kent, & Kent, 2000), especially at the end of the day when a patient is either tired or has been speaking for a long time (Simmons, 2005). The voice can also develop a nasal tone as a result of air leakage in the nose. The tongue can also present with many fasciculation’s or spastic with many slowed movements in all directions (Scott & McPhee, 2005). The tongue, lips, and pharynx movements can slow down and become limited, which results in increasing intelligibility and ultimately in a complete loss of the ability to speak (Simmons, 2005).
AAC devices. The loss of the ability to communicate effectively can be devastating on a psychological level to both caregiver and patient and often results in impaired social closeness (Murphy, 2004). Augmentative and alternative communication (AAC) devices are commonly used when communication becomes impaired so that despite the loss of speech, ALS patients can continue in roles (i.e. parent, spouse, employee) that are important in their lives (Doyle & Phillips, 2001; Gruis, Wren, & Huggins, 2011). In order to fulfill these roles, Light (1988) maintains 4 essential areas of social interaction are necessary: (a) sharing of new information, (b) meeting basic needs, (c) establishing and maintaining social closeness, and (d) following the rules of social etiquette. Many types of AAC technology are able to store and retrieve messages in order to fulfill communication needs in all four of these areas (Bardach & Newman, 2003). Quick needs of ALS patients are often communicated using unaided or low technology methods (Fried-Oken et al., 2006). Examples of this might include: (a) writing, (b) hand signals, (c) sign language, (d) letter boards, (e) word lists, and (f) picture boards. All of these AAC devices are utilized for patients (ALS Association, 2010). Electronic AAC devices are also suitable for many ALS patients but must be customized to meet the individual needs of the patient and careful assessment of physical function, level of education, and comfort with technology are all important factors to consider (Gruis Wren, & Huggins, 2011; Simmons, 2005). Not all AAC devices are high technology or expensive and some ALS patients are using a speech to voice application for IPAD that costs $1.99 to download and works well for typing in a message and having the device speak for that patient (ALS Association, 2010).
**Pseudobulbar affect.** Pseudobulbar affect describes a condition where pathological laughing or crying occurs that is disproportionate or inappropriate to external stimuli or internal feelings (Mukund, Kaplan, & Senno, 1996). It is often very embarrassing for both ALS patient and family caregiver and is most commonly treated with antidepressants. It does not represent a mood disorder (Simmons, 2005), such as bipolar disease or depression, and commonly co-occurs with other pre-existing conditions, such as stroke, dementia, or multiple sclerosis (Iannaccone & Ferini-Strambi, 1996; Lauterbach & Schweri, 1991; Schiffer, Cash, & Herndon, 1983; Seliger & Nornstein, 1989). Pseudobulbar affect is thought to be caused by a lack of restraint originating in the bulbar region of the brain, which is responsible for normal crying or laughing (Gelinas, 2007). Selective serotonin reductase inhibitors (SSRI’s) are commonly prescribed as an initial treatment and are generally well tolerated by most ALS patients. In ALS patients with pseudobulbar affect, the response to SSRI’s is much faster than with patients with depression, and positive effects can be seen as quickly as 48-72 hours after the initial dose (Simmons, 2005). Other medications such as lithium (Shader, 1992) and levodopa (Udaka, Yamao, & Nagata, 1984) are also effective. A new drug, Neurodex, is awaiting Federal Drug Administration (FDA) approval pending clinical drug trials. Initial findings with this drug have shown neurodex to decrease the severity and frequency of pseudobulbar episodes (Gelinas, 2007). Last year Avanir Pharmaceuticals announced a phase III clinical trial of dextromethorphan (20 mg) and quinidine (30 mg) has shown these drugs to be effective for treatment of pseudobulbar affect (EurekAlert, 2009; Gordon, 2011). The drug was originally called Zenvia or PVP-
923 (AVANIR, 2010) but when approved by the FDA on October 29, 2010 its brand name became Nuedexta (Drugs.com, 2012).

**Sialorrhea.** The human body produces between four to six cups of saliva daily and normally this saliva moves around in the mouth and is swallowed unconsciously. However if the muscles responsible for swallowing are weakened and the lips or jaw are not controlling the saliva, it is difficult to maintain that saliva in the mouth and drooling occurs (Carr-Davis, Blakely-Adams, & Corinblit, 2007; Gordon, 2011). Sialorrhea is the medical term given to excess drooling or salivation. With ALS, there are two types of secretions that are a problem: serous and mucous (Simmons, 2005). Serous secretions come from the salivary glands and mucous originates from the nose and lungs (Newall, Orser, & Hunt, 1996). In ALS, sialorrhea (Wrong Diagnosis, 2010) is related to salivary gland production. It is not associated with overproduction of these glands, but from the ALS patient’s inability to handle or swallow saliva (Simmons, 2005) and occurs in 50% of ALS patients (Miller, Jackson, & Kasarskis, 2009). Sialorrhea places the ALS patient at higher risk for aspiration while placing the ALS patient with embarrassing and socially limiting situations. Sometimes suction machines are helpful as well as anticholinergic medications (Gelinas, 2007; Gordon, 2011) such as glycopyrrolate, atropine, amitriptyline, and hyoscymine. One problem from the utilization of this drug therapy can be the thickening of the mucus that accumulates deep in the throat (Simmons, 2005).

When oral medications fail to be effective for sialorrhea, botulinum toxin is often offered and injection into each parotid gland, with higher doses up to 75 units producing maximum results (Lipp, Trottenberg, & Schink, 2003). If this is ineffective, injection into the submandibular gland can be done (Simmons, 2005). Radiation
treatment is another treatment that can reduce sialorrhea and is targeted at the parotid, submandibular and sublingual glands of the ALS patient (Gordon, 2011; Stalpers & Moser, 2002).

For treatment of the thick mucus that pools in the throat and is difficult for the ALS patient to cough up or clear, beta-blockers such as propranolol or metoprolol are utilized (Newall, Orser, & Hunt, 1996). This mucus is especially dangerous because it places the patient with ALS at increased risk of aspiration. The mucus is believed to originate in the glands with beta-adrenergic receptors. For this reason, beta-blocker medications are employed (Simmons, 2005). The use of a mechanical cough-assist device is also helpful by its ability to increase peak cough expiratory flow (Mustfa, Aiello, & Lyall, 2003). New alternative therapies also include (a) reduction of alcohol, caffeine and dairy products along with increased fluid intake; (b) papaya tablets; (c) sugar free citrus lozenges; and (d) grape seed oil (Gordon, 2011).

**Sleep-wake disturbances.** Sleep-wake disturbances in ALS patients are common. Complaints such as (a) insomnia, (b) disturbed sleep, (c) nightmares, (d) morning headaches, (e) nocturnal awakenings, and (f) daytime sleepiness are symptoms that are usually associated with interrupted nocturnal gas exchange and hypoventilation (Coco, Mattaliano, Spataro, Mattaliano, & La Bella, 2011). There is also an increased incidence of restless leg syndrome while asleep and increased daytime somnolence. Coco et al. found that poor quality of sleep is correlated with the severity of the ALS and daytime somnolence.

**Frontotemporal dementia.** Frontotemporal lobar degeneration (FTLD), particularly frontotemporal dementia (FTD) is now recognized as part of the spectrum of
neurodegeneration in ALS (Anderson, & Miller, 2002; Bigio, Lipton, White, Dickson, & Hirano, 2003; Forman et al., 2006; Lomen-Hoerth, 2004; Lomen-Hoerth et al., 2003; Silani et al., 2011). About 10% -15% of ALS patients with FTLD become demented (Forshev & Hulihan, 2007) but up to 50% can be distinguished from non-FTLD ALS patients upon neuro-cognitive testing (Lomen-Hoerth, 2004). FTD is typified by personality and social conduct changes (i.e. social dis-inhibition and distractibility) as well as loss of insight with memory still intact. Work generation (Forshev & Hulihan, 2007), problem solving, and planning abilities (Neary, Snowden, & Gustafson, 1998) are often compromised. As in Alzheimer’s disease, ALS patients with FTD will progressively lose the ability for decision-making (Abrahams, Leigh, & Goldstein, 2005; Mendez, Anderson, & Shapira, 2005; Mendonca, Ribeiro, Guerreiro, & Garcia, 2004). ALS patients with bulbar presentation appear to have higher risk of FTD (Lomen-Hoerth et al., 2003). FTD ALS patients need to be monitored more closely for safety concerns, such as gorging or impulsive behavior, like accumulating huge credit card debt. End of life discussions, including durable medical power of attorney, PEG tubes, or long term mechanical ventilation, need to take place well in advance of advanced FTD (McCluskey, 2007; Simmons, 2005).

**Rilutek.** Riluzole (Rilutek) is the only drug available in the United States that is Food and Drug Administration (FDA) approved for treating ALS (Gelinas, 2007; Radunovic, 2007; Simmons, 2005). In a controlled trial of riluzole in ALS patients by Bensimon et al. (1994), muscle strength rate declined, survival rate increased at 1 year, and median survival was increased by 83 days. It has been shown to be most effective when given early diagnosis and with less severe forms of ALS (Simmons, 2005). In a
placebo-controlled, double blind study by Bensimon et al., (2002), ALS patients with a FVC less than 60% and those over 75 years of age showed no effect of taking rilutek on either rate of deterioration or on survival rate (Simmons, 2005). It is also unclear if or when rilutek should be stopped (Radunovic, Mitsumoto, & Leigh, 2007). It is tolerated relatively well but will be stopped if the patient’s liver function test values exceed five times the upper limit of normal values (Radunovic, Mitsumoto, & Leigh, 2007), which occurs in less than 4% of patients (Simmons, 2005).

**Introduction to Family Caregiving**

Many families are finding themselves in the position of providing primary care for family members who are disabled or ill. Primary caregivers are characterized as “people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework, and self-care” (Australian Bureau of Statistics, 1999). As a result of many patients living longer with life altering medical conditions along with the sky rocketing price of healthcare, many family members are replacing skilled healthcare workers in providing complex medical care to their loved ones. Not only has the provision of care changed (McCorkle & Pasacreta, 2001), but many of these family members find themselves assuming the unfamiliar role of providing high technological care as well as increased psychological support in their homes (Aoun, Kristjanson, Currow, & Hudson, 2005).

The contributions made by America’s family caregivers often go unrecognized by public officials making financial and policy decisions, yet these unpaid caregivers provide the majority of long-term services and support for individuals with disabilities of all ages (Fromme et al., 2005). Many of these family caregivers provide health related
care. In fact, the economic value of their caregiving is estimated to be worth approximately $350 billion, which is more than the entire amount spent by the U. S. government for Medicare services for the same time period (Gibson & Houser, 2007). Without the contributions of family caregivers, both state and federal health and long-term care budgets would be overwhelmed by the demand for services. In fact, the US does not have enough direct care workers to replace family caregivers (Institute for the Future of Aging Services, 2007). With the aging population and increased survivorship of many illnesses, the number of family members providing care to the loved ones is expected to rise over the next decade (Rabow, Hauser & Adams, 2004; Sorrell, 2007).

As of November 2006, there were between 30 million and 38 million adult caregivers (18 years and older) providing care to adults who had some amount of limitation in an activity of daily living (ADL). These caregivers provide approximately 21 hours of caregiving each week or 1080 hours per year (Gibson & Houser, 2007).

Literature shows that caring for a relative places the caregiver at risk for having more physical and mental health problems (Erlingsson, Magnusson, & Hanson, 2011; Gaugler et al, 2003; Lackey & Gates, 2001; Levesque, Ducharme, Zarit, Lachance, & Giroux, 2008; Lyons, Zarit, Sayer, & Whitlatch, 2002). Spousal caregivers have an even greater risk of death (Schultz & Beach, 1999) and higher mortality rates (Rhee, Degenholtz, Sasso, & Emanuel, 2009) than their non-caregiving counterparts.

**Palliative care home care.** Palliative care focuses on the provision of health care to those who are terminally ill with the goal of assisting families and patients during the illness and after the death of that family member. Maximization of quality of life is always a goal for both the patient as well as the family (Palliative Care Australia, 2000).
Research from the UK and Australia has shown that up to 90% of terminally ill patients live at home during the last year of their life and one-third of all palliative care patients die in the home setting with family members providing the primary care for them (Palliative Care Australia, 1998; Robbins, 1998). It is reported that 50% to 70% of terminally ill patients prefer to die in the comfort of their own homes (Grande, Addington-Hall, & Todd, 1998).

There are three reasons for this increase in palliative care home services. First, there is a marked reduction in the number of hospital beds available for terminally ill patients. Secondly, most terminally ill patients do not want to have formal institutionalized medical care if it can be provided as capably in the home setting. Lastly, there is demand from an increasingly aging population, where mortality and morbidity increase as a person ages (Aoun, Kristjanson, Currow, & Hudson, 2005).

The preference of patients wanting to spend their final days at home is in agreement with the governmental goal of shifting healthcare into the community and away from formalized institutions, especially when cost containment is a goal (Chochinov & Kristjanson, 1998). Despite the desires of patients, families, and governmental systems, most family caregivers feel woefully ill-prepared to meet the complex challenges awaiting them in taking care of a dying family member in their home setting (Aranda & Hayman-White, 2001; Kristjanson, Hudson, & Oldham, 2003; McCorkle & Pasacreta, 2001; Yates, 1999).

**Caregiving Literature Review**

Zarit (2004) speculates that end-of-life literature focusing on family caregiving has been overlooked in the general caregiving literature due to the relatively short
duration of terminal illnesses when compared to illnesses such as Alzheimer’s disease, which can require a decade or more of caregiving responsibilities. Most research on the phenomenon of family caregiving has concentrated on dementia (Haley, LeMonde, Han, Burton, & Schonwetter, 2003), but increased interest in family caregiving of cancer, palliative care, and terminally ill patients is emerging (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Given & Given, 1996; McCorkle & Pasacreta, 2001; Weitzner, Haley, & Chen, 2000).

General caregiving literature has focused largely on three broad areas of caregiving: (a) The impact of caregiving, (b) unmet needs of the caregiver, and (c) caregiver differences. The literature from these three topics will now be examined.

**The impact of caregiving.** Research examining the demands caregiving places on the carers has largely been devoted to two types of caregivers; those who provide care to palliative care patients and those who care for cancer patients. Most of the research examined has been from caregiver populations in the US, UK, Canada, and Australia (Aoun et al., 2005).

Caregiver stress has been examined and the following sources of stress have been revealed: (a) family role changes, (b) transportation concerns for treatment, (c) lack of knowledge about how to care for the patient, (d) insufficient social support, (e) apprehension about being alone after the death of the patient, (f) uncertainty about treatment plans, and (g) financial concerns (Grbich, Parker, & Maddocks, 2001; Kristjanson & White, 2002; Rose, 1999). Caregivers also have been found to have (a) diminished self-confidence, (b) less leisure time of their own, (c) frequent exacerbation of past illnesses, (d) loss of control over activities they perform daily, (e) employment
changes, and (f) feelings of distress (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996; Stajduhar & Davies, 1998; Steele & Fitch, 1996). In addition to the caregiving role, these carers also need to adapt to many changes in their family life (Erlingsson, Magnusson, & Hanson, 2011). For example, many need to relocate due to increased financial burden or new modifications needed to accommodate their terminal loved one. This can have a huge negative impact on the caregiver’s own health (McGrath, 2001; Vachon, 1998).

Recent research into caregiver health has shown stress, exhaustion, anxiety (Blue & Sherman, 2010; Funk et al., 2010; Stajduhar et al., 2010) as well as experiencing uncertainty in demanding caregiving situations (Duggleby et al., 2010; Greenwood & Mackenzie, 2010) had a negative impact on a caregiver’s health.

Many caregivers report the need to sell assets, refinance or re-mortgage their home, or work an additional job to help pay for the increased health care costs of caregiving (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). In addition to this financial strain, support is often unavailable to many caregivers based on being geographically isolated from such services (McCorkle & Pasacreta, 2001).

Anxiety has been studied with caregivers and the 46% of informal palliative caregivers reported anxiety and 39% revealed they were depressed within a year prior to the death of their loved one with cancer (Ramirez, Addington-Hall, & Richards, 1998). In this same study, about 50% of the caregivers disclosed they had problems sleeping and about 33% claimed to have experiencing weight loss during that same time period. Both caregivers and the patients rated anxiety as the most severe problem experienced in that year.
The impact on the older adult caregiver has also been examined and those older spousal caregivers who experienced stress from their caregiving roles had a 63% higher chance of early mortality than non-caregivers (Schulz & Beach, 1999). Findings from this same study showed that the high physical demands, feelings of loss and distress, and biological vulnerabilities of being older can increase these caregivers risk for impaired physiological functioning and physical health problems, which increases their risk for mortality. Another study looked at elderly caregivers and found that the introduction of hospice for the care recipients decreased the risk that the caregiver would become ill and die while going through the bereavement period (Christakis & Iwashyna, 2003).

**Unmet needs of the caregiver.** Research examining needs of the caregiver providing support to palliative care patients has revealed four areas of unmet needs for the carer: (a) communication, (b) support from health care providers, (c) information, and (d) provision of services (Aoun et al, 2005). Kristjanson, Hudson, and Oldham (2003) also examined unmet palliative care family needs and determined (a) emotional support, (b) daily patient care knowledge, (c) how to keep their loved one comfortable, and (d) knowledge about where to obtain aids (i.e. wheelchairs, hospital beds) for their loved one to be of primary concern to caregivers, yet these needs go largely unmet. Their research showed that providing the informal caregiver with information was central to providing support to these caregivers.

Communication between health care providers and caregivers is often lacking and many caregivers state they are not provided adequate amounts of information, especially about disease, treatment options, and prognosis, which could alleviate much of the fear and anxiety expressed by family caregivers. Many health care providers only provide
information to caregivers when their loved one is in an emergency illness situation. Those caregivers who appear to be coping well and who do not request information are assessed as coping well and without need of help (Harding & Higginson, 2003). Hudson, Aranda, and Hayman-White (2003) confirmed these findings and stated many caregivers found inadequate health care provider support to be the most formidable challenge they faced in the care of their loved one. These researchers also discovered that caregivers are reluctant to disclose fully to some health care providers because they do not want their own needs to be perceived as being more important than their loved ones. In addition, care providers regard their distress as being unavoidable and part of the caregiving experience. Putting strategies into place that provide caregivers with the information they need about care tasks and disease progression has also been researched (Haley, 2003) and the benefits of improving communication skills of health care professionals have been explored. Haley has also shown that although many caregivers receive support after the death of their loved one, other caregivers, especially those who have a loved one die in a nursing home setting, are often forgotten or ignored.

Zarit (2004) purports three reasons why health care providers need to be inclusive of caregiver needs. First, caregivers are essential members of the health care team due to the vital care they provide to their family members. Secondly, through their caregiver efforts, societal costs for terminal and chronic health care are greatly reduced. Most importantly, Zarit asserts the care they provide helps improve the survival rate of their sick loved one.

**Differences among caregivers.** Differences among caregiver reactions to the process of caregiving have also been explored by researchers. Findings show differences
in how caregivers react to the stress of caring for a loved one. Some show symptoms of severe depression and substantial drop in self-esteem, yet others facing the same stress do not experience these symptoms. To examine this phenomenon, stress process models have been utilized (Haley, Levine, Brown, & Bartolucci, 1987; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990). This research has focused on identifying risk factors for caregivers as well as exploring theoretical frameworks to provide targeted caregiving interventions. These stress process models have examined both primary stressors for caregivers, or stressors that arise directly for the caregiving of the patient, as well as secondary stressors, such as lack of social support/interaction, or declining caregiver health. Weitzner, Haley, and Chen (2000) have applied the stress process model to caregiver research in end of life and cancer and developed a theoretical model based on their findings.

**Caregiver distress.** There is lack of agreement in the literature about caregiver distress. Results of some studies have supported a link between the degree of patient impairment and greater distress in caregivers (Given & Given, 1996; Sales, Schulz, & Biegal, 1992), yet other research has shown little relationship between patient impairment and depression in caregivers (Beery et al., 1997; Haley & Bailey, 1999; Kurtz, Kurtz, & Given, 1995). Depression has also been shown to be more likely in caregivers if they felt less satisfied in their caregiving role, or if they found little meaning in the experience of caregiving (Folkman & Moskowitz, 2000; Haley & Bailey, 1999; Oberst, Gass, & Ward, 1989). Finally, research demonstrating overall risk to the health and well being of end-of-life caregivers to be homogenous with risks faced by long-term disease caregivers (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Rabow, Hauser, & Adams, 2004).
**ALS Caregiving.** The care of people living with ALS is often associated with a particularly intensive caregiving experience and recognition of the burden on caregivers has increased (Armon, 2006; Pagnini et al., 2010). Pagnini et al. found caregiver burden, depression and anxiety to be positively related to each other. In addition caregiver burden, anxiety and somatic expressions of depression are positively related to the ALS patient’s loss of physical functions. Some research findings have shown that caregiving time increases with the progression of ALS with the amount and intensity of the caregiving experience increasing as well. Estimates of caregiving time average 11 hours per day, but this time increases as the final stages of the disease approach (Murphy, Felgoise, Walsh, & Simmons, 2009). This caregiving occurs largely away from a formal medical setting, instead taking place in the community where family members assume most of the responsibility for the care of these ALS patients (Mockford, Jenkinson, & Fitzpatrick, 2006). For this review of the methodologies applicable to ALS caregivers, this nurse researcher has focused the literature search on informal caregivers, or “non-professional caregivers,” most commonly family members who provide care to loved ones from the start of their ALS diagnosis throughout their illness trajectory.

Financial concerns for ALS caregivers are great due to the many out of pocket costs associated with caring for their loved one. For example, for patients with no pharmaceutical insurance coverage, the out of pocket cost for riluzole average $550 per month in order to extend their lives by only 2 additional months (Mitsumoto & Rabkin, 2007). The cost of maintaining the patient’s quality of life and autonomy in the home setting for as long as possible demands expensive equipment and home renovation. Some of this possible equipment includes: (a) power wheelchairs, (b) speech aids, (c)
mechanical lifts, (d) handicapped vans, (e) ramps, (f) hospital beds, and (g) respiratory aids. The following table 2.1 gives an approximate cost of commonly used equipment for ALS patients along with an estimated cost. Although some items can be covered by insurance, out of pocket expenses to caregivers and patients can climb to thousands of dollars per year. Even with the financial help of the Muscular Dystrophy Association and ALS Association, this can contribute to overwhelming financial burdens for both caregiver and the ALS patient they care for (Mitsumoto & Rabkin, 2007).

Table 2.1 Approximate costs of various interventions for patients with ALS

<table>
<thead>
<tr>
<th>Category</th>
<th>Item</th>
<th>Cost ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs related to percutaneous enteral gastrotomy (PEG) feeding</td>
<td>Gastroenterologist consultation</td>
<td>500</td>
</tr>
<tr>
<td></td>
<td>Procedure</td>
<td>2200-2400</td>
</tr>
<tr>
<td></td>
<td>One-day hospital admission</td>
<td>3950</td>
</tr>
<tr>
<td></td>
<td>Food (6 cans of 8 ounce Ensure Plus)</td>
<td>260/month</td>
</tr>
<tr>
<td></td>
<td>Enteral pump rental</td>
<td>560/month</td>
</tr>
<tr>
<td>Mobility Aids</td>
<td>Manual wheelchair</td>
<td>600</td>
</tr>
<tr>
<td></td>
<td>Low-tech power wheelchair</td>
<td>500-8000</td>
</tr>
<tr>
<td></td>
<td>High-engineered power wheelchair</td>
<td>10,000-40,000</td>
</tr>
<tr>
<td></td>
<td>Hoyer mechanical lift</td>
<td>1000</td>
</tr>
<tr>
<td>Respiratory Aids</td>
<td>Noninvasive ventilator</td>
<td>6000</td>
</tr>
<tr>
<td>Item</td>
<td>Cost</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>------------</td>
<td></td>
</tr>
<tr>
<td>Mechanical volume ventilator</td>
<td>18,000</td>
<td></td>
</tr>
<tr>
<td>Pulse oximeter</td>
<td>1200</td>
<td></td>
</tr>
<tr>
<td>Apnea monitor</td>
<td>4600</td>
<td></td>
</tr>
<tr>
<td>Suction Machine</td>
<td>375</td>
<td></td>
</tr>
<tr>
<td>In-Exsufflator</td>
<td>6500</td>
<td></td>
</tr>
<tr>
<td>Communication Aids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Augmentative device (low tech)</td>
<td>200-1500</td>
<td></td>
</tr>
<tr>
<td>Augmentative device (high tech)</td>
<td>4000-15000</td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Riluzole (Rilutek) 50 mg orally taken twice a day (BID)</td>
<td>550/month</td>
<td></td>
</tr>
<tr>
<td>Home Assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>50-75/hour</td>
<td></td>
</tr>
<tr>
<td>Licensed Practical Nurse</td>
<td>35-45/hour</td>
<td></td>
</tr>
<tr>
<td>Home Health Aide</td>
<td>15-20/hour</td>
<td></td>
</tr>
</tbody>
</table>

Note: These costs are estimates from vendors in New York City. Costs may vary by location, as does the insurance coverage for the listed items. Mitsumoto & Rabkin, 2007

Interest has grown in the realm of the caregiving experience and the World Health Organization stated that identifying the needs of family caregivers is a primary objective for palliative care (World Health Organization, 1990). In addition, holistic family
focused care is one of the established goals of palliative care (National Consensur Project for Quality Palliative Care, 2009). ALS family caregivers provide the majority of support and play a pivotal role in clinical decision-making (Emanuel, Fairclough, Slutsma et al., 1999), therefore, understanding more about this population is warranted.

**ALS caregiving and quality of life (QOL).** By far, the largest category of research in ALS caregiving has revolved around the concept of quality of life for either ALS caregivers (Murphy, Felgoise, Walsh & Simmons, 2009; Williams, Donnelly, Holmlund, & Battaglia, 2008), or compared QOL in ALS patients and their caregivers (Bolmgjo & Hermeren, 2001; Ganzini, Johnston, & Hoffman, 1999; Gauthier et al., 2007; Gelin, O’Connor, & Miller, 1998; Jenkinson, Fitzpatrick, Swash, Peto, & the ALS-HPS Steering Group, 2000; LoCoco et al., 2005; Rabkin, Wagner, & Del Bene, 2000; Roach, Segerstrom, & Kasarskis, 2009; Trail, Nelson, Van, Appel, & Lei, 2003). Quality of life has been a prime area of research focus because a high correlation has been noted between ALS patient and caregiver distress, which includes anxiety, depression, and QOL (Rabkin, 2000). It is also been shown that the well being of ALS caregivers impacts the well being of their loved one with ALS. Following is a synthesis of the QOL literature, first focusing solely on the ALS caregiver and then QOL research that combines both the ALS patient and caregiver.

**Quality of life research focusing solely on ALS caregiver.** Two research studies (Murphy et al., 2009; Williams et al., 2008) examined ALS family caregiver needs and QOL and both focused solely on the perspective of the ALS caregiver and did not include the focus of the ALS patient in their research. Williams and colleagues used a mixed qualitative/quantitative method of Concept Mapping as well as individual
interviews with ALS family caregivers (n=19) to identify 109 needs of the caregiver. These needs were then sorted and rated by 12 of the family caregivers, then analyzed using multidimensional scaling and cluster analysis. Family caregivers also completed the SF-8 QOL measure. Their analysis revealed a four-stage cluster map showing the trajectory of needs of the ALS caregiver. Results indicated that ALS caregivers who live with their ALS patient family member have decreased mental and physical health than family caregivers who do not live primarily with their ALS patient family member.

Murphy and colleagues (2009) also focused solely on QOL in ALS caregivers, but concentrated on problem solving skills as a predictor of QOL and psychological morbidity in ALS caregivers. Their purpose was to identify factors that lead to family caregiver distress. They used correlational and hierarchical multiple regression analyses and found that social problem solving and spirituality were the best predictors of QOL for ALS caregivers. The level of care provided by the caregivers did not contribute to predicting psychological morbidity or the QOL of the caregivers. They also found that reported caregiver QOL was primarily in the average or high range. This was consistent with other findings showing lack of correlation between caregiver QOL and severity of the ALS patient disease trajectory (Elliott & Shewchuk, 2003; LoCoco et al., 2005; Rabkin et al., 2000).

Quality of life research including ALS caregivers and ALS patients. Other research studies have examined QOL in ALS caregivers and patient dyads. Rabkin, Wagner, and Del Bene (2000) compared and contrasted ALS caregiver and patient perceptions of anxiety, clinical depression, and QOL and found that neither clinical depression nor significant depressive symptomatology is an inevitable outcome of a life-
threatening illness, (e.g. ALS) and concluded that depressive symptoms commonly reflect a pre-existing vulnerability as opposed to an expected consequence of the illness. They interviewed 56 ALS patients and 31 caregivers on one occasion and 20 different patients were re-interviewed on a second occasion. Methods used included: (a) structured clinical interview for DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, fourth edition), (b) completion of a packet of self-report scales and questionnaires including: Beck Depression Inventory, Schedule of Attitudes toward Hastened death, QOL, spirituality and degree of hopelessness; (c) The ALS functional rating scale, (d) spirometry measures of forced vital capacity, and (e) Karnofsky Performance Index were used to assess physical status. These measures were then statistically analyzed using (a) Pearson’s Correlations, (b) Univariate analysis of variance, and (c) t test for group comparisons. Depressive symptoms and psychological distress were not related to the degree of patient disability, progression of the illness, or time from initial diagnosis. With caregivers, perceived burden of caregiving was significantly associated with finding positive meaning in the caregiving experience. A significant relationship was found between caregiver and patient distress, which suggests the importance of paying attention to the mental health needs of the caregiver and how it might impact patient distress.

Gelinas, O’Connor, and Miller (1998) also explored QOL but their focus was QOL for ventilator-dependent ALS patients along with their caregivers. Their findings were extremely limited because of the difficulty in measuring QOL, which was related to the ALS patient’s advanced state in the illness trajectory. All of the ALS patients had great difficulty communicating and only one patient was physically capable of writing, so
the SF-12 and ALSQOLI scales were unable to measure QOL in the patients. Their caregiver results showed that caregiver burden was often regarded as excessive. The ability to successfully adapt to ventilator usage was not correlated with how well prepared the caregiver or patient were prior to the ventilator decision was made, but rather how strong the friendship was between the two and how available a strong support network was to them.

Another group of researchers, Ganzini, Johnston, and Hoffman (1999) compared perceptions of ALS patients and their caregivers in relation to ratings of pain, suffering, and QOL. Their research revealed a greater concordance between the caregivers and ALS patients with the concepts of pain and suffering than with QOL. They separately interviewed 100 ALS patients and 91 family caregivers and used a 6 point Likert scale to assess (a) suffering, QOL, and severity of pain; (b) level of disability was measured with Sickness Impact Profile and Hopelessness, and (c) social support, church membership and religious experience were measured with undisclosed standardized scales. Major depressive disorder was diagnosed with criteria from the DSM-IV manual and three items taken from the Zarit Burden Inventory were revised to assess patient beliefs that their medical condition stressed, burdened, or caused financial hardship to their family. Spearman’s r was used for correlation; Mann-Whitney was used for median comparison as well as logistical regression.

QOL research has also focused on separating the needs of the patients from the caregivers. Bolmsjo and Hermeren (2001) conducted one of the rare qualitative inquiries comparing perception and experiences of ALS patients and their caregivers and examined eight pairs of ALS patients and their caregivers and noted that the two groups should be
viewed as having their own needs and preferences as related to the disease. They found that perceptions of needs as well as how the ALS disease is viewed, judged, evaluated, and processed greatly differ among patients and their caregivers. Also, the need for caregivers to have someone to confide in and give them support was important. One of the main limitations of this qualitative study is that it consisted of a single interview with no follow-up interview to validate the information derived. It also did not state whether the patients and caregivers were interviewed separately or together, which could greatly impact their findings because many caregivers are reluctant to be totally open in their responses while the care recipient is present, as evidenced in the ALS clinic where I am a research assistant. Ensuring the privacy of that caregiver to freely make comments without the influence of the patient in the room could greatly change their results if this was not done. This study was examined because it is one of the rare qualitative studies examining perceptions of ALS patients with ALS caregivers and although it does not specifically address QOL, it does address the congruency of perceptions between the two groups.

Trail, Nelson, Van, Appel, and Lai (2002) examined QOL, depression and attitudes toward treatment options between ALS patients and caregivers and their quantitative study included use of the Appel ALS rating scale (AALS), the ALS functional rating scale (ALSFRS), McGill Quality of Life Questionnaire Single Item Scale (MQOL-SIS), and the Beck Depression Inventory-II (BDI-II). Overall, their research showed that patients generally overestimated caregivers’ QOL by a small amount, but ALS caregivers underestimated the patients’ QOL by a greater amount. There were no significant differences between ALS patients and caregivers on scores of
QOL. Their findings were not consistent with those of Rabkin et al. (2000) because Trail et al. found ALS caregivers to be more depressed than the ALS patients on the BDI-II scale measuring depression while Rabkin et al. showed caregivers to be less depressed than their ALS patient family members.

Passage of time has also been explored in the concept of QOL. Roach, Segerstrom, and Kasarskis (2009) found time is not a factor in impacting QOL in patients; however QOL that is related to physical symptoms and total QOL diminished in ALS caregivers. This quantitative inquiry used the McGill Quality of Life Questionnaire to give insights into changes over time in total QOL. This was one of the few research studies that also examined the variable of gender and concluded that gender was mostly unrelated to patient and caregiver QOL, however younger caregivers had lower QOL scores across many domains examined. Roach, Segerstrom, and Kasarskis believe low QOL among ALS patients is largely a result of pre-existing individual differences, but both individual differences, like age and progression of the ALS disease impact QOL of the caregivers.

Roach, Segerstrom, and Kasarskis’ (2009) findings were confirmed by Gauthier and colleagues (2007) whose research showed that passage of time did not impact QOL in ALS patients, however caregivers overall psychological well being and QOL declined with the progression of the ALS disease. Gauthier et al. found the changes in the relationships between ALS patients and their caregivers that occur as the disease progresses are often devastating to the caregivers. For this study, two interviews were scheduled; one for a baseline and one nine months later. Patients were given the Zung Depression scale (ZDS), Self-Perceived Burden Scale (SPBS), McGill Quality of Life
Questionnaire (MQOL), and ALS Functional Rating Scale (ALSFRS). Caregivers were administered ZDS, MQOL, and Caregiver Burden Inventory (CBI). Comparisons were made with t-test and Fisher exact test.

Lo Coco and colleagues (2005) findings disputed those of Roach, Segerstrom, and Kasarskis (2009) and Gauthier and colleagues (2007) because Lo Coco’s study showed no correlation between QOL in ALS patients and their informal caregivers and could discover no concordance between caregivers and ALS patients due to their low ratings of QOL, which suggests that QOL is not interrelated between these dyads. Also, ALS caregivers who have lower QOL scores were not always involved with caring for the most physically or mentally impaired patients. Lastly they discovered that those ALS patients and family caregivers who reported spirituality as being important in their lives had higher QOL scores than those who did not endorse spirituality. This cross-sectional study aimed to address the QOL in ALS patients and caregivers and used the health related World Health Organization quality of life –BREF (WHOQOL-BREF) and individual schedule of evaluation of individual QOL- direct weighting (SEIQOL-DW) QOL, and the ALS functional rating scale (ALS-FRS) instruments in 37 ALS couples.

Another study examined caregiver “well-being” as opposed to QOL. Jenkinson, Fitzpatrick, Swash, Peto, & the ALS-HPS Steering Group (2000) assessed the health status of ALS patients and how patient health status is associated with caregiver well being using three measures commonly used to address the impact of the disease: (a) SF-36, which is a measure of well being and function; (b) the ALS Functional Rating Scale, and (c) the Carer Strain Index. The quantitative research showed that all three commonly used measures provide a valid plus meaningful descriptive picture of the impact of ALS.
Internal reliability of the measures was high and association between the measures provided evidence of their validity. Moreover, it showed that the health status of the patient can have significant impact on the health of the caregiver and suggested that caregivers have a lower health status than the general population. Caregivers were also impacted by the patients’ physical limitations by placing increased physical demands upon them as the physical limitations of the patients increased. Greater negative emotional reactions in patients also corresponded with greater emotional demands being placed on the caregivers.

**Concept of burden in ALS caregivers and patients.** The concept of burden has also been explored in ALS caregiving literature due to the unique demands the disease places on both patients and caregivers. Hecht and colleagues (2003) found that the burden of care increases as the functional impairment of the patient increases. They also discovered the addition of formal paid caregivers to the home did not decrease the burden of care of the family caregiver. Hecht et al. state this is because the home care given by paid caregivers is often inadequate and occurs too late in the illness trajectory to relieve the amount of burden in caring for these patients by the family caregiver.

Pagnini et al. (2010) examined ALS caregiver burden and found that the ALS patient’s degree of ALS decline is directly related to caregiver burden, anxiety, and depression. In addition this increased amount of caregiver burden is exhibited through a higher level of anxiety and depressive symptoms.

Chio, Gauthier, Calvo, Ghiglione, and Mutani (2005) conducted research aimed at examining whether ALS caregiver burden was associated with the ALS patient’s feelings of being a burden. Their results showed that caregiver burden was positively correlated
to that family caregiver’s level of depression and their own perception of their QOL, and unlike some other chronic diseases, caregiver burden increased as the patient’s disability worsened. They also posit that ALS patients have a good perception of how they are progressing clinically with their disease as well as the impact they have on their family caregivers.

**Comparison of needs between ALS caregivers and ALS patients.** Comparison of needs of ALS patients with their family caregivers has also been explored. Trail, Nelson, Van, Appel, and Lai (2004) used the Appel ALS rating scale (AALS) and an internally generated 19-item survey examining the three most important concerns to patients and caregivers. For this study, 66 ALS patients and 61 ALS caregivers were recruited to complete the checklist. Their findings revealed the greatest ALS patient stressors to be: (a) concern regarding the progression of their illness and dependency issues, (b) worries about the ability to speak, and (c) muscle weakness. The ALS caregivers identified their three greatest stressors as being: (a) worries about the progression of the ALS disease, (b) concern regarding their loved one’s ability to swallow or eat, and (c) worry about the physical and emotional well-being of their ALS family member. They assert these differences in the two groups are due to: (a) the influence of differences in life roles, (b) differences in the amount of physical disabilities due to the ALS disease, and (c) differences in future expectations by both groups.

Bolmsjo and Hermeren (2001) also challenged the notion that ALS caregivers and patients have similar views of the ALS disease and experience problems and needs in the same way. They found differences between the perceptions of ALS patients and their caregivers in five areas: (a) how they perceive their needs; (b) how they view, judge, and
evaluate the ALS illness; and (c) how they view the process of the disease. Because of these differences, family caregivers and patients should be assessed separately because their perceptions of need can be very different. This study was also a rare qualitative exploratory inquiry and utilized semi-structured interviews with eight ALS patients and eight family caregivers. It utilized a phenomenological approach. Also revealed by the caregivers was the need for more information about ALS as well as the need for someone that the caregiver could confide in. Sharma et al. (2011) also examined perceptions of ALS patients and their caregivers in relation to end-of-life decision-making and found that family members were often incorrect when identifying what preferences an ALS patient would have in family members making end-of-life decisions on the behalf of that ALS patient. The use of family meetings enhanced this the communication between family members and ALS patients and led to fewer disconnects in the decision-making process.

Two final studies compared ALS caregivers and patients but their focus was entirely different. First, Ganzine, Johnston, McFarland, Tolle, and Lee (1998) examined the attitudes of ALS patients and their caregivers towards assisted suicide. Their results showed 73% of the caregivers and patients had the same attitude towards the concept of assisted suicide. Those who would consider assisted suicide were more commonly (a) male, (b) had higher amounts of education, (c) less religious than those opposed, (d) scored higher on hopelessness scales, and (e) rated their QOL as being poorer. Depression was not associated with the desire for assisted suicide. Specific to the caregiver, perception of a loved one’s suffering, social support, or economic burden was not associated with attitudes about assisted suicide.
The second study examined communication preferences and information seeking behavior among ALS caregivers and patients revealed that both groups valued current research, disease modifying therapies, and outcome discussion about ALS as being most important to them (Chio et al., 2008). However, the ALS patients differed from the caregivers when they revealed that when the diagnosis, or “bad news” discussion took place, communication with the neurologist was adequate and they believed the physician had understood their feelings. Caregivers did not agree with these two points as strongly as the ALS patients did. Caregivers also were more likely than patients to seek out information about the disease from alternate sources, like the Internet or support groups. This is most likely due to their tendency to want to protect, or act on behalf of their loved one (Friedrichsen, Strang, & Carlsson, 2001). The low incidence of ALS patients seeking additional information could be attributed to use of denial as a protective defense mechanism (Houpt, Gould, & Norris, 1977).

**Current ALS Research**

**ALS stem cell research.** In September 2010, for the first time in the United States, stem cells were directly injected into the spinal cord of an ALS patient. Neuralstem Inc., which is a Maryland based Biotech Company, funded the research, which took place at Emory University in Atlanta, Georgia (ALS Association, 2011a). The first phase of the study was to determine if the invasive injection into the spinal cord is safe for ALS patients. A total of 12 ALS patients participated in the study. The first patient received several injections of stem cells in the lumbar spinal cord region because this is the area that controls leg function. The stem cells, which came from the spinal cord of an eight-week-old fetus were neural stem cells and have the ability to turn into
various types of nerve cells. They are not the same stem cells that are used with human embryonic stem cells, which is a controversial practice that destroys the embryo when the stem cells are removed. Pre-clinical work with rats has shown Neuralstem’s cells to extend the life of rats in the study (Falco, 2010). As of April 2011, 12 of the ALS patients in this trial had stem cells transplanted into the lumbar region of the spine. Of these 12, two ALS patients showed continued decline of their lower extremity function and eight showed lower extremity function scores that were the same or improved after the treatment. All survived the injection, which validated the safety of the trial. A total of 18 ALS patients will undergo the stem cell injections. After the mandated FDA safety data approval, the clinical trial is to progress to cervical injections to at least six ALS patients (ALS Association, 2011a).

**NeuRx diaphragm pacing system.** On October 5, 2011, the Food and Drug Administration (FDA) approved the NeuRx Diaphragm Pacing System (DPS) for ALS patients who have stimulatable diaphragms but are experiencing chronic hypoventilation (ALS Association, 2011b). The approval was based on the demonstration that NeuRx DPS could help ALS patients live longer as well as sleep better than the current standard of care alone. This was based on a multi-center clinical trial of over 100 patients. In ALS as the phrenic nerve to the diaphragm muscles fails, ALS patients lose the ability to breathe without mechanical ventilation. It is estimated that over 3000 of the 30,000 people in the US with ALS could benefit from the NeuRx DPS treatment. With ALS patients, NeuRx DPS is implanted via laparoscopic surgery and provides electrical stimulation directly to the diaphragm muscles. Repeated use of NeuRx DPS conditions
the muscles of the diaphragm, which delays respiratory failure and as a result the need for a tracheotomy and ventilator support (ALS Association, 2011b).

ALS genetic research. In 2011, two independent studies, both funded by the ALS Association, identified a genetic abnormality that is associated with the most common cause of ALS and frontotemporal dementia (FTD). A unique mutation was discovered and in this mutation a short DNA sequence was repeated many more times than in individuals without ALS (ALS Association, 2011c). This mutated repetition series is associated with approximately 50% of familial ALS cases in Finland and more than 30% of familial ALS in other European countries. This same genetic mutation was identified by researchers at Mayo Clinic in Florida. This identification of the genetic lesion on chromosome 9p21 is the strongest genetic risk factor for the most common form of ALS, sporadic, according to the ALS Association.

Head injury and ALS. A 2010 study published in the Journal of Neuropathology and Experimental Neurology suggests there may be a link between repeated head injury and ALS incidence (ALS Association, 2011d). Researchers discovered toxic proteins in spinal cords of athletes examined (n=12). Although this was a small sample size, the ALS chief scientist, Lucie Bruijn said the “results were exciting, however additional studies are needed. (¶ 4)”

National ALS Registry. As of October 19, 2010, the National ALS Registry was established with the goal of every ALS patient in the United States self-enrolling in the Registry. It was the largest ALS research project endeavored in the United States. The Registry collects data about not only the number of ALS patients, but also information about ALS that will hopefully be successful in finding what causes the disease, how it
can be treated, and how it can be prevented (ALS Association, 2012a). The ALS Association worked with Congress to enact the ALS Registry Act and obtained funding to design, build, and finally implement the National ALS Registry at the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR). All ALS clinics highly recommend their ALS patients self-register for this confidential registry, which can be done easily on the ALS Association website (www.alsa.org).

**Pathways to Hope.** In 2012, the ALS Association released a publication *Pathways to Hope: The State of Research into Amyotrophic Lateral Sclerosis*, which was the first report to document the most current advances in ALS research and review research efforts from the late 1800 to the 20th century. This publication provides a comprehensive overview of the current state of ALS research as well as offering insight that many of the neurodegenerative diseases, including ALS, Parkinson’s, and Alzheimer’s have commonalities. These commonalities have led to increased collaboration and information sharing among researchers. Through this increased collaboration, it is hoped that a breakthrough in any of these diseases could have positive application to the others (ALS Association, 2012b).

**Theoretical Perspectives**

**ALS Caregiving Trajectory.** When examining theoretical frameworks that might capture the essence of caring for a patient with ALS, the ALS trajectory was considered. ALS represents an expected death trajectory, which is represented by a progressive downward deterioration from diagnosis to death (Penrod, Hupcey, Shipley,
Loeb, & Baney, 2011) distinguished by loss of all voluntary movement including the loss of function of those muscles responsible for swallowing, speaking, and ultimately breathing.

Research on disease trajectories began in the 1960’s and has been applied to many illnesses including cancer (Murray, Kendall, Grant, Boyd, Barcley, & Sheikh, 2007), end stage renal disease (Jablonski, 2004), heart failure (Hupcey, Penrod, & Fenstermacher, 2009), and amyotrophic lateral sclerosis (Bremer, Walsh, Simmons, & Felgoise, 2004). Wiener and Dodd (1993, p. 20) define the trajectory of a disease as signifying “not only the physical unfolding of a disease, but to the total organization or work done over the course of the disease.” This is important because caring for an ALS patient is not a static phenomenon but involves a process that is ongoing and changing over time (Silva, 2008). These family caregivers need to meet the multi-dimensional needs of the patient, including (a) symptom management, (b) emotional, financial, and spiritual support; (c) personal and instrumental care; and (d) treatment monitoring (Kim & Given, 2008).

When considering theoretical frameworks that might capture the essence of caring for a patient with ALS, the ALS expected death trajectory was considered. A nursing theory that would capture this complex caregiving journey from the diagnosis through progressive, hallmark symptoms (i.e. swallowing/speech difficulties, loss of mobility, nutritional deficits/PEG tube placement, communication device augmentation, psychological support, respiratory muscle loss) ending ultimately in death was a paramount consideration. Three nursing theories, (Meleis’ Theory of Transitions, Parse’s Theory of Human Becoming, and Newman’s HEC) were considered for their application as a theoretical frame to the ALS caregiving trajectory. Meleis’ Theory of Transitions (Schumacher & Meleis, 1994) was the first nursing theory considered
because it held potential for elucidating the multiple transitional points that exist in the ALS illness trajectory.

**Meleis Theory of Transitions.** Schumacher & Meleis (1994, p. 119) describe transitions as “a passage from one life phase, condition, or status to another….Transition refers to both the process and outcome of complex person-environment interaction.” Meleis and Trangenstein (1994) state that transition can involve more than just one person and is highly embedded in the situation or context. Transitions are not mutually exclusive, but a complex process whereby many transitions can occur simultaneously during a time period. Transitions “denote a change in health status, in role relations, in expectations, or in abilities. It denotes a unique constellation of patterns of responses over a span of time” (Meleis & Trangenstein, 1994, p. 256). Meleis states her theory is middle range and asserts transitions to be a central concept for nursing (Watson & Pulliam, 2000). She asserts nurses play a key role in transitions because they frequently are the primary caregivers of patients as well as families who experience transitions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Nurses also serve in a preparatory and anticipatory guidance role for both families and patients as they facilitate the learning of new skills needed for the patient’s illness occurrence.

**Types of transitions.** There are four kinds of transitions that nurses encounter with patients and their families (Meleis & Trangenstein, 1994). The first, *developmental transitions*, has dealt mainly with the transition of becoming a parent, or journeying through life stages (i.e. adolescence or mid-life). While the majority of the developmental transitions research has focused on individuals and dyads (like mother-daughter), families have also been addressed.
Situational transitions, the second transitional type, have included transitions in educational and professional roles. Also, changes in family situations such as: (a) divorce, (b) widowhood, (c) nursing home entry, (d) homelessness, (e) immigration, (f) moving out of abusive relationships, and (g) near death experiences have been studied using this type of transition.

The third type of transitions, health-illness, has focused on individuals and families in many illness contexts. This research describes transitions through levels of care, for example from critical care to step down units, to rehabilitation, and back to the community setting.

Lastly, in 1994, Meleis added a fourth kind of transition, organizational transitions, which occur with environmental changes that may be related to social, political, or economic alteration in the environment external to the organization. The transition could also be an alteration in the structure or dynamics of the organization itself. Examples of this include: (a) role changes, (b) leadership changes, (c) new policy or procedure adoption, and (d) introduction of new technology. Specific to nursing, her theory has addressed (a) changes in educational preparation, (b) research methods, and (c) curricular content (Meleis et al., 2000).

Properties of the transition experience. Meleis asserts transitions are complex, evidenced in the identification of five key properties of the transitional experience (Meleis et al., 2000). The first, awareness, is related to the concepts of knowledge, recognition of the transition experience, and perception. Key to this property is the assertion that a person needs to have awareness of the changes that are occurring at that time. Engagement, the second property, is defined by the amount or degree a person
shows he or she is involved in the inherent transitional processes. *Change and difference* are closely related properties but have a key distinction. Transitions occur both as a result of change as well as result in change. She uses the example of a person being diagnosed with coronary heart disease (CHD) as regarding the disease diagnosis as a transition. With the same diagnosis, other CHD patients could regard the long-term process of the disease, which involved new roles and situations to adapt to, as more of a transition. Difference can also be understood by unmet expectations, feeling different from others, or seeing others and the world in different ways. The fourth property, *time span*, is represented by movement over a period of time and is characterized by identifiable beginning and end points. Lastly, *critical points and events* are identified by key marker events, such as death, birth, disease diagnosis, or the stoppage of menstruation.

**Uses of the theory of transitions in nursing.** Meleis’ Theory of Transitions has been used in nursing research with the following phenomena: (a) menopause in low income Korean immigrant women (Im, 1997), (b) parents and the diagnosis of congenital heart defects (Messias, Gilliss, Sparacino, EM, & Foote, 1995), (c) effects of racism on transition to motherhood for African American women (Sawyer, 1997), (d) transition to motherhood for a group of African American women (Sawyer, 1999), and (e) shifting patterns of self-care and caregiving during chemotherapy (Schumacher, 1994). Non-nursing literature use of Meleis’ Theory of Transitions has included: transitional research methods (Chick & Meleis, 1986), and transnational immigration of Brazilian women in the US (Messias, 1997). Critical characteristics of her theory include a qualitative approach with theory development as a goal. They also represent a feminist perspective.
(post-positivistic or integrative-interactive (Newman, 2008) in both the design as well as the data interpretation, which allows the inclusion of gender, culture, race, and class to the inquiry (Meleis, 2000).

**Discussion.** The evaluation of the Theory of Transitions led to the awareness that it would not be the best fit for the phenomenon of interest; ALS caregiving. The rationale for this decision was based on several concerns posed by utilizing this theory. First, when considering the five properties of transitions, three were found to be problematic. The first property of awareness requires an individual to have awareness of the changes that are occurring at that time and with the ALS caregiver this can be very problematic because of the rapid progression of the disease, which is experienced by many of the families. This swift decline in a patient’s functional abilities leaves many family caregivers with a high level of uncertainty as they try to manage the steep downward trajectory of the disease. Many caregivers struggle to manage the symptoms of the disease; therefore, recognizing the changes may be unrealistic for the caregiver.

Secondly, the issue of transitions versus change is inconsistent in the ALS caregiver literature. The ALS caregiver experiences many changes throughout the illness trajectory but researchers have yet to agree upon the most important transitions for caregivers (Goldstein & Leigh, 1999). For example, some have been identified, such as initial diagnosis and when respiratory efforts are compromised, but others such as PEG tube placement, loss of mobility, and loss of speech are not consistently regarded as transitions by the caregiver literature. Some caregivers regard these events as life impacting transitions yet other caregivers interpret these events as changes in the trajectory of the disease and have varying levels of distress regarding them. This lack of
consistency in the classification of key transitions for ALS caregivers would make use of the theory of transitions in nursing challenging for guiding studies of ALS caregiving.

Lastly, the concept of a time span being clearly characterized with identifiable end points is problematic with ALS. This does not happen with the ALS trajectory where the caregiving role ends with the death of their loved one, but the caregiving experience lasts well past death and cannot be clearly delineated as having an ending point where a “new beginning” occurs (Martin & Turnbull, 2001; Radunovic, Mitsumoto, & Leigh, 2007).

There have been only two caregiving studies using Meleis’ transitional theory and they involved the caregiving experience with a patient receiving chemotherapy (Schumacher, 1994), and parents and the diagnosis of congenital heart defects (Messias, Gilliss, Sparacino, EM, & Foote, 1995). These both appear to be appropriate uses of the theory because both represent a relatively short caregiving experience with clearly defined beginning and ending points. These distinctly delineated starting and end points of the transitions involved are one of the critical characteristics of this theory. The Theory of Transition is not as applicable to the longitudinal, complex caregiving trajectory (Penrod, Hupcey, Shipley, Loeb, & Baney, 2011) that is present with an ALS caregiver. No studies applying the Theory of Transitions have been carried out over an entire illness trajectory, and none have explored a known death trajectory that can encompass years to evolve, like ALS. Utilizing Meleis’ theory for a specific point in time in the transition of the ALS disease, such as the diagnosis of the disease, or one point along the trajectory could be effective, but using this theory to represent the entirety of the ALS disease with its multiple critical events, and lack of clearly defined end points
would not be acceptable to gain meaning of the caregiving experience over the entire trajectory of the illness, which is the goal of this research study.

Also, according to the literature, transition theory indicates the potential for transformative experiences that can arise out of the process of transition, but Meleis does not specifically address this. Transformative experiences would require a restructuring of the self as well as how the illness is perceived by the participant in order to regain some levels of control. Meleis’ transitional theory does not lend itself to this degree of abstraction (Larkin, Casterle, & Schotsman, 2007). Nor have any of her studies been done with a unitary transformative paradigm (Newman, 2008). However there are theories that do address this notion of restructuring of the self and are positioned in the unitary transformative paradigm. For this reason, Parse’s Theory of Human Becoming and Newman’s Theory of health as expanding consciousness were both explored for their theoretical fit to the phenomenon of ALS caregiving by family members and will be reviewed next.

Parse’s Theory of Human Becoming. When Rosemary Parse introduced her Theory of Human Becoming in 1981, it was regarded as a radical new way of thinking. She used assumptions from Rogers’ Science of Unitary Human Beings and existential phenomenology to formulate her theory. Additionally, she utilized the three major principles of Roger’s theory (helicy, complementarity, and resonancy) along with Roger’s four major concepts (energy fields, openness, pattern, and organization) to shape the development of the theory (Parse, 1987). Based on her definition of health, the health-illness continuum was regarded as irrelevant as were the care plans based on specific problems and diagnoses. She asserts this approach embraces the idea that
authority, responsibility, and the consequences of decision making reside with the individual, not the nurse (Parse, 2009).

The human becoming theory postulates that quality of life from the individual’s perspective is the true goal of nursing practice (Cody, 2009). The theory is constructed around the three themes of: (a) rhythmicity, (b) meaning, and (c) transcendence (Mitchell & Bournes, 2010; Parse, 2009). Rhythmicity is represented by the unity of life encompassing opposites in the rhythmic patterns of relating and is “dwelling along with the yaw, pitch, and roll of the human-universe experience.” Meaning is “explicating what was, is, and will be” while transcendence “moves beyond the meaning moment with what is not-yet” (Parse, 1998, p. 69-70). Practicing nurses utilizing this method live the three processes of illuminating meaning, synchronizing rhythms, and mobilizing transcendence (Cody, 2009).

Her theory is grounded in the belief that as humans, we co-author our own health or becoming by engaging in a mutual process with the universe, co-creating patterns that are distinguishable, which detail human and universal uniqueness. For Parse, humans and the universe are viewed as inseparable, each one co-participates with the other in the experience of living (Parse, 1987).

Parse describes two concepts that should be appraised prior to selecting a phenomenon for study: nature and structure. Nature refers to experiences that are commonly encountered that exist in the human-universe interrelationships and are related to health. Structure refers to the paradoxical living of the remembered, the now moment, and the not-yet all at once moment (Parse, 1987).
Process of theory of human becoming. Parse’s theory involves three methodological steps. The first is *dialogical engagement*, where a nurse, who is in true presence with the patient, focuses on the story brought forth from that participant. This engagement is recorded and the nurse does not plan specific questions in advance of the interview, but the method allows the researcher to ask the participant to elaborate further about the experience being explored. The second step, *extraction-synthesis*, involves the sorting of the main quintessence found in the dialogue between the nurse and participant, but should use the language of the participant. This is achieved through dwelling with the transcribed dialogues in order to uncover meaning as described by the participant. Lastly, *heuristic interpretation*, involves the weaving of the structured essences along with the major principles of human becoming theory. The use of this theoretical framework creates an enhanced knowledge base as well as the creation of further research ideas (Parse, 2008).

Uses of theory of human becoming in nursing. The Theory of Human Becoming has been employed by many nurse researchers. Research utilizing this method include studies of the following: (a) the concept of hope (Allchin-Petardi, 1999), (b) grieving (Pilkington, 2005), (c) time passing (Northrup, 2002), (d) suffering (Daly, 1995), (d) taking life day-by-day (Mitchell, 1990), (e) doing the right thing (Smith, 2006), (f) feeling loved (Baumann, 2000), (g) feeling alone while with others (Gouty, 1996), (h) having courage (Bournes, 2002), and (i) persevering through the difficult time of ovarian cancer (Allchin-Petardi, 1998).

Discussion. When this nurse researcher first examined Parse’s theory of human becoming, it appeared that this theory was getting much closer to what would best allow
the examination of the entire phenomenon of ALS caregiving. One strength of her theory is it has been used exclusively in nursing and has been used to explore a broad number of concepts that transverse over various lengths of time and could be considered suitable to trajectory diseases, such as ALS. Parse also shared her view of health as being an evolving pattern where there is no definable starting or ending point but instead represents a meaningful aspect of the dynamic pattern of the whole of an evolving person/environment relationship. However, there were parts of her theoretical perspective that represented a weakness for a research study. First, her theory emphasizes the beginning part of her research method, the dialogical engagement with the participant and is less focused on verification of what was discovered through a second interview or engagement. The endorsement of a single interview was problematic because this single encounter lacked the ability to verify or clarify the essences that emerged from the first engagement. The language used to describe her theory and method was very difficult to understand and maneuver through, which would narrow the utility of the product of the researched. However, the exploration of this theoretical framework seemed to affirm to this nurse researcher that this was a correct path of thought, but the proper fit for studying the phenomenon of ALS caregiving was still lacking. Therefore, the exploration into other nursing theoretical frameworks that would be situated in the unitary transformative paradigm (Newman, 2008) as well as similar in the view of health as representing a meaningful aspect of the dynamic pattern of the whole of an evolving person/environment relationship was warranted. For this reason, Margaret Newman’s health as expanding consciousness (Newman, 1994, 1995, 2008), situated in the unitary transformative paradigm, was explored next.
**Paradigmatic perspective of health as expanding consciousness (HEC).** The *Unitary transformative paradigm* (Newman, 1994, 1995, 2008), or *simultaneity paradigm* as Parse named it (Pilkington, 2007), allows for action oriented, participatory and emergent research that can change focus as the research progresses. In other words, the researcher goes to wherever the research leads him or her. In this paradigm, the researcher is an active participant in the evolving pattern of the whole. There is no separation of parts, and as a result, there is no ability to predict or to control. Change is unpredictable and unidirectional and is always moving towards higher levels of complexity. Through pattern recognition, knowledge is gained and this knowledge reflects not only the viewer but the phenomenon as well (Newman, Sime, & Corcoran-Perry, 1991). In this paradigm the nurse researcher and ALS family caregiver co-create a new pattern of the whole that is manifest in the nurse researcher/ALS family caregiver process. The ALS family caregiver’s pattern of the whole emerges from dialogue within this nurse researcher/ALS family caregiver process where nothing is viewed from the outside looking inward. The nurse researcher and ALS family caregiver join together as one to experience new insights together.

This paradigmatic perspective is vastly different from two other prominent nursing paradigms. The *particulate-deterministic* paradigm posits that phenomena are entities that are capable of being reduced and isolated into something that is definable and measurable. The relationship between beings is orderly, linear, highly predictable and causal. In this paradigm, health is contrasted with clearly definable characteristics that range from healthy on one end to unhealthy on the other (Newman, Sime, Corcoran-Perry, 1991).
The last paradigm, *interactive-integrative*, evolved from the particulate deterministic and views reality as being contextual as well as multidimensional. It stems from a social interactive perspective and considers multiple variables with some predictability. Multiple antecedents are believed to cause change in a phenomenon (Newman, 2008).

With the choice of these different paradigmatic perspectives, the natural fit for examining the entirety of the experience of caring for an ALS patient that could give the most meaning to this nurse researcher as well as to the ALS family caregiver was the unitary transformative paradigm because it no longer holds the researcher to be an observer from the outside looking in on a phenomenon. Instead, through actively presencing together with a family caregiver, mutual meaning could be derived. Margaret Newman’s theory of health as expanding consciousness is firmly situated in this paradigm (Newman, 1994, 1995, 2008) and will now be examined.

**Margaret Newman’s health as expanding consciousness theory.** There are many similarities between the Theory of Human Becoming (Parse, 1987) and health as expanding consciousness (HEC). First, they are both firmly situated in the unitary transformative paradigm and both are nursing theories designed for nursing practice and nursing research for the purpose of enhancing the science of nursing. Both embrace the same definition of health and illness as not opposites of each other, but as manifestation of the implicate pattern of that individual. Newman (1994) takes this one step further than Parse and asserts health is a synthesis of the opposites of disease and non-disease that derives something totally different: a transformation, or an expanding conscious. In other words, health is expanding consciousness.
To demonstrate this notion of health and illness being a manifestation of the implicate (as opposed to explicit) pattern of an individual, Newman (1986, 1994) uses the illustration of Bohm’s mental imagery of a fish swimming gracefully in a fish tank. Visualize that there are two different cameras centered on the fish, one at the narrow end and another at the wide side of the tank. Both cameras film the fish from different angles and contain images of the fish and flora that are obviously related, in timing, movement, and space relations. Each camera provides a valid picture of the contents of the fish tank, but neither portrays the whole picture. The projections are different points of view of the same but larger reality, just as disease or absence of disease are differing points of view or a greater reality. They cannot be detached from the whole just as the view of health as an evolving pattern of the whole requires a non-fragmentary worldview.

Nurses practicing from the HEC theoretical frame consider the various different physical manifestations of their patients to provide increased awareness of their implied, implicit pattern. HEC nurses develop multifaceted degrees of awareness that enable them to sense the underlying pattern in an individuals’ physical appearance and symptoms, emotional delivery, spiritual insights, and movements. HEC research requires the nurse researcher to be fully present with the ALS family caregiver without judgment, goals, or intervention strategies and this interaction creates a pure but also accurate reflection of the implicate pattern. It embraces the concept of being rather than doing for and being represents caring in its most respectful manner. In the context of this nurse researcher/ALS family caregiver relationship, patterns can be identified and as this occurs, action potential increases and transformation becomes a possibility. The HEC theoretical framework posits pattern to be a manifestation of consciousness and
represents the whole of a person’s relationship with the environment while giving an understanding of the meaning of the relationships all at one time (Newman, 1994).

In her definition of consciousness, Newman draws upon the work of Bentov (1978) who describes consciousness on a continuum ranging from rocks (who have little interaction with the environment) to plants (providing carbon dioxide through the ingestion of nutrients in the soil) to animals (capable of moving and interacting freely) to humans (who can make reflections and have the ability to participate in opportunities to interact with and try to control the environment) to spiritual beings (who are on the far side of the spectrum). Consciousness reconciles inconsistencies in quantum physics and relativity. For instance, the fact that observation affects results at the quantum level can be explained if all matter has some form of mind. The following quote by Christian de Quincey describes consciousness: “If both mind and matter are real, and are not separate substances, and neither can emerge or evolve from the other, then both matter and mind have always existed together, are coextensive, co-eternal and in some way, co-creative. Panpsychism, variously called panexperientalism or radical materialism, proposes that matter (or physical energy) itself is intrinsically sentient or experiential, all the way down” (Van Cleve, 2010, ¶ 2). When de Quincey says, "all the way down," he means from the entire universe down through the sub-atomic particles or waves.

Newman (1994) regards death as a transformational door whereby a person’s consciousness continues to expand and becomes part of a universal consciousness. Richer relationships that are more meaningful, open, loving and caring exemplify expanding consciousness. It can also be evidenced by people transcending their own
egos or by their ability to dedicate their energy to something that is greater than themselves, and learn to build order against the trend of disorder.

Another tenet of the HEC theory is that the process of pattern recognition is mutually transforming to both the nurse researcher and ALS family caregiver. Newman (1994) also uses imagery to describe this. Imagine throwing two stones into a calm, clear lake. When the stones impact, two waves of concentric circles emanate and grow from the point of impact of the stones on the water and these concentric circles continue to grow until the two-wave patterns meet and become enfolded into each other. The interference pattern continues to grow and encompasses the whole environment. This new pattern emerges and travels back to the center of each concentric circle. HEC models this because to be in touch with another individual and the surrounding environment requires the nurse to be “in touch with oneself, and sense into one’s own pattern” (Newman, 1994, p. 106). Both the nurse researcher and ALS family caregiver are interpenetrating aspects of one whole, or as Newman states (1994, p. 106) “in a holographic view of the world, the totality of existence is enfolded in each region of space-time. The order that has been recorded in the complex movement of electromagnetic fields (light waves) is present everywhere and enfolds the entire information of the universe in each region of space and time.”

The more a nurse can sense into him or herself and trust the information that is present, the more explicit that nurse can be in expressing his or her own truth and in knowing other individuals. Newman states the highest form of knowing is love, so she puts forth that nurses should love themselves, similar to many spiritual teachings (Newman, 1984). Keen (1978, p. 88) has examined the relationship between science and
religion on the basis of supporting the idea that each individual is a microcosm of the larger macrocosm and states, “consider the enormity of the self each of us is invited to inhabit and love.”

Newman (1984) uses the analogy of a hologram and pattern. In a hologram, every part contains information about the whole. Even the smallest parts, though fuzziest in nature, still provide information about the whole. This fuzziness in pattern is similar to the beginning of an interaction with another person where there is a sense of meaning or pattern that is unclear. However, if one persists with the interaction, meaning will become more evident as that person’s pattern begins to emerge.

In the discipline of medicine, medical practice is separated into 3 parts: assessment, diagnosis, and intervention. The emphasis remains on the individual, either in isolation or in the larger context of family and environment. According to Newman (1984), the nursing paradigm should have no separate parts; instead the process should be one of sensing into the pattern of the whole. There is no fixed pattern form but rather a continuous flow of relationships that merge into each other. An analogy would be music and the ability of a musician to provide a moving, interpenetration of varying rhythms, harmonies and relationships in the music performed. The music has no separate parts as is the analogy to nursing where the individual field (patient) is one or continuous with the family and environment.

The HEC theoretical framework goes beyond a nurse researcher and ALS family caregiver listening purely for facts. Instead it involves listening for understanding of meaning and requires attending with one’s whole being. Newman also asserts the nurse
researcher needs to sense her own pattern prior to and during the interaction with the ALS family caregiver (Newman, 1994).

As a research methodology, Newman uses a six-step method for her inquiry. She starts with a taped interview, opening the dialogue with a simple open-ended statement such as: Tell me about the most meaningful person(s) in your life. This question is modifiable to be appropriate for the research focus. Next the nurse researcher proceeds in a non-directive manner. If the ALS family caregiver needs help, the nurse can prompt him or her to think about something that is prominent in their memory. During this process the nurse researcher is an active listener and can clarify or reflect as needed.

Next the interview is transcribed. Following the transcription, Newman (1994) proposes the development of a narrative where the researcher selects key statements that are deemed to be most important to the ALS family caregivers and arranges these key data segments into chronological order to highlight the most noteworthy events. Patterns of the whole will emerge, consisting of segments of the caregiver’s relationships over time. This step is unique to HEC.

Also unique to Newman (1994) is the development of a diagram or pattern analysis, which is a graphical representation of significant relationships depicting the narrative in sequential pattern configurations. This is commonly represented through the use of a wavy line, which represents the flow of pattern across the life span. To this wavy line, another smooth wave is drawn to represent periods of non-chaos or disruption. Large, frenetic loops are then added to represent periods of chaos and turbulence. Lastly, Young’s Spectrum of the Evolution of Consciousness (Newman, 1994, p. 44) is used to
assess the pattern analysis for expansion of consciousness. Newman asserts this helps solidify patterns that emerge in the experience.

Follow-up is the next step and again unique when comparing Parse’s Theory of Human Becoming to Newman’s HEC theory. A second interview is conducted where the diagram (pattern analysis) is shared with the ALS family caregiver. This diagram is simply a graphical drawing of the caregiver’s story. This mutual viewing opportunity provides the caregiver the ability to confirm, clarify, or revise the story. Also, if the nurse researcher has questions about any parts of the story, this gives him or her the opportunity to clarify it. The ALS family caregiver may express that pattern recognition is happening and the caregiver and nurse researcher can mutually reflect on the caregiver’s life pattern.

Newman’s last step is application of the theory and this occurs after the interviews are completed. The nurse researcher then completes a more intense analysis of the data in conjunction with the HEC theory. The nature of the sequential patterns of interaction are evaluated in terms of quality and complexity and interpreted based on their location on Young’s spectrum of consciousness. Pattern similarities can be then designated through themes and stated in propositional form.

**Uses of HEC theory in nursing.** Health as expanding consciousness is a nursing theory that is meant for nursing practice as well as nursing research (Newman, 1994). As a theoretical framework, HEC represents a grand theory, but when used as a methodology it represents a nursing middle range theory (M. Newman, personal communication, August 19, 2009). HEC research has been applied to a wide range of populations: (a) life patterns of persons with coronary artery disease (Newman & Moch, 1991), (b) life
meaning and cancer (Barron, 2000), (c) gay men who are HIV positive (Lamendola & Newman, 1994), (d) maintaining weight loss in women (Berry, 2002), (e) ovarian cancer in Japanese women (Endo, 1998), (f) families with children who had been frequently hospitalized (Litchfield, 1993), (g) living with chronic skin wounds (Rosa, 2006), (h) older adults living with chronic obstructive lung disease (Noveletsky-Rosenthal, 1996), (i) expanding consciousness through creative movement in midlife women (Picard, 2000), (j) rural African American women (Smith, 1995), (k) pregnant women hospitalized for complications of maternal-fetal health (Kalb, 1990), (l) patients with hepatitis C (Thomas, 2002), (m) women with multiple sclerosis or rheumatoid arthritis (Neill, 2005), and (n) adolescents with insulin-dependent diabetes and school nurses providing care (Schlotzhauer & Farnham, 1997).

Newman states that research within the theory of health as expanding consciousness is praxis, which she asserts is a “mutual process” between nurse researcher and ALS family caregiver “with the intent to help” (Newman, 2008, p. 21). In addition, this process centers on the transformation from one point to another and incorporates the direction of an a priori theory. For this reason, research and practice with the theory are entwined.

When first introduced, Newman’s theory of health was very useful to nursing practice because it incorporated the concepts of time and movement that were used by the nursing profession and inherent to nursing interventions like range of motion and ambulation (Newman, 1987). As a result, early research with the HEC theory utilized the concept of time, space or movement. Mentzer and Schorr (1986) examined the concept of time duration as an index to consciousness in a research study of institutionalized

In 1986, Marchione examined the meaning of disabling events in families where the addition of an individual into a nuclear family was a disruptive event for the family, creating disturbances in time, space, movement and consciousness and put forth that pattern recognition could be utilized to better understand family interactions. With the further evolution of the theory during the 1980’s, praxis research also included practice as having the function of assisting patients with pattern recognition (Newman, 1990). Schorr (1993) conducted a study of music and pattern change evidenced with chronic pain.


Newman states her research historically over time has aided not only those participating (i.e. ALS family caregivers), but also the nurse researcher because the nurse researcher gains a better understanding of self as a nurse researcher as well as understanding limitations of previous methods used by that nurse researcher. Newman (1994) posits nursing research should focus on investigations that are participatory where
the family caregiver is a partner as well as a co-researcher in the inquiry for health patterns.

**Discussion.** The interest in studying the phenomenon of ALS caregiving evolved through this nurse researcher’s work as a research associate at an ALS clinic in Pennsylvania. The courage, strength, and devotion of these family caregivers led to a desire to examine their life patterns in order to better understand the experience of caring for someone with a terminal illness, specifically ALS. As different nursing theories were examined, the importance of a paradigmatic fit with the phenomenon of ALS caregiving became apparent and the unitary transformative paradigm provided the best opportunity to fully participate and engage as an active participant in the caregiver’s energy field as a co-creator of meaning. The mutual partnership this paradigm provides allows both the nurse researcher as well as the ALS caregiver to co-create meaning out of a very complex caregiving experience. When examining nursing theories within this paradigm, this nurse researcher was impressed by the “fit” between the utilization of Margaret Newman’s health as expanding consciousness theoretical framework and the phenomenon of ALS caregiving. After meeting with Dr. Newman in person in August, 2009 to discuss this research idea, this nurse researcher became more convinced that this theoretical framework and method would be the most appropriate for discovering the true essence (i.e. life patterns) of the ALS caregiving experience.

Despite the unspoken need to understand the story of an experience such as ALS caregiving, individuals rarely take the time to consider what is meaningful to them. This is particularly true with ALS caregivers due to the frequent rapid decline of the illness trajectory, which leaves many caregivers burdened in providing symptom management at
that point in time. Using the HEC theory will allow caregivers to experience pattern recognition through a period of high turbulence in their lives, the ALS disease of their loved one. Through this pattern recognition, mutually experienced with a nurse researcher, great opportunities exist for growth, healing and transformation of both the nurse researcher and family caregiver. Through the process of sharing identified patterns of meaningful relationships and events in that ALS caregiver’s life journey, pattern recognition by family caregivers can be fostered through additional thinking and reflection. The analysis of identified patterns across various family caregivers can reveal commonalities that can reveal truths about the caregiving experience of an ALS patient from diagnosis through death.

**Chapter Summary**

This chapter has focused on the literature collection establishing the evolution and selection of an appropriate nursing theoretical framework to shape this research inquiry. Health as expanding consciousness is the theoretical framework that was chosen to guide this research endeavor. This theory is well established as a nursing framework that provides a research methodology to understand life experiences, such as ALS caregiving, within that caregiver’s perception of context and meaning. This chapter has also examined the literature surrounding the phenomenon of informal caregiving, as well as informal caregiving specifically for an ALS patient. This conceptual discussion has focused on the concepts of impact of caregiving, unmet needs of caregivers, differences among caregivers, QOL, burden, and the comparison of needs and perceptions of ALS caregivers and patients. This research will begin to fill a gap in the literature about the experience of being an ALS caregiver, using a holistic approach that utilizes the
identification of life patterns, which have the potential to be transforming to both nurse researcher and caregiver. Results of this study will be used to plan further research that will develop a better understanding of the experience of being a caregiver of an ALS patient. This deeper insight into the caregiver’s perspective can direct innovative models of assessment as well as provide deeper levels of understanding of this phenomenon.
Chapter Three

Methods

Introduction

The purpose of this research study is to advance understanding of the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient through a unitary transformative lens for the advancement of nursing science. An enhanced understanding from the family caregiver perspective will provide information about the caregiving experience to enable nursing to identify needs and issues of the ALS caregiving population. This chapter provides a detailed description of the methodology chosen for this study. For any research study, the methodology chosen is based on the research question. For this study, the research question “What are the life patterns of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative paradigmatic lens?” guided not only the theoretical framework selected, but the research methodology as well.

The rationale and research method, health as expanding consciousness (HEC) Research Protocol (Newman, 1994) is presented. The procedure, including (a) criteria for participant selection and recruitment, (b) setting, (c) recruitment/sampling, (d) sample size, (e) data collection, (f) researcher as instrument, (g) data analysis, (h) data management, and (i) audit trail are detailed. Prigogine’s theory of dissipative structures and Young’s Spectrum of the Evolution of Consciousness are explained. Ethical considerations, including protection of participating family caregivers, and approval of research with human participants are discussed. Finally, strengths of the research findings are detailed.
Research Design

A qualitative design was chosen for this study based on many factors. First, there is increasing awareness that qualitative methods are more appropriate than quantitative methods when little is known about a phenomenon (Munhall, 2001). Next, words when organized into stories or incidents, display a concrete, vivid picture that provides meaning into a phenomenon that pages of summarized numerical data cannot achieve (Miles & Huberman, 1994). Qualitative methods provide a source of rich, well-grounded descriptive data that provide researchers with explanations of events or processes in distinguishable local contexts. Qualitative studies also have the advantage of being able to represent a chronological flow so that events can be ordered to reveal which events led to certain consequences yielding fruitful descriptions of phenomena (Miles & Huberman, 1994). Lastly, qualitative findings have the quality of “undeniability,” which Miles and Huberman (1994) state comes from the ability of the words (data), when arranged into stories or meaningful events, to provide a more “concrete, vivid, meaningful flavor” that is more convincing to a reader (p. 1).

Just as the phenomenon of inquiry propels the development of the research question, so the research question drives the choice of research method (Parse, 2001). For this study the research question is “What are the life patterns of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative paradigmatic lens?” It is proposed that qualitative methods would be best suited to address this research question because qualitative methods will allow the consideration of the nurse researcher’s own observations while also revealing the family caregiver’s meanings that they bring to their own caregiving experiences.
Along with the research method, determining the appropriate paradigm is dependent upon the research question. For example, Denzin and Lincoln (2005) maintain that there is no one single paradigm that all social scientists can associate with. Instead, researchers must understand the basic ontological, epistemological, and methodological assumptions of each paradigm before choosing which perspective could provide the most significant and important insights of a phenomenon. For this HEC study, examination of an appropriate paradigm to examine ALS caregiving was chosen. Next the research question was identified and finally the choice of a theoretical framework and methodology were selected. The research method must be congruent with the theoretical framework chosen within the paradigm (Parse, 2001). For these reasons, the unitary transformative paradigm was chosen as most appropriate to frame this HEC research study.

**Worldview: Unitary Transformative Paradigm.** Paradigms provide a philosophical lens to view the world and phenomenon of interest (Parse, 1999). Morse and Field (1995) maintain that as a collection of concepts and prepositions that are logically connected, paradigms provide a theoretical perspective and orientation that routinely directs research approaches about a phenomenon. The unitary transformative paradigm goes beyond a holistic perspective of an individual and the environment to include a view of the person as being unique as reflected in the moment. The interaction of a person and environment reflects a manifestation of wholeness. The phenomenon of interest is viewed as a unitary, self-organizing energy field that is enclosed in a larger self-organizing energy field of person/environment interaction. The unitary transformative paradigm is sharply contrasted to previous, linear, causal paradigms.
(Picard & Jones, 2005). Change in the unitary transformative paradigm is viewed as unidirectional, unpredictable, transformative, and moves through stages of disorganization and organization toward more complex organization. Disruptive periods are regarded as a segment in reorganization (Newman, 1994). The unitary transformative paradigm was chosen as appropriate for this study because family caregivers of ALS patients are viewed as a unitary, whole, self-organizing energy field that is encased within the whole of the environment, also a self-organizing energy field. Likewise, the nurse researcher is a unitary, self-organizing energy field within the family caregiver’s environment. These two (i.e. the nurse research and family caregiver) participate equally in the nurse researcher/ALS family caregiver process to construct a new self-organizing energy field, or a new whole (Newman, 1994, 1995, 2008).

**Rationale for Selection of health as expanding consciousness (HEC).** Through the embracing of health as encompassing disease, the researcher will be able to enter into meaningful, transformative relationships with ALS family caregivers regardless of each caregiver’s position along the ALS disease trajectory. The research focuses on the nurse researcher/ALS family caregiver relationship by identifying the family caregiver’s unfolding patterns. This theory has no boundaries (Picard & Jones, 2005); it is applicable across cultures and encompasses the complete spectrum of health concerns (Newman, 1984). Nursing research utilizing health as expanding consciousness incorporates theory, research, as well as practice whereby both nurse researcher and participant (i.e. ALS family caregiver) are fully engaged with each other. HEC is unique in the ability to make a difference in not only the participant, but in the nurse as well because both may be transformed through the experience. As participants experience periods of
disorganization, uncertainty, or unpredictability, HEC provides the nurse researcher with the opportunity to reflect on these periods and identify patterns, which can lead to reflection and ultimately transformation to a higher level of organization, or expanded consciousness (Newman, 1994, 1995, 2008). This process requires an authentic effort by the researcher to prepare him or herself to engage in conscious interaction with the ALS family caregiver. This is key to the nurse researcher/ALS family caregiver research process and the integration of patterns from the nurse researcher and ALS family caregiver occur in order to foster discovery, awareness, and revelations.

Newman (1994) asserts periods of disruption in pattern, such as the ALS disease, may be a catalyst for the expansion of consciousness. Participants in research studies (Fryback, 1993; Lamendola & Newman, 1994; Moch, 1990) have reported being thankful for the new insights that are gained through an illness experience, such as ALS. New insights gained by the reorganization of priorities in life to accommodate what is truly meaningful in life while attending to self-care and the experience of discovering pleasure in simple everyday occurrences have been identified as meaningful to the participants.

Often the illness experience can be a catalyst to reflect on self-care. Prior to the disruption of an illness experience, such as ALS, family caregivers often devoted their obligations to others as primary over basic activities of self-care or restoration. This illness experience can serve as a “wake-up” call (Picard & Jones, 2005, p.15) for attending to the importance of personal needs (Demarco, Picard & Agretelis, 2004; Kiser-Larson, 2002; Moch, 1990; Neill, 2002; Newman, 1995; Picard, 2000).

Several research studies have used health as expanding consciousness (HEC) to explore family patterns. Yamashita (1999) examined family patterns where a loved one
had schizophrenia. Yamashita’s research showed that when family members were able to engage with a HEC researcher, they were able to engage in dialogue that provided the opportunity for insight as well as the realization for potential for action and change. With these families, when they were able to accept the illness it signified a turning point for the family members, which was manifested by the family members becoming more open, asking for help, and talking about their situation with others. Picard’s (2002) research with families after the loss of a child and Endo’s (2000) study of families with women diagnosed with ovarian cancer showed family members regulate energy and rhythm in response to other family members while concealing feelings of sadness or grief to one another. Through the utilization of HEC, dialogue ensued about accepting the illness and sharing the meaning of the illness experience so that family members were able to see the “larger shared family pattern of meaning” (Picard & Jones, 2005, p. 17). Lastly, Tommet (2003) and Litchfield (1999) showed through their research with families with ill children that the nurse-parent interaction was a mechanism to the families in discovering meaning while experiencing the chaos of family-environment pattern as they traversed the multiple facets of the health care system.

Lastly, HEC utilizes reflection about emerging and developing patterns through time rather than emphasis on a solitary moment. Through the presence of the nurse researcher in mutual exploration of life patterns with the ALS family caregiver facilitation of reflection and further insights occur through this partnership. Neill (2002) and Barron (2001) both changed their concept of nursing after experiencing the praxis nature of HEC. Based on her own transformation in the research process of HEC, Barron asserted she could not return to her former definition of nursing practice which was not
based in the mutuality of the HEC based dialogue. For these reasons, Newman’s Theory of health as expanding consciousness and research method has been chosen to examine life patterns of family caregivers providing care to an ALS family member.

**Procedure**

**Participants: Criteria for Selection.** Each ALS family caregiver participant met the following inclusion criteria:

- Was either a spouse, significant other, or offspring of the ALS patient providing the majority of supportive care to that ALS patient through self identification
- Was an individual who resides in the same residence as the ALS patient
- Was able to communicate in English (as per ALS clinic assessment)
- Was able and willing to participate in the study
- Was at least 18 years of age

Exclusion criteria included:

- Was diagnosed with ALS him or herself
- Was a current participant in the approved study (NIH/NINR 5RO1 NAR01027-03; PI: J. Penrod)

**Setting for Recruitment.** A multidisciplinary ALS center was chosen for the recruitment site for this research study. This ALS clinic specializes in the diagnosis and treatment of ALS, PLS (primary lateral sclerosis), and related disorders. Like other ALS clinics, the multifaceted needs of the patient/family unit are addressed by a multidisciplinary team of health care specialists including: (a) nursing, (b) neurology, (c) pulmonary medicine, (d) neuropsychology, (e) physical therapy, (f) occupational therapy,
(g) nutrition, (h) pastoral/spiritual care, and (i) speech-language pathology. The ALS clinic states its purpose is to establish a definitive diagnosis and then once a diagnosis is established, to provide comprehensive care in a supportive and understanding environment that is focused on neurological functioning and quality of life. Patients are seen on a 3-month basis in the outpatient clinic and as the disease progresses and the patient is no longer capable of coming to clinic, home visits and supportive care, including hospice, are coordinated by a clinical nurse specialist. This ALS center has been recognized for achieving excellence in clinical practice as well as research. Approximately 90 new patients are diagnosed annually with about 150 being followed by the clinic at any given time (S. Walsh, personal communication, July 2010). This clinic uses approximately 11 multidisciplinary clinicians to provide this holistic based care.

**Participants: Recruitment/Sampling.** Recruitment of family caregivers from the multidisciplinary ALS clinic, located in Central Pennsylvania, began after approval was obtained from the Offices of Regulatory Compliance of the associated medical center. Purposive sampling (people are selected based on their potential to inform the research) was employed initially so that data appropriateness, or selection of research participants who can best inform the research, was achieved (Morse & Field, 1995). Two ALS family caregivers were recruited initially and as the research progressed, sampling became theoretically driven by the evolving, iterative analysis employed by the nurse researcher until a total recruitment of eight family caregivers occurred. Only one to two caregivers at a time were actively participating in the interview process so that life patterns were examined first on an individual caregiver level (Aim 1) and then built to life patterns across all family caregivers (Aim 2). This also permitted the researcher the
ability to seek key informants while promoting a full, rich understanding of the
caregiving experience.

Following IRB approval, an invitational letter signed by the ALS clinical team
neurologist (Appendix A) and invitational letter from the nurse researcher (Appendix B)
were mailed out to a purposive sample of two ALS patient systems (patient and family
caregiver) along with pre-visit forms from the ALS multidisciplinary team. At the next
ALS clinical visit, the ALS nurse manager sought verbal consent for the release of
limited contact information to allow the nurse researcher to contact her/him. Following
verbal consent for the release of information, the nurse researcher contacted the first two
family caregivers to fully explain the research study and solicit participation. If the
family caregiver agreed to participate, a mutually convenient time and place for an
interview was set. All interviews were audio taped with the participants’ permission.
Written informed consent under principles of full disclosure was obtained prior to data
collection. One signed copy of the informed consent was given to the family caregiver
and the nurse researcher retained a second copy. This procedure starting with the mailing
to a purposive sample was repeated until adequate sample size was obtained, which for
this study was determined to be eight caregivers, based on Newman’s research protocol
(Newman, 1994). All eight ALS family caregivers were given a $20.00 gift card for
each interview completed.

**Sample Size.** Adequate sample size is influenced by the research method,
sampling strategy, projected research outcome as well as the researcher’s experience in
assessing the quality of the data collected (Sandelowski, 1995). The adequacy of data
collected is related to the amount of data that has been obtained (i.e. number of families
interviewed as well as the number of interviews) and whether data saturation of the HEC study has occurred. In addition, estimation of the sample size is influenced by the desire for pattern identification that is unique to each family caregiver and then the identification of themes across family caregiver participants. A total of twelve ALS family caregivers were approached by the ALS nurse manager for recruitment to this study, with eight family caregivers agreeing to participate. This sample size of eight has been shown to be adequate by previous research utilizing HEC (Falkenstern, Gueldner, & Newman, 2009; MacLeod, 2008; Newman & Moch, 1991; Tommet, 1997). Utilizing Newman’s research methodology, the nurse researcher strived to identify unique as well as similarities of patterns across family caregivers experiencing similar life events (i.e. ALS caregiving) while still recognizing the uniqueness of individual person as well as nurse researcher/ALS family caregiver relationships (Newman, 1994; Newman, Smith, Pharris, & Jones, 2008).

**Data Collection.** The interviews were conducted in a place and time most convenient for the family caregiver. In previous research studies utilizing Newman’s methodology, most participants have invited the nurse researcher come to their home (M. Newman, personal communication, August, 2009). Often, home settings provide an environment that is most comfortable for the family caregiver because of its familiarity as well as a place that can offer privacy, quiet, and solitude. Utilization of the home sets a contextual scene which has been shown to be very effective as a form of interviewing because it allows the researcher to see and experience the caregivers’ environment while enabling the caregiver to remember specific details about caregiving that occur in that setting (McClain, 2009). Of the eight ALS family caregivers who were recruited for this
study, seven requested their homes be utilized for the interviews. One ALS family caregiver chose to have the interviews done in a quiet coffee shop near her employment, which allowed for maximum convenience with her busy professional work obligations.

The data collection phase spanned three months. Two audio taped interviews with each ALS family caregiver took place. Each interview lasted 60 to 150 minutes in length, which is adequate based on past research utilizing HEC (Newman, 1994; Picard & Jones, 2005). This time frame was adjusted to each family caregiver’s interpretation of when they were finished recalling meaningful events about their ALS caregiving experience. The second interview was scheduled and conducted within a one-week time frame. The review of the chronological pattern analysis during the second interview provided the ALS family caregivers the opportunity to reflect on the pattern diagram in terms of accuracy and clarify and/or modify the diagram in terms of what he or she deemed as meaningful. The second meeting, in addition to supporting further reflection, insight and meaning, increased verification of results of first interview. In addition, it provided the opportunity to explore with the family caregivers the therapeutic value of the HEC process and how this research experience had impacted their lives.

**Researcher as Instrument.** As congruent with Newman’s methodology (Newman, 1994), the nurse researcher was the main instrument of this research study. Newman asserts not only can the researcher be the most important instrument, but he or she needs to be a participant as well because both functions combine to better understand and give meaning to life patterns revealed. Upon communication with an experienced Newman HEC nurse researcher (S. Falkenstern, personal communication, August, 2009), the following recommendations, based upon her experience with utilizing this
methodological approach, were utilized. First, 24 hours prior to an interview I obtained adequate sleep, nutrition, exercise, and centering time. Secondly, I tried to present myself as relaxed, reflective, personable, and friendly to the ALS family caregivers upon the first interview. Next, I sought common ground with the family caregivers to build rapport. Lastly, using Newman’s suggestion to speak from “the center of your truth” was helpful in permitting myself to relax and offer reflective comments that enabled the participants to relate, reflect, or talk about their experiences. These tips helped this experienced Newman nurse researcher embrace the HEC framework and method (S. Falkenstern, personal communication, August, 2009) and were suggestions I utilized for this research study.

Immediately after the initial interview, field notes were recorded to capture impressions and observations about the family caregiving environment, and feelings and insights about the experience. Field notes also provided supplementation of other forms of data, including taped recordings because recorded interviews do not portray the environmental setting, non-verbal communication or impressions of the researcher (Morse & Field, 1995). In addition, Morse and Field assert field notes provide a record of a researcher’s personal immersion in the participant’s sphere of existence and contain valuable information about the contexts within which the participants reside. The utilization of field notes to record these impressions were important in capturing life patterns as well as describing the environment of the family caregivers. According to Newman, field notes give early impressions of each family caregiver’s pattern of the whole (M. Newman, personal communication, August, 2009). The notation of the nurse researcher’s own sense of time, movement, and space in comparison with the family
caregiver’s rhythm was helpful in preparation for future interviews with that family caregiver.

Newman (1994) suggests the following questions as initial inquiries to begin dialogue: What are the most meaningful events in your life as a family? Who are the most meaningful persons in your life as a family? Falkenstern (2009) used the following statement to begin discussion: “Let’s think about the most meaningful persons in your life.” This technique enabled families of special needs children to talk about their special needs child as well as the family member’s experiences with him or her. In addition, Falkenstern suggested the following questions to guide the research inquiry: (a) are there any special people who made a difference in your life? (b) What events still stand out in your mind? (c) What would have helped you the most? (d) What could health care professionals (doctors, nurses) done differently? All of these questions would be applicable to the application of health as expanding consciousness to ALS caregivers as well. For example, after asking “Could you please tell me about the most meaningful people and experiences in your life?” This might be followed-up at an appropriate time with “how do you think this has impacted you as an ALS caregiver?” This approach was utilized for the first two ALS family caregivers, but this nurse researcher found the opening question of “Could you please tell me about the most meaningful people and experiences in your life?” too broad and not focused enough on the main purpose of this research study, which is “What are the life patterns of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS)?” For ALS family caregivers 3-8, the following opening question was utilized: “Could you please tell me about your husband/wife for whom you provide care?” Narrowing the opening question in this
manner proved to be effective in focusing on the experience of ALS family caregiving. Throughout the interviews, branching questions were utilized to clarify and restate the caregiver’s responses in the interview.

**Data Analysis.** From the start of the first interview, utilizing nurse researcher as instrument, data analysis began because both are interwoven together as congruent with Newman’s methodology (Newman, 1994). The data for each of the caregivers consisted of two interviews and the ensuing narrative stories and pattern diagrams. Within 24 hours, the nurse researcher listened to the audio taped interviews and made field notes about interview insights. Data analysis took place in two parts. First, the analysis of individual caregiver data (Aim 1), which was followed by examination of data across all participant caregivers for identification of patterns across family caregivers of ALS patients (Aim 2), congruent with Newman’s research methodology (1994) and hermeneutic dialectics (Cohen, Kahn, & Steeves, 2000; Gadamer, 1976; Newman, 1994).

The following HEC protocol was carried out with all ALS family caregiver participants (Aims 1 and 2) based on Newman’s research protocol (Newman, 1994):

1. The nurse researcher started the analysis by a period of centering and focus of thoughts. The interviews were transcribed verbatim by the nurse researcher. Verification of the transcript occurred within 48 hours after transcription was completed by the nurse researcher. Repeated, in-depth reading and listing of the transcripts occurred to record impressions, and insights gained while listing and reading the recorded audio taped interviews. This process enabled the nurse researcher to gain insights on the caregiver’s reflections as pattern recognition for each family caregiver emerged.
2. Repeated readings of the interviews over time enabled the nurse researcher to develop a narrative summary, which reflected the essence of each family caregiver’s story. Through the interaction with each caregiver, the nurse researcher embraced the concept of a “whole” from which meaning could be derived from the narrative dialogue. Significant phrases, words, and statements were highlighted in the narrative.

3. The narratives were then placed in chronological life order. Meaningful events and persons were placed within the appropriate time frames. Sequential patterns and pattern shifts were documented along the chronological time trajectory. Identification of patterns of the whole as reflection on the caregiver’s meaningful events and relationships over time then took place.

4. Next, identification of sequential patterns and construction of a diagrammatic picture occurred. This diagram was based on Prigogine’s Theory of Dissipative Structures (Prigogine & Stengers, 1984).

5. The diagrammatic picture was shared with the family caregiver at the second interview. The second interview, which occurred within one week of the first interview, provided a time for clarification and reflection between the nurse researcher and caregiver. Pattern recognition from the first interview was shared at this time with the caregiver and discussed in detail.

6. Data from both interviews was examined utilizing Newman’s Theory of health as expanding consciousness (HEC). Individual life patterns (identified as themes) emerged from the data. The next stage of data analysis involved examination across all family caregivers for comparison of patterns (Aim 2), which was done
in consultation with the HEC scholar on the dissertation committee. Immersion in
the data through repeated readings of all caregiver narratives and diagrammatic
pictures enabled the nurse researcher to synthesize into one pattern of the whole
across all family caregivers by the identification of common patterns. Patterns of
the whole for each family caregiver as well as the pattern of the whole across
family caregivers was examined using Prigogine’s theory (1984) of dissipative
structures and discussed according to Young’s (1976) Stages of Evolution of
Consciousness. Examining each family caregiving as to their placement on
Young’s Stages of Evolution of Consciousness proved to be very difficult when
attempted after the life patterns of the individual ALS family caregivers was
completed. This is the usual protocol that Newman (1994) recommends, but this
nurse researcher could not neatly place many of the ALS family caregivers into
just one of Young’s Stages of Evolution at this point in the analysis process
because many of the ALS family caregivers appeared to be in more than one of
Young’s Stages. This assumption proved to be correct once life patterns of the
whole across all ALS family caregivers was complete and Young’s Stages of
Evolution were discovered to be non-linear and not stagnant in nature based on
the emerging data, which is explicated further in chapter 5. Even though this
nurse researcher changed the timing of the placement on Young’s Stages,
incorporating each family caregiver’s pattern of the whole enfolded in one pattern
of the whole, this placement was essential to understanding the phenomenon of
the nurse researcher/ALS family caregiver process that facilitates health as
expanding consciousness in family caregivers of ALS patients.
**Data Management.** Data management began with the verbatim transcription of the digitally recorded interviews. In order to reduce threats to validity, once each interview was transcribed, the nurse researcher verified the interview for accuracy by listening to the digital recording while visually reviewing the transcript word-by-word. The interviews were viewed on a password-protected computer and the original files were stored on an external hard drive in a locked office. Each original transcript was cleaned of all potentially identifying information such as names of participants, family caregivers, and identifying locations. The final result was a cleaned, verified transcript used in data analysis.

**Audit Trail.** Morse and Field (1995) emphasize the use of an audit trail to document the researcher’s decisions, insights, and choices. Rodgers and Cowles (1993) maintain that there are several areas of documentation that need to occur. First, field notes (dated and ordered) placed interviews within the context they occur. Methodological approach changes, including the rationale, were noted in memos or researcher’s logs. This was especially true when the initial interview question changed focus based on experiences from the first two interviews. Recording subjective interpretations as field notes was also important to examine as interpretations changed as the research progressed, revealing important insights into the phenomenon. Lastly, Morse and Field assert that an audit trail assists the nurse researcher in establishing theoretical rigor. For these reasons, this nurse researcher maintained field notes on all interviews as well as on all decisions made in the research process, such as the evolution of life patterns for individual as well as across family caregivers so that accountability was enhanced (Creswell, 2007) from the start to the end of the research project.
Ethical Considerations

**Human Participant Approval.** Prior to the submission to the Office of Regulatory Compliance of the associated medical center/Pennsylvania State University for this research study, this nurse researcher successfully completed the online program and subsequent testing for research with human subjects as mandated by the Office of Regulatory Compliance. An expedited review was requested because all participants were adults and this research presents limited risk to them. The completed application for Research with Human Subjects once approved is on file with the Office of Regulatory Compliance. Invitation Letters (Appendix A and B) were written based on guidelines from the Office of Regulatory Compliance. There were two copies of the Informed Consent Form that were signed by the participant and the nurse researcher. A copy of the Invitation Letter and Informed Consent Form were given to each caregiver. The nurse researcher kept the other copy of the Informed Consent Form.

**Protection of the Families.** Participants in this research study were at minimal risk for the loss of confidentiality. Safeguards to confidentiality included the coding of all ALS family caregivers ensuring the identify of the caregivers could not be determined by anyone but the nurse researcher. This assurance of confidentiality was emphasized when consent was obtained and in subsequent interviews. All documents related to this research study were kept in a secure, locked location. Only the nurse researcher and HEC expert committee member had access to the audiotapes and transcripts while data collection was occurring. These audiotapes were generated during interviews but were transcribed without identifiable information. All audio recordings were coded by interview as well as an alphabetical character such as ALS family caregiver (CG) 1.1 and
1.2, ALS family CG 2.1 and 2.2, and secured in a password protected computer file. In addition, pseudo names were given to each ALS family caregiver in the narrative analysis. After the dissertation is completed, all audiotapes, field notes, and identifying written data will be destroyed as mandated by the Office of Regulatory Compliance.

There were not interventions or treatments associated with this research study. All caregivers were informed that they could stop any interview or withdraw from participating in the research study at any time without penalty. No participant reported any negative effects from taking part in this study.

Confidentiality may be breached only if the nurse researcher, acting in good faith has reason to believe that the family caregiver of ALS family member are at risk for injury or are in any danger due to illegal activities, domestic violence, mental health problems, or maltreatment. All nurses are mandated reporters of neglect and abuse and the nurse researcher will take this responsibility seriously in this research endeavor. The need to breach confidentiality did not occur with any of the eight ALS family caregivers.

**Strength of Research Findings**

In any research study, the end result of the research is to fully understand a phenomenon that has clinical relevance. Lincoln and Guba (1985) assert traditional approaches to validity and reliability are best suited for research studies based on a quantitative design. For qualitative research studies, Guba (1981) proposes the use of the terms credibility (in place of internal validity), transferability (replacing external validity), dependability (in place of reliability) and confirmability (replacing objectivity).

**Credibility.** Lincoln and Guba (1985) assert credibility represents the truth value of the qualitative research and a qualitative research study will be credible if others
reading the study are able to recognize the experience after reading about the experience through that study. Guba (1981) asserts a major threat to credibility is lack of time in the field, which is necessary to understand the phenomenon fully. Credibility was enhanced through the prolonged engagement of the nurse researcher in an ALS clinic and the consistent interaction through observational research with the ALS team and family caregivers. This nurse researcher also demonstrated credibility in qualitative methodology by serving as a research assistant with some of the leaders in the field of nursing research utilizing qualitative methodology. Lastly, credibility was enhanced through the process of peer debriefing with the dissertation chair and HEC research expert committee member. The mutual partnership between the nurse researcher and ALS caregivers in combination with the actualization of the HEC by the nurse researcher as delineated by Newman’s methodology affirmed that nurse researcher was integral to the experience. This enhanced the nurse researcher’s ability to understand the experience of being an ALS caregiver via health as expanding consciousness (HEC).

Transferability. Transferability refers to the probability that the research findings will have meaning to other people in similar settings (Lincoln & Guba, 1985). When interview data contains rich and thick description of a phenomenon, the findings are more likely to be transferable to a similar population. To ensure that thick and rich descriptions were obtained, the nurse researcher utilized broad, open-ended questions and all interviews were conducted in a comfortable, safe environment chosen by the caregiver. For seven of the eight ALS family caregivers, this took place in the caregiver’s home setting, which provided the opportunity for the caregiver to feel comfortable in the privacy of their home and thus enhance the ability of the caregiver to
speak honestly and truthfully about his/her caregiving experience. This setting also gave
the nurse researcher valuable insights through the interviewing experience to learn about
the social setting where caregiving takes place. It also allowed the nurse researcher to
understand the data within a holistic approach, including relevant contextual and
environmental factors that impacted the phenomenon of ALS caregiving. In addition, this
process of more than one interview enhanced the transferability of the findings (Guba,

**Dependability.** Lincoln and Guba (1985) state the utilization of an audit trail
enhances both the dependability of the research process as well as the confirmability of
the research product. An audit trail provides the researcher with a way to track the entire
qualitative research study from the beginning to the end. This means that another
researcher should be able to follow the decision trail used by the researcher of the
original study to be auditable. It also means that another researcher could examine the
data and arrive at a similar or comparable conclusion. In consultation with the HEC
expert committee member, analysis meetings took place to achieve dependability for this
HEC study.

**Confirmability.** Confirmability is concerned with assuring that the data is not
based on research bias. In other words, the integrity of the findings is rooted in the data,
the interpretations, and the outcomes of the study (Lincoln & Guba, 1985). Through the
HEC analysis procedure, all eight caregivers were given the opportunity to confirm the
nurse researcher’s graphical representation of their life events and emerging patterns via
the second interview. This enabled each caregiver to assess the nurse researcher’s
interpretations of their patterns of the whole to accurately reflect the caregiver’s intended
meaning. The nurse researcher then synthesized the pattern of the whole of the nurse researcher/ALS family caregiver process through reflection of her experience with each individual family as well as synthesizing the pattern of the whole across families.

**Prigogine’s Theory of Dissipative Structures.** The construction of a diagram derived from the narrative was used to summarize sequential pattern configurations. Caregiver diagrams were constructed based on a conceptualization of Prigogine’s theory of dissipative structures (Figure 3.1) that has been adapted by Newman (1994). The following is a description of the evolution of new forms based on Prigogine’s theory.

Figure 3.1. Prigogine’s Theory of Dissipative Structures

Prigogine’s theory of dissipative structures (Prigogine, 1976; Prigogine & Stengers, 1984) asserts that supposedly negative events, like developing a disease such as ALS, are a part of the process of expanding consciousness (Newman, 2008). According to this theory, systems fluctuate in an orderly fashion until some disturbance occurs, such as the diagnosis of ALS, and at the time of this disruption the system proceeds in a self-organizing yet apparently random manner until a new direction is chosen, which is at a higher level of organization. According to Newman, this disturbance represents a pathway to higher levels of consciousness when examined within the total context of that phenomenon.

As the nurse researcher charted the family caregiver diagrams on a time trajectory, the family caregiver’s ability to self-organize paralleled Prigogine’s theory of dissipative structures. Family caregiver diagrams were shared with the family caregivers during the second interview, but it is important to note that there was no interpretation of meaning from the nurse researcher. Family caregivers were asked to confirm the accuracy of the diagrams and clarify when needed. The nurse researcher and ALS family caregiver then reflected together on their pattern diagram to gain additional insights.

**Young’s Spectrum of the Evolution of Consciousness.** Young’s Spectrum of the Evolution of Consciousness has as its central theme the premise that the self, or a universe, is of similar nature with a beginning and an end that is represented by complete freedom as well as unrestricted ability to choose. There are seven steps represented in a sequential manner starting with losses of freedom as identity as a physical being evolves
towards a reversal of those losses as entropy is reversed and understanding, or total freedom finally emerges (Newman, 1994). Young (1976) asserts the goal is to obtain a higher level of development through interaction with others.

Figure 3.2 Young’s Stages of Evolution of Consciousness

In the above diagram, (Figure 3.2) Young’s stages are listed. The process starts with a beginning point of potential freedom. This period of potential freedom is followed by a second stage Newman called binding, when we are born and is characterized by loss of the individual for the sake of the collective. There is no demand for initiative because all is regulated for the person and there is no sense of self (i.e. all decisions are made by others for that person). Binding means being bound in time and space as the physical body develops. The third stage, centering, is represented by individualism emerging as the self breaks from authority. Self-consciousness and identity materialize and the individual focuses on self while relying on traditional ways of relating to the world (Picard & Jones, 2005). It means learning the “laws” of how things work by interacting with the environment through movement in time and space. Choice, the fourth stage
illustrates a turning point where emphasis is placed on exploration for laws. It involves the eventual realization that current strategies are no longer solutions to the situation at hand. Different kinds of solutions are required as a new awareness of self-limitation prefaces inner growth. This turning point embodies an “inward, self-generated reformation” (Newman, 1994, p. 45). A disequilibrium occurs as represented by life disruptions, such as illness, death, divorce, or any unexpected event, such as the diagnosis of ALS. There exists a tension between keeping old ways of being versus freedom in letting go towards a new evolving pattern. This destabilization of established order, present in this stage, encourages movement as well as the expansion of consciousness (Picard & Jones, 2005).

As a new “law” is learned, de-centering, or the fifth stage occurs. In this stage there is a shift from the development of self towards something even bigger than the individual self. Form is transcended and the predominant element is energy in the form of animation, or vitality. Pattern is at a higher level than form and the pattern can be presented in many different forms. This is the stage where the individual experiences high levels of unlimited growth while constructing order in the face of disorder. It represents Newman’s concept of “boundarylessness”, where the individual is cognizant of expanding beyond his or her own physical boundaries (Picard & Jones, 2005). Of this stage, Young (1976, p. 216) stated “there will come a time in the lives of each of us when we will go on or be destroyed, but this time will not come until we wield so much power that the misuse of it would destroy ourselves.” Newman posits it is within the two stages of choice and decentering that an individual journeys to higher levels of consciousness (Newman, 2008).
Most individuals cannot experience the sixth and seventh stages, *unbinding* and *real freedom* respectively, unless transcendence occurs. *Unbinding* “involves increasing freedom from time… one of going more deeply into the present and having the experience of all time” (Young, 1976, p. 47). *Unbinding* occurs as the person is capable of being more fully present in that moment in time. *Real freedom* is unconditional love, absolute consciousness, which “embraces all experiences equally and unconditionally…” (p. 48). It represents a state of unity in which all opposites are reconciled (Picard & Jones, 2005, p. 12).

The pattern of the whole for each ALS family caregiver was synthesized by reflecting on each ALS family caregiver’s sequential patterns revealed in the chronological pattern diagram and the interview narratives. Interpretation and meaning emerged from the data through the use of hermeneutic dialectics. After identifying patterns of the whole for each ALS family caregiver, data from all the ALS family caregivers was synthesized into one pattern of the whole across all ALS family caregivers by reflecting on all the chronological pattern diagrams and narratives and emerging common life pattern themes. Analysis of life patterns of the whole across all ALS family caregivers was done in conjunction with the HEC scholar on the dissertation committee. As common themes emerged, color highlighted statements from each ALS family caregiver were sorted into appropriate categories. Lastly, the life patterns of the whole for each ALS family caregiver were discussed narratively according to their appropriate placement on Young’s Stages of Evolution of Consciousness.
Summary

This chapter has provided a description of the research design, the choice of the Unitary-Transformative paradigm to frame the study, as well as rationale for selection of the HEC research method. The HEC research protocol is congruent with the theoretical framework of the study as well as embracing the nurse researcher’s view of nursing practice. Additionally, the protocol, including (a) criteria for participant selection and recruitment, (b) setting, (c) recruitment/sampling, (d) sample size, (e) data collection, (f) researcher as instrument, (g) data analysis, (h) data management, and (i) audit trail are detailed. Finally, ethical considerations, including protection of participating family caregivers, and approval of research with human participants were discussed. Lastly, Prigogine’s theory of dissipative structures, Young’s spectrum of the evolution of consciousness and strength of research findings were explicated. The unique contributions of this HEC study can reveal the complexity of human experiences of health in relationship to nursing and the environment of caring for a loved one with amyotrophic lateral sclerosis.
Chapter 4
Discussion of Findings

The purpose of this research study is to advance understanding of the experience of family caregivers who care for a patient with amyotrophic lateral sclerosis (ALS) through a unitary transformative lens for the advancement of nursing science. Key to this purpose is the nurse researcher/family caregiver process of health as expanding consciousness (HEC). Insights from this nurse researcher/family caregiver process are presented first. Next, life patterns of the eight individual family caregivers of ALS patients are integrated into a thematic pattern of the whole representing the ALS caregiving experience across all caregiving families (Aim 2). The forced vital capacity (FVC) for all eight ALS patients is illustrated. Lastly, the narrative summary, pattern analysis, spectrum of consciousness, and life patterns exhibited by eight individual family caregivers of ALS patients (Aim 1) are presented.

**Brief overview of the method.** A total of eight ALS family caregivers participated in the study. These eight ALS family caregivers had to meet the following criteria: (a) was a spouse, significant other, or offspring of an ALS patient providing the majority of supportive care to that ALS patient through self identification; (b) resided in the same residence as the ALS patient; (c) was able to speak English (per ALS clinic assessment); (d) was willing and able to participate in the study; and (e) was at least 18 years of age. The following exclusion criteria was used: (a) was diagnosed with ALS him or herself, and (b) was a current participant in the approved study (NIH/NINR 5RO1 NAR01027-03; PI: J. Penrod). These participants were recruited from a multidisciplinary ALS center in Pennsylvania and purposive sampling was initially employed and then
theoretical sampling took place based on the evolving, iterative analysis employed. Once an invitational letter was mailed out to a purposive sample of two ALS patient systems (ALS patient and family caregiver), the nurse manager of the ALS clinic approached the family caregivers at their next clinic appointment and sought verbal consent for the release of limited contact information to allow the nurse researcher to contact him/her. Following verbal consent for the release of information, the nurse researcher contacted the first two family caregivers to fully explain the study and solicit participation. If the family caregiver agreed to participate, a mutually convenient time and place for an interview was set. All interviews were audiotaped and a total of two interviews took place with each ALS family caregiver. All ALS family caregivers received $20.00 for each interview completed. Data collection lasted three months with interviews lasting between 60-150 minutes in length. Chronological pattern analysis diagrams were presented to ALS family caregivers for reflection and clarification and confirmation during the second interview, which was completed within a week of the first interview. All audiotaped interviews were transcribed verbatim and verified by listening and following the transcript line by line within 24 hours after being transcribed. The families were coded as ALS family caregiver 1 through 8 (in order of their recruitment) and all were given random pseudo names to ensure confidentiality. Repeated reading of the interviews over time enabled a narrative summary to be developed which reflected the essence of each family caregiver’s story. Through the interaction with each family caregiver, the nurse researcher embraced the concept of a “whole” which meaning could be derived from the narrative dialogue. Data from both interviews were examined
utilizing Newman’s Theory of health of expanding consciousness. Individual life
patterns (identified as themes) emerged from the data (Aim 1).

After identifying patterns of the whole for each ALS family caregiver, data from
all the ALS family caregivers was synthesized into one pattern of the whole across all
ALS family caregivers by reflecting on all the chronological pattern diagrams and
narratives and emerging common life pattern themes (Aim 2). Lastly, the life patterns of
the whole for each ALS family caregiver were placed according to their appropriate
placement on Young’s Stages of Evolution of Consciousness.

**Nurse researcher/ALS family caregiver process**

The pattern of the whole of the nurse researcher/ALS family caregiver process did
not emerge immediately upon interviewing ALS family caregivers, but became apparent
as the interviews and interpretations of the interviews progressed. Through the analysis
of researcher logs, field notes, and ALS family caregiver interviews the following nurse
researcher/ALS family caregiver pattern of the whole was revealed for this study: (a)
**establishing a time and place for the nurse researcher and ALS caregiver to form a
relationship**, (b) **developing a bond with each ALS caregiver**, (c) **creating an atmosphere
which allows the caregiver and nurse complete freedom to express themselves openly**, (d)
**offering a sense of timelessness for insights about the ALS caregiving experience**, and (e)
**transformation as the nurse researcher and ALS family caregiver come together to find
meaning in the chaotic experience of informal family caregiving for an ALS patient.**

**Establishing a time and place for the nurse researcher and ALS family caregiver
to form a relationship** was easily done. All of the eight family caregivers volunteered for
the research study readily and every first interview was conducted within a week of the
nurse researcher contacting the ALS family caregiver. I made myself available to the
family caregivers at their convenience and at a place of their choosing. One family
caregiver chose to meet at a coffee shop close to her workplace and the remaining seven
caregivers elected to have the interviews done in their homes. There was no time limit
established for each interview, but rather the flow of the interaction between the nurse
researcher and the ALS family caregiver determined the length of the interviews. All of
the family caregivers appeared willing and eager to share their ALS caregiving
experiences with the nurse researcher and interviews lasted between 60 and 160 minutes.
Second interviews were completed within one week of the first interview, again at a time
and place that was at the convenience of the family caregiver.

*Developing a bond with each ALS family caregiver* occurred effortlessly and
rapidly within the context of the first interview, which could have been due, in part, to the
willingness of the ALS family caregivers to share their stories about their ALS caregiving
journeys. All of the ALS family caregivers appeared eager to tell the nurse researcher
about their caregiving experiences and this created a very welcoming atmosphere for the
nurse researcher to join with them. I purposefully tried to create an open, caring,
empathetic, centering presence, which I believe created the opportunity for mutual
connectedness between the ALS family caregiver and myself. I tried to utilize my past
two years of professional experience in an ALS healthcare clinic to bring an intuitive
sense of presence as the interviews unfolded.

*Creating an atmosphere that allows the family caregiver and nurse researcher
complete freedom to express themselves openly* was vital and I tried to show the family
caregivers that I was non-judgmental and empathetic to their caregiving experiences
through my relaxed body language and sincere, caring spontaneous responses. Through my reactions to their emotive responses, such as sadness, anger, or frustration, I tried to presence with them while giving them whatever time they needed to recover from their emotions. Through sharing some of my own caregiving difficulties, I embraced the concept of “opening of self” to the family caregiver, which is essential to the mutual growth of both nurse researcher and the family caregiver (Newman, Lamb & Michaels, 1992). The “opening of self” showed to the family caregivers that I did not judge them while conveying that I understood the difficulty of the caregiving experience. Long silent periods that occurred were difficult, but my experiences as a research assistant for two years, helped me deal with the discomfort this often brings to nurse researchers.

*Offering a sense of timelessness for insights about the ALS family caregiving experience* occurred naturally as the caregivers and I interacted together about the experience of caregiving for an ALS patient. I was not aware of the passage of time and often would discover that two hours had passed in a time period that seemed to last only minutes to me. I purposely did not wear a watch or position myself where I could see a clock while conducting the interviews so that I would not be distracted from the interaction with the caregivers. Also, many insights occurred after the tape recorder was turned off and we were saying goodbye. The family caregivers would think about “one more thing” or want to clarify something they had said earlier in the interview. There were family caregivers who would also make notes between the two interviews about something that they wanted to explain further or they had forgotten. This created a sense of timelessness that extended beyond just when the tape recorder was recording.
Transformation as the nurse researcher and ALS family caregiver come together to find meaning in the chaotic experience of family caregiving for an ALS patient occurred when insights revealed through pattern recognition revealed a path of action that represented a change in a way of thinking and therefore a new action or path was realized. As the nurse researcher, I was not a “change agent” but rather through my experiences combining with the ALS family caregiver’s experiences, a new transforming energy emerged and insights that were revealed showed a new avenue of potential action.
The nurse researcher/ALS family caregiver process and use of self as instrument. The nurse researcher/ALS family caregiver process (as seen in Figure 4.1) is neither a linear nor a stagnant process. It is represented as an expanding spiral, as a spiral has been used to symbolize dialectic communication in research literature (McIntosh, 2007; Takeuchi & Nonaka, 1995). The use of dialectic communication is embraced in Newman’s theory of health as expanding consciousness and is evident through the use of self as instrument where the nurse researcher is actually the research
Newman (2008) identifies “being fully present” as the instrument (i.e. self as instrument) whereby nurses (i.e. nurse researchers) and patients (i.e. ALS family caregivers) move to higher stages of themselves (i.e. consciousness). Newman states (p. 51), “The essence of the nurse researcher/client (i.e. ALS family caregiver) process is in being fully present in the transformation of ourselves and others as we search for meaning in the lives of persons who have come to critical junctures in their lives.” The ability of the nurse researcher and ALS family caregiver to connect and relate to each other in a meaningful way happens through the utilization of self as instrument so that dialogue/co-creation of meaning can take place. Meaning is revealed through this dialogical activity and as insights occur, action potential is revealed.

Being “fully present” is key to utilization of self as instrument because being “fully present is essential to a transforming relationship” (Newman, 2008, p. 53). The concept of presencing has been represented by many different terms such as: (a) commitment, (b) openness, (c) full engagement, (d) genuine dialogue, (e) transcendent togetherness, (f) free-flowing attentiveness, and (g) transcendent oneness (Smith, 2001). Miller and Douglas (1998, p. 29) assert presence involves “putting everything else aside and focusing completely on the client; being with the individual with all aspects of oneself.” Parse (Newman, 2008, p. 53) identified true presence as “a way of being that values the other’s dignity and freedom to choose and is more than caring or active listening.”

Newman (2008) used the terms hermeneutic and dialectic to describe the HEC method, which allows life patterns to be revealed. Newman (p. 9) identifies hermeneutic as “the search for meaning and understanding through interpretation,” and dialectic as
“both the process of the method (i.e. between nurse researcher and ALS family caregiver) and the content of the search (i.e. the ALS family caregiver’s interaction with others). Through use of self as instrument, being fully present with the ALS family caregiver, the nurse researcher enters into a dialectic relationship when the ALS family caregiver is experiencing uncertainty and disruption in his/her life. Research by Graves showed dialectic communication as a living system of evolution where stages of communication were related to each other in a dialectical spiral of development (McIntosh, 2007). Graves stated each discrete stage of development is shaped and formed by its relationships to the other stages. This same evolving process was used to develop the pictorial representation of the nurse researcher/ALS family caregiver process used in this research study. All five steps identified in the process spiral back and forth as communication and co-creation took place.

The first step in the process, establishing a time and place for the nurse researcher and ALS caregiver to form a relationship occurred first with every ALS family caregiver and laid the foundation for developing a bond between the nurse researcher and ALS family caregiver. This first step was accomplished through the willingness of each ALS family caregiver to meet with the nurse researcher amidst hectic professional and family demands that were present with all caregiving families. The remaining four steps occurred sequentially but also flowed forward or back and around each other as the interviews took place. These five steps, which represent hermeneutic dialectics in action, allowed the nurse researcher and ALS family caregiver to create an environment that contained no limit or boundaries for freedom of expression through time, space and movement.
Forced Vital Capacity (FVC) of ALS Patients in the Study

Forced vital capacity (FVC) measurements, at the time of the interviews, are listed in the following graph. A FVC value reveals the amount of air that a person can exhale with force after that person inhales as deeply as they are able (WebMD, 2011). Forced vital capacity is important in ALS because according to Simmons (2005), it remains the most commonly used respiratory measure to evaluate respiratory function in ALS patients and is used to rate disease progression of ALS patients. FVC is performed at each ALS clinic visit. When an ALS patient reaches a FVC of 50% end-of-life discussions are done with the patient and family members at the clinic visit because sufficient respiratory function is important if end-of-life measures such as a diaphragm pacemaker or peg tube are to be completed. Similarly, if the ALS patient’s FVC is 30% or less, hospice arrangements are initiated so when hospice services are required, all necessary preparations are in place (ALS Association, 2010). The range of FVC values (as reported by the ALS family caregivers) for the ALS patients cared for by the family caregivers in this study ranged from 14%-92% and are presented in the following graph (Figure 4.2).

Figure 4.2. Forced Vital Capacity (FVC) Values for ALS Patients in Study (as reported by the ALS family caregivers)
Thematic representation of emerging pattern of the whole across all ALS caregivers

After patterns of the whole were identified for all eight individual ALS family caregivers, then these individual patterns of the whole were examined for emerging patterns of the whole across all eight ALS family caregivers. Nine patterns of the whole across all ALS family caregivers were identified (Aim 2). These nine patterns of the whole were: (a) suspicions emerge but ALS diagnosis is delayed, (b) support that helps the caregiver, (c) support can make caregiving more difficult, (d) looking toward the future, (e) adaptations from ALS, (f) obstacles to the caregiving role, (g) caregiver respite, (h) focus of others, and (i) strategies aiding the caregiving role. These nine patterns of the whole are listed in Table 4.1 along with their corresponding patterns of the whole for the individual ALS family caregivers. In the following narratives the pattern of the whole for each individual ALS family caregiver is listed first and is immediately followed in parenthesis by the corresponding patterns of the whole across all ALS family caregivers.
### Table 4.1. Thematic representation of emerging pattern of the whole across all ALS caregivers

<table>
<thead>
<tr>
<th>ALS CG</th>
<th>1 John</th>
<th>2 Alex</th>
<th>3 Andy</th>
<th>4 Hannah</th>
<th>5 Brittany</th>
<th>6 Aaron</th>
<th>7 Karen</th>
<th>8 Barbara</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suspicions emerge but ALS diagnosis is delayed</td>
<td>Troubling symptoms emerge</td>
<td>Something is wrong</td>
<td>&quot;Something's happening&quot;</td>
<td>Vague symptoms and unnecessary surgery</td>
<td>Unrecognized symptoms and misdiagnosis</td>
<td>Misdagnosis and &quot;vague symptoms&quot;</td>
<td>&quot;There's something wrong&quot; and &quot;Unnecessary surgery&quot;</td>
<td>&quot;His heart is a priority&quot;</td>
</tr>
<tr>
<td>Support that helps the caregiver</td>
<td>Support from family and the ALS team</td>
<td>Resources that help him</td>
<td>Resources that help</td>
<td>Support that helps her</td>
<td>Support from others can add more work</td>
<td>Support of friends and neighbors</td>
<td>&quot;I like to be told that someone else sees what I do&quot;</td>
<td>&quot;A strong, loving partnership&quot;</td>
</tr>
<tr>
<td>Support can make caregiving more difficult</td>
<td>Support can create stress</td>
<td>Disappointment in support</td>
<td>Family support can be a disappointment</td>
<td>Support is sometimes more work</td>
<td>Looking to the future</td>
<td>&quot;Chaos in their everyday lives&quot;</td>
<td>Support can be &quot;missing&quot;</td>
<td>&quot;Drawbacks&quot; of support</td>
</tr>
<tr>
<td>Looking toward the future</td>
<td>“Day by day”</td>
<td>Planning ahead</td>
<td>Difficult decisions for the future</td>
<td>Locked in: The future is before them</td>
<td>Changes since her husband’s ALS diagnosis</td>
<td>Planning for the future</td>
<td>“I’m just worried about today”</td>
<td>Journey to the &quot;end point&quot;</td>
</tr>
<tr>
<td>Adaptations from ALS</td>
<td>Changes in their lives</td>
<td>A “new role”</td>
<td>Adapting to her changing health</td>
<td>Many different roles of her life</td>
<td>&quot;Financial ruin&quot;</td>
<td>“Changes in my life”</td>
<td>&quot;Watching my husband deteriorate&quot;</td>
<td>&quot;Drawbacks&quot; of support</td>
</tr>
<tr>
<td>Obstacles to the caregiving role</td>
<td>&quot;Taking time for me”</td>
<td>&quot;Speed bumps” of the ALS disease</td>
<td>Roadblocks put up by his wife</td>
<td>A new “stage”: A new “hurdle”</td>
<td>She does &quot;try to relax&quot;</td>
<td>&quot;Makes caregiving harder&quot;</td>
<td>&quot;My husband is controlling&quot;</td>
<td>&quot;Changes in how they do things&quot;</td>
</tr>
<tr>
<td>Caregiver respite</td>
<td>Attention is on his wife</td>
<td>&quot;Speed bumps” of his caregiving</td>
<td>What makes his caregiving harder</td>
<td>Brain throwers: Making caregiving more difficult</td>
<td>Her own form of relaxation</td>
<td>&quot;Simple life and simple pleasures&quot;</td>
<td>His actions have consequences</td>
<td>&quot;Altogether, is it a gift or a curse?&quot;</td>
</tr>
<tr>
<td>Focus of others</td>
<td>Keeping life uncomplicated and simple</td>
<td>&quot;Sleep and breathe trains&quot;</td>
<td>Focus on how his wife is doing</td>
<td>Others ask about her</td>
<td>&quot;My needs matter too&quot;</td>
<td>&quot;Supported by others&quot;</td>
<td>&quot;Support makes it easier for me&quot;</td>
<td>Others focus on her husband</td>
</tr>
<tr>
<td>Strategies aiding the caregiving role</td>
<td></td>
<td>Focus is on his mom</td>
<td>Relying on past life experiences to guide his current caregiving</td>
<td>The &quot;definition of hope&quot;</td>
<td>Attitudes: She is &quot;not alone&quot; and &quot;gifts&quot;</td>
<td>&quot;Easy going and laid back personality&quot;</td>
<td>&quot;A life within a life&quot;</td>
<td>&quot;I’m a winner either way&quot;</td>
</tr>
</tbody>
</table>

The table above illustrates the emerging patterns of the whole across all ALS caregivers, highlighting the support and obstacles they face in their caregiving roles. Each caregiver's experience is represented with themes such as "Financial ruin," "Sleep and breathe trains," and "Simple life and simple pleasures," reflecting the complexities of living with ALS and the impact on caregivers' lives.
Presentation of Families

Eight ALS family caregivers were recruited and participated in this research study. There were four male family caregivers and four female family caregivers ranging from ages (27-85). Four of the family caregivers worked full-time in addition to their caregiving duties and four family caregivers were retired. Seven of the family caregivers were spouses of the family member with ALS and one caregiver was a son whose mother had ALS. These family caregivers were coded as ALS caregiver 1 through ALS caregiver 8, corresponding to his or her sequenced participation in the research study and then assigned pseudo names for the narrative to ensure confidentiality. All family caregivers were White in ethnicity. The demographics for the ALS family caregivers are represented in Table 4.2.

Table 4.2. Participant Demographics

<table>
<thead>
<tr>
<th>ALS family caregiver (CG) # (Name)</th>
<th>ALS family gender</th>
<th>ALS patient gender</th>
<th>Years Married</th>
<th>Time in CG Role</th>
<th>Employment</th>
<th>ALS patient presentation</th>
<th>Years Married</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALS family CG 1 (John)</td>
<td>Male</td>
<td>Mid 80’s</td>
<td>Early 80’s</td>
<td>2 years</td>
<td>Retired</td>
<td>Initially bulbar; now includes limb</td>
<td>58</td>
</tr>
<tr>
<td>ALS family CG 2 (Alex)</td>
<td>Male</td>
<td>Late 20’s</td>
<td>Late 50’s</td>
<td>2.5 years</td>
<td>Starting new job</td>
<td>Initially Limb now includes bulbar</td>
<td>N/A</td>
</tr>
<tr>
<td>ALS family CG 3 (Andy)</td>
<td>Male</td>
<td>Late 60’s</td>
<td>Late 60’s</td>
<td>1.5 years</td>
<td>Retired</td>
<td>Initially Limb now includes bulbar</td>
<td>48</td>
</tr>
<tr>
<td>ALS family</td>
<td>CG 4</td>
<td>(Hannah)</td>
<td>Female</td>
<td>Mid 40’s</td>
<td>Mid 40’s</td>
<td>3 years</td>
<td>Works Full time</td>
</tr>
<tr>
<td>------------</td>
<td>---------------</td>
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<td>----------</td>
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<td>-----------------</td>
</tr>
<tr>
<td>ALS family</td>
<td>CG 5</td>
<td>(Brittany)</td>
<td>Female</td>
<td>Early 40’s</td>
<td>Early 40’s</td>
<td>3 years</td>
<td>Disabled; Home-Schools Daughter</td>
</tr>
<tr>
<td>ALS family</td>
<td>CG 6</td>
<td>(Aaron)</td>
<td>Male</td>
<td>Mid 60’s</td>
<td>Mid 60’s</td>
<td>4 months</td>
<td>Retired</td>
</tr>
<tr>
<td>ALS family</td>
<td>CG 7</td>
<td>(Karen)</td>
<td>Female</td>
<td>Early 60’s</td>
<td>Late 60’s</td>
<td>2 years</td>
<td>Works full time</td>
</tr>
<tr>
<td>ALS family</td>
<td>CG 8</td>
<td>(Barbara)</td>
<td>Female</td>
<td>Early 70’s</td>
<td>Early 70’s</td>
<td>4.5 years</td>
<td>Retired</td>
</tr>
</tbody>
</table>

**Narrative Summary: ALS Caregiver 1 (John)**

ALS caregiver 1 (John) is an elderly man in his mid 80’s who has been the primary caregiver for his wife (Jane), who is in her early 80’s, since November 2010 when she was diagnosed with ALS. They have been married for 58 years and have four grown children. One adult child, a nurse, lives close by, one child was killed 31 years ago in a car accident, and the other two children visit intermittently. They have lived in their current home for over 50 years. John has been retired for over 25 years. Prior to his retirement, he was a World War II veteran and later worked in maintenance and operations at a major Army National Guard facility.

Jane’s initial symptoms were bulbar (difficulty with speech, swallowing, and chewing) in nature but have now progressed to include limb (arm and leg weakness)
involvement as well. Her current symptoms/adaptations include: (a) inability to speak or eat, (b) weight loss, (c) frequent falls, (d) excessive drooling, (e) difficulty with ambulation, (f) difficulty with position changes such as sitting to standing (get up and go), (g) use of Percutaneous Endoscopic Gastrostomy (PEG) tube for medications and nutrition, (h) use of pen/paper or augmentative and alternative communication (AAC) device, and (i) severe scoliosis. While at home, Jane uses a walker, but then utilizes a wheelchair for ambulation outside the home. At the time of the interviews, John reported Jane’s most current FVC value was 14%.

John’s primary caregiver duties include: (a) administering PEG tube feedings four times a day, (b) transportation, (c) fall prevention vigilance, and (d) assistance with bathing and dressing.

Thematic representation of emerging pattern of the whole for John

Troubling symptoms are present (Suspicions emerge but ALS diagnosis is delayed). John told me in our first interview at his age he “has a lot of trouble with details” and could not remember when Jane first started showing symptoms of ALS. He said, “I’m not sure about the symptoms…She started to slow down…” but that was all he could remember. At the second interview, Jane wrote the following message, which John read to me about her early symptoms of ALS. From the start of Jane’s symptoms in March 2009, there was a delay in her ALS diagnosis, which was made in November 2010. John read the following summary to me:

She had a mini stroke between November 2008 and January 2009 and didn’t know about it and went to the doctor [family doctor] and he sent her to get an MRI. That was in March 2009 and he [family doctor] said she had a mini-stroke
on the left side of the brain. She was slurring her words so he sent her to a
neurologist, who then sent her for speech therapy at the hospital. She could talk
and she had 6 weeks of therapy. Then she was having trouble swallowing and her
speech wasn’t clear. She was doing mouth exercises and still had slurred speech
so the doctor sent her to a speech therapist to treat her swallowing and speech.
After 5 months, where she had 3 days a week therapy, she couldn’t talk. She’s
lost 30 pounds and severe weakness set in…She fell 5 times; 2 in the tub; 2 in the
bedroom and one outside on the cement porch…She then went to the neurologist
at the ALS clinic and he said she had ALS…

**Changes in their lives (Adaptations from ALS).** Since Jane was diagnosed
with ALS in November 2010, daily life has changed for both John and Jane. These
changes have impacted not only their daily routine, but have involved adapting their life
style to the loss of enjoyed hobbies and social activities.

I guess the biggest change with things here is that I just have to be patient and
stick around the house here. If I can help [Jane], I have to help her out…It’s like
a job…a full-time job…I don’t sleep very sound…I don’t rest good at night…I
stopped fishing because I have no one to make the trout anymore…Now I’m just
a spectator [to other fishermen]…I used to catch trout and eat them and [Jane]
would make them. I can’t cook. Now, TV dinners…that’s about it… I don’t have
to buy much [at grocery store] because I’m only getting really for myself…All the
chores that she did-the washing and the cooking and things like that. I’m trying to
adapt to them. I still can’t really run the washer by myself. I can do the dishes as
far as that goes…I can’t keep the place as in shape like she did and that.
Sometimes too many dishes get setting around, but I know she wants me to [keep the house clean]… …We used to go out to Fort [Name] and take a walk, but she can’t do that anymore… She sticks around the houses here…She ain’t ready to go anywhere…I think she gets too tired…We don’t go to the store anymore. The only time is for medical reasons if we go someplace… It’s really changed that part of our life-Doing things together…She used to be more active in the church…She used to drive everywhere…She was a good driver…Now she doesn’t drive so the car’s always setting here…

According to John, Jane’s inability to verbally communicate anymore has been the “most stressful event” for him since her diagnosis. This loss of speech has forced new forms of communication to develop between John and Jane.

It’s really difficult with her not being able to talk…She writes me notes…I kid about she wrote 5 books telling me what I’m supposed to do because I didn’t do any of this stuff around the house here…Sometimes, I don’t know [what she wants]. I say, “I don’t understand what you want me to do.” She has a box [alternative communication device] but doesn’t use it very often. The only time is when we go to the hospital or a doctor’s office, but she don’t use it for me…I know what’s going on now as far as if the dishes are setting there and she points to them dishes, I know…It’s still difficult. My, oh my….She gives me a signal when she needs me [ringing of doorbell device that she wears]. That works good. Even when I’m sleeping I can hear that…

John said that as a result of the loss of verbal communication between himself and his wife, he especially loves talking to other people, even strangers.
I usually strike up a conversation with anybody that’s anyplace that I’m at. You know, just really say, “Hi, how are you doing?” and I say, “Do you live around here?” and that kind of stuff. Just carry on a conversation with them.

**What makes caregiving harder (Obstacles to the caregiving role).** John said there are some things that make caregiving difficult for him. Some examples he gave were his advanced age, health problems, and memory problems.

I’m too old now…I have a pacemaker…I have prostrate cancer…I can’t do much anymore…I get too tired…I cut the grass for a half an hour then I rest…I get the days mixed up…I’m not that strong anymore…I have to watch her now about falling…She only weighs 100 pounds but if she falls down or something like that, why she feels real heavy for me…I can’t get her up…I’d be lost keeping track of the amount of pills that she takes and I wouldn’t like that at all to be picking the pills out that she’s taking because I take 15 myself a day and I have enough trouble with keeping straight on mine because at 85, I start to forget a lot of things…My mind is getting that I forget what I have to take…

Caregiving is also difficult due to demands that Jane places upon John.

I feed her four times a day, 8:30, 12:30, 4:30, and 8:30 again…I don’t understand it but if it’s 8:30 she wants to be fed at 8:30. Not at 8:25 or later. I don’t understand why a couple minutes means anything but she runs like it’s a flight schedule…

John said he doesn’t have friends of his own age to do activities with or talk to. This has created a lack of close friends to serve as a support system that could help him in his
caregiving role. John got quite teary speaking about his former friends that have now passed away.

I like to check on the fishermen [at nearby National Guard grounds], but I don’t know the fishermen anymore. I lost track of them because my buddies got too old like me. They quit fishing…They are all dead…I had friends that I used to go to see…they died…A lot of my buddies, my active buddies, are gone. I’m the last one of the bunch…

Support from family and the ALS team (Support that helps the caregiver).

Although he says that there have been “many challenges” related to caregiving, John has received support from many sources, which he said really helps him greatly in caring for his wife.

My daughter lives close by and without her I couldn’t handle this…I couldn’t do anything without her help…My daughter comes here quite a bit. Anytime there’s any kind of a question, [daughter] knows the answer…She’s a nurse…She knows all this medical [information]…She understands what’s happening…When things pop up like that [medical questions], I usually check with [daughter] and she makes the call [to ALS nurse manager]…Everything that she [Jane] wants done, I can really do and if I can’t, my daughter comes and knows the answer to what I’m supposed to do…[Daughter] has a 16 year old daughter…We pay her to run the sweeper, jobs like that…My daughter does the washing…Then for supper, [Daughter] brings me different things that I just have to maybe warm up…
Jane also provides support for John. He said he is especially proud of how, despite having ALS, she is still “mentally okay” and how her ability to manage her own medications takes away a job that could be overwhelming to him.

She gets her pills ready and everything like that because I’d be lost keeping track of the amount of pills she takes and I wouldn’t like that at all to be picking the pills out that she’s taking because I take 15 myself a day. I have enough trouble with taking mine [pills]; keeping straight on mine…She can still order her pills. She sits here and I get the phone and she orders them [by touch tone phone]. She gets them shipped from [Company]…I never learned it [how to order pills] yet…The ALS team has been a tremendous resource for John. They advise him on not only ALS, but have also suggested having a paid caregiver come into the home to help with Jane’s care.

They’re [ALS team] really nice up there…The last time we were up, we talked with, it must have been a dozen people and even a pastor lady…They gave her [Jane] a prayer shawl. She really loves it…I thought they were really, really helpful…They’ll be telling me what I gotta do or something like that…There’s somebody going to come in [to aid Jane]…We have to pay her. She said that she was going to come once a week for about 2 hours…She gave her a shower and dusted…She’ll be coming Friday again…

**Support can create stress (Support can make caregiving more difficult).**

After the last ALS clinic visit, the ALS team suggested to John that he could use some help in the home with Jane. The ALS team arranged for a home health aide to come into the home once a week to help with basic household chores and perform some basic care,
like bathing, for Jane. Instead of being a help to John, he found the services this home health aide performed “redundant” to what he and his daughter and granddaughter already do for Jane. John “resented having to pay for these services that were already in place” for his wife.

We had that other lady. She came and dusted and that kind of stuff and gave [Jane] a shower and that. I don’t know what group that is. We have to pay her, you know. She said that she was going to come once a week for about 2 hours and she’ll be coming Friday again this week. She gave her a shower and dusted. It wasn’t a help. It wasn’t as far as I’m concerned. No, I help [Jane] in the shower. I don’t dust but the granddaughter does that when she comes and the granddaughter was here Wednesday. She didn’t do anything my daughter and granddaughter or I can’t do with her. It’s redundant. I don’t see why we have to have her in here. It makes me uncomfortable and I have to pay her for things we do for [Jane] already. I don’t like it…

“Taking time for me” (Caregiver respite). Hunting and fishing were two of the “greatest joys” of John’s life until he shared, “age and weakness made it too difficult” for him to participate in those activities. Today, he still “loves the out of doors” but is “no longer an active hunter or fisherman.” Now he watches and relaxes by just being with nature where it’s quiet and peaceful for him. He calls this “taking time for me.”

I’m too old now [to go hunting or fishing]. That deer I shot [pointing to mounted deer on wall]…but I couldn’t drag him down to my truck. I had to go down to the truck at the road and wait for another hunter…it took till almost 9:00 and I shot it right after 7. A hunter came by and I flagged him down and I said I got a deer
laying up there and I can’t drag him down…He helped drag the deer and put it on
the vehicle…I couldn’t believe that I couldn’t drag that deer that far…Hunting
and fishing doesn’t interest me as much now because I myself am too tired…Now
I will go away for an hour or so. Sometimes I sneak away too long and they start
wondering where I’m at! (Laughter). But sometimes the time goes too fast…I
usually go when [Jane] lays down in the afternoon…I go over to [Fort name]. I
really enjoy that-just watching the people and everything. Yesterday I was out. I
saw 2 deer and 3 turkeys…It’s a pretty quiet place. It’s out in the mountains
there. There’s 3 lakes out there and then I get out and watch the people and watch
their dogs. I check on the fishermen…Check out the lakes and watch something
with the plain people [Mennonites]…They come by and I sometimes say to the
man, I say [PA dutch word for how are you]…The man I talked to yesterday, he
said [PA dutch words]…

**Keeping life uncomplicated and simple (Strategies aiding the caregiving role).** John stated when anyone asks how he is doing, he always replies, “I’m hanging in
yet.” He tries to keep life “uncomplicated and simple,” which includes having others
make major decisions about the care of Jane.

I’m over that stage about getting into complicated things. I worked with the
military and that was the most detail and work. You go by their rules and
regulations. But I retired and I just retired from everything…The way [Jane] is
now, she tells me what to do. I’ve been able to do that [fulfill her
wishes]…Usually whatever she wants to do, that’s what we’re gonna do. I try to
comply with whatever that is…Everything that she wants done, I can really do
and if I can’t, my daughter comes and knows the answer to what I’m supposed to do or how to handle certain things…You know, I hate to complain about something because the next thing you know, they [ALS team] want to help you and I don’t want to. Don’t want any others to get too involved. They have their own thing to do so go do your job and we’ll try and get through ours… Because I don’t want to get it too complicated for myself…I try to keep life uncomplicated and simple…

Even when it comes to his own health John states, “The doctors say when I go to my doctors they say I never complain. Well, I don’t tell them but I’m scared to complain because I’ll get more pills…And I have enough trouble with mine…I take 15 myself a day…”

John did not hesitate on what he would tell a new ALS family caregiver based on his experience. Keeping the pace of his life simple and slower is something that John would recommend to any new ALS caregiver. He stated:

Just slow down and accept the pace, the new pace, because you’re going to have to change some of the things you’ve been doing. For me, because of my age, this would have been a lot tougher 20 years ago when I was active and doing a lot of things. But this happened and I slowed down that I’m not too keen on doing a lot of things. Because you really have to slow down and accept the situation…

**Attention is on his wife (Focus of others).** Even though others tend to focus on Jane and not him or his health, John said “this does not bother me”.

They don’t seem to ask me how I’m doing other than, how you doing or something, but I mean, they don’t get into any kind of detail about my
condition…Not to brag or anything, they look at me and think I should be doing alright. I look alright…They figure well, he doesn’t look like he needs help yet, you know…I figure they know it’s not maybe an easy job but so far, I guess I’m doing alright…

“Day by day” (Looking toward the future). John said he does not look far into the future and realizes that difficult decisions will be coming, but states he goes “day by day” and faces decisions “when they’re [deterioration of wife’s condition] about to happen because I believe that’s the way life is, you know, and that’s what we gotta do then…” He stated, “I imagine that there are going to be some tough decisions to be made as far as [wife] goes…It’s sort of the end of things as far as that goes [realizes ALS is terminal]…

In regards to involving Hospice services or the utilization of ventilator to extend his wife’s life, John said that neither of those decisions have had to be faced yet, but the ALS team introduced the idea of Hospice at his Jane’s last clinical visit. Even though he said Jane refuses to leave their current home, John said he “would be ready to move to the Veterans hospital” were his health to deteriorate.

They [ALS team] were concerned about her weight because some way they grade her [wife] and each time it gets lower and lower and when you get to a certain rating, then they want to get Hospice in. I guess it’s down that far…all her pep and that went down…About hospice, we’re still thinking about that…We’re putting that off for a while, yeah we’re putting that off for a while. We still didn’t decide on that… I think if [Jane would get worse, yes that [hospice] would be good…She wanted to check with the one doctor [ALS neurologist] about what he
thinks…I guess it was more or less up to use to do what we thought to do…I’m not too keen on doing things here at the house. If [Jane’s] that bad that she has to get into some kind of a professional or hospital caretaking because it’s too involved for me…Maybe we’ll talk now (about Hospice) that the boys [his two sons] are coming on the weekend…I’m not too happy if that [bringing equipment into the home] has to happen. We just don’t have the room for any kind of medical equipment to come in here…I know she don’t like to leave the place [their home]. She don’t want to go in a home. She’s not like me. She wants to stay here…I’m ready…I’m ready to go to the vet’s hospital…I’d team up with some of those old-timers…

Figure 4.3. Chronological Pattern Diagram: ALS caregiver 1 (John)
The chronological pattern diagram for ALS family caregiver 1 (John) is presented above. However, a brief review of the process involved for not only this ALS family caregiver but for all of the family caregivers was as follows:

Through repeated readings of the interviews, meaningful events and persons were placed in chronological life order within appropriate time frames. Sequential patterns and pattern shifts were documented along the chronological time trajectory. Indications of patterns of the whole as reflection on the family caregiver’s meaningful events and relationships over time then took place. These patterns of the whole are indicated in the diagrammatic chronological pattern diagram, which is based on Prigogine’s Theory of Dissipative Structures. All Chronological pattern diagrams along with their accompanying pattern diagram narrative follow each ALS family caregiver’s narrative summary.

**Chronological pattern diagram narrative: John**

When reviewing the pattern diagram with John, he started with the event that has been the highest stressor for him, which he immediately identified as Jane’s inability to talk. This was closely followed by her inability to eat and the death of their son (ranked #3). He commented about his son, “He’d be running for president by now. He was a smart boy. He could have done anything he really wanted to…” John ranked being diagnosed with prostrate cancer as #4 and stated, “I’m surprised I lasted as long as I did on that. I can hardly believe that…” Jane’s diagnosis of ALS ranked #5 and I found it interesting that he did not really know what ALS was when Jane was diagnosed, which could account for his placing the ALS diagnosis as #5. When asked if he knew anything about the disease when she was diagnosed, he said, “Not really when they said Lou
Gehrig’s Disease and the other-the real disease name. ALS, I don’t know the words that make that up…I knew who he was and that kind of stuff but I wasn’t that involved in sports over the years.” John ranked not being able to see his friends anymore because he needs to be home with Jane as #6. He stated, “I don’t get to see my friends anymore. I just hang around the house-sit around-watch the neighbors.” Completing the diagram were his own need of a pacemaker (#7), considering Hospice services (#8) and lastly Jane getting her PEG tube (#9). John really did not seem to understand exactly what hospice was and asked me “What is this, hospice or something?…I don’t know…” When I replied that they can provide extra services for Jane, he stated, “I don’t know what the scoop is, but I don’t know if I need any kind of help in what I’m doing unless [Jane] gets worse…” John said the PEG tube was the lowest stressor for him because “It’s not too hard of a task to do that [administer tube feedings]. You’ve gotta be careful to not spill or any of that kind of stuff. Nothing technically hard to understand…”

**Transformations/Insights**

When asked whether talking with me had given him any added insights or anything new to think about, John’s response was, “Oh yeah. You asked the questions about what we’re doing and what’s happening. It gives me an idea of what’s going to happen yet that I’ll probably have to make some big decisions about. Get hospice to help out here…”

John relies on his daughter to solve problems and answer questions with the ALS team and follows whatever Jane wants in relation to her care. He wants to keep his life “simple” and finds that having others make decisions about Jane’s care works well for him and he is satisfied with this arrangement (Binding Stage—where decisions are made
by others and there is little sense of self). He recognizes that a hospice decision (choice point-a turning point where there is a destabilization of established order) will be coming in the future, but prefers to live day to day with Jane’s care. John relies on established ways or order, evidenced by his reluctance to bring new equipment into his home (Centering Stage-focus is on self and a reliance on established order) and therefore John spirals between the Binding Stage and Centering Stage of Young’s Stage of Evolution (Newman, 1984).

**Narrative Summary: ALS Caregiver 2 (Alex)**

ALS caregiver 2 (Alex) is a young man in his late 20’s who has been the primary caregiver for his mother (Rebecca), the ALS patient since May of 2009 when she was diagnosed. Alex’s father resides in the home but has limited caregiving duties due to working 50-60 hours a week as a blue-collar worker in a nearby factory. Rebecca and Alex’s father have been married for over 30 years and are both in their late 50’s. Alex is one of two grown children but he has assumed the caregiving role because at the time of Rebecca’s diagnosis, Alex was laid off from his job. His sister lives several hours away and only comes home once every two to three months. When she comes home, she will take over his caregiving duties, but otherwise, Alex provides care 24/7 to his mom.

Although Rebecca’s initial presentation of ALS was limb involvement, the disease has now progressed to include bulbar (speech, swallowing, and chewing) symptoms as well. Her current symptoms/adaptations include: (a) weight loss, (b) inability to lift up her arms, (c) slurred, nearly inaudible speech, (d) bi-pap use when sleeping, (e) increasing choking episodes when eating, (f) leg spasms, (g) transfer disc usage, and (h) utilization of a wheelchair for mobility. With the exception of when she is
bathed or toileted, Rebecca stays in a powered-reclining chair in her living room. Her medication management includes Rilutek (for ALS), Zoloft (for mood stabilization) and topaz (for incontinence). Rebecca’s most current FVC value at the time of the interviews was 38%.

Alex’s primary caregiving duties include: (a) meal preparation, (b) bathing, (c) feeding, (d) toileting, (e) laundry, (f) cleaning, (g) transportation, and (h) staying at home 24/7 to care for Rebecca.

**Thematic representation of emerging pattern of the whole for Alex**

“*Something is wrong*” (*Suspicions emerge but ALS diagnosis is delayed*). Although Rebecca was diagnosed in 2009, she first showed symptoms in the summer of 2008 and the family knew that “something was wrong” with her. Alex said the following:

…Mom’s a Girl Scout. She couldn’t make the Scout sign with the right hand anymore, so, we did the whole blood test thing. It was carpal tunnel [what they originally thought]. No—finally, this is what it was [ALS] and okay, great…The GP had a bunch of blood test run to make sure it wasn’t carpal tunnel or Lyme disease or all that other stuff. So, basically this [ALS] is what was left…GP said yes [to diagnosis of ALS], the neurologist locally said yes [to diagnosis of ALS], and then we went up to see [ALS neurologist] and [ALS neurologist] said yes [to diagnosis of ALS]…it took six months to narrow everything down…

**A “new role” (Adaptations from ALS).** When Alex started to take care of Rebecca, he was out of work and had no formal caregiver training but credited being a Boy Scout as well as having a wheelchair bound friend as helping him care for his mom.
Becoming an ALS caregiver was a new role in life and required adapting his entire way of life to this new 24/7 caregiving role.

People ask what experience you’ve had as a caregiver and really, I haven’t done this before. I kind of fell into it. The economy was down and I didn’t have a job… I got laid off in March of ’09. I did a few things for a while and then that didn’t work out and this happened and then from May of ’09 through December of ’09 I basically didn’t get paid to do this directly through an agency. Dad threw me a few bucks a week to take care of the general chores and then finally in December ’09 some money got released from the state that I got paid to do it officially…It’s not a lot of money but it’s enough to get by and make something work…I deal with this 24/7. I may get paid for 49 hours, but I do this 24/7… It all happened so suddenly, but I have a very good friend of mine that back in the early 80’s, he fell off a roof and broke his back so he’s been in a wheelchair for over 20 years now…Helping him around the house over at his place, so I kind of knew how to take care of someone in that respect. It’s just applying it to a different disability…because with him, he’s a biplegic…with ALS it’s a different thing…I was a Boy Scout for 7 years; an Eagle Scout, the whole be prepared thing and all that…

Becoming a full time caregiver to Rebecca also required Alex and his dad to “re-negotiate” to adapt to this “new role” in Alex’s life.

When I first started doing this [caregiving for Rebecca], we [Alex and his dad] had some miscommunication back and forth…every 3 months we have the caregiver survey [completed for each ALS clinic visit], so I basically screamed
for help in there [at ALS clinic visit]…We batted fists back and forth, jokingly, and we worked things out that now he knows I need time [for respite] and I get time and all that stuff…This is a new role for me…

Before Rebecca was diagnosed with ALS, Alex said his life was “quite different” and “in many ways much easier” with only himself to be responsible for. Being a caregiver required Alex to leave his “old role” in life, which he said was “hard for a guy of his age”.

I hate to sound superficial, but some things were a little easier…I’d get home and dinner would be on the table…I’d just quick call, I’m not going to be home for dinner, eat without me. And of course now, It’s…I need to be home to make dinner…I have a lot more added responsibility and I can’t just run around an do things on a whim anymore.

As Rebecca’s physical condition deteriorated, family and friends now come to Alex’s home instead of making Rebecca leave her home.

Mom’s in the chair. She’s in the chair in the morning until I put her to bed at night. She’s in that chair except to go to the bathroom…She doesn’t get out as much but her friends come here…One of her friends will come over, grab a pizza from the shop down the street or sometimes somebody will come over for lunch or that kind of thing…before we used to go to [city] but now with mom having the condition she does, it’s kind of hard because at my grandmother’s, she’d have to climb steps and all that so they [relatives] come out here now…for Christmas and that kind of stuff…
Rebecca was very involved in Girl Scouts until ALS made her wheelchair bound. At that point she could no longer stay overnight at the summer camps and retreats. Alex made changes so that Rebecca could still have a Girl Scout experience.

Well, Mom’s a Girl Scout…Mom was on staff for over 10 years, they knew about Mom’s thing [ALS diagnosis] the first year after she got diagnosed. Mom was still in the transport chair yet, but Mom was fine. They took her down, they showered her, they clothed her all the way. Now this past year, Mom was in a wheelchair and couldn’t stay overnight but I got, of the 5 days, I had Mom down there 4. I’d take her down. We’d usually do lunch, stay late and I also had a friend that lived nearby that I’d let her go for a little while then come back…

Before Rebecca was diagnosed, Alex’s parents had planned to take a vacation out west to a national park. Although they had to make some adaptations based on her physical condition, Alex’s parents still went on this vacation.

…before Mom got diagnosed, Mom and Dad had planned to go to [national park in west] and ALS did not stop them from doing it. They took the transport chair and went out and did, like a week and a half in [2 national parks in western US]…4 months after she got diagnosed…Dad got the map and they went all over the place. If it was non-wheelchair accessible place, they didn’t go there…Dad pushed Mom all over the place…

Alex and his dad are planning a weekend away as a family, but now “plan ahead” to adapt to the physical needs of Rebecca.

We’ve learned by now to call ahead to the hotel. Get a handicapped accessible room, then Dad and I just need to make sure to give Mom a break…The big thing
is the bathroom. It’s still generally handicapped accessible, not an ALS specific bathroom- for bathroom breaks. Dad and I will have to go up and one person will hold Mom while the other person takes care of her pants and then we do the opposite…You know, you’re just learning to compensate and get used to doing these kind of things; plan ahead…We bring the transfer disk along- you just make do…We’ve done restaurants, we bring along sippy cups….If you give them a sippy cup, they’ll fill it up and all that and everything’s good to go. You’ve just gotta learn to prepare for it…

When asked about how they go to restaurants with Rebecca and use the bathroom, Alex replied,

Usually we put an incontinence pad and Depends on Mom…When we go out to [ALS clinic] we’ll go out to eat but she won’t go again until she gets home, cuz she’s not comfortable and it’s one of those, you have one woman and two guys. Okay, let’s check what bathroom we go into…We just get around it and she’s pretty good…Even around here [at home] we still have her in pads and Depends…It’s just better to have a protection than have an accident happen…

**Planning ahead (Looking toward the future).** Alex helped Rebecca write out her advance directive and Alex said this process seemed to “provide peace” to both Alex and Rebecca.

Mom basically has her fair say in everything. Dad’s the moneyman and I’m the caregiver. I did it with her [advanced directive]. I won’t say Dad has a disconnect, but it’s kind of like he’s at work so he isn’t as tuned to Mom’s needs as I am. She’s my mother. I grew up with her… so I specifically did that
[advanced directive] with her because we didn’t want to have, I hate to say it, but we didn’t want to have Dad force a decision on her or decide for her. I read all the options for Mom, what do you want, you know, cuz this is gonna be engraved in stone forever… She actually doesn’t want a tube [PEG tube]…Since doing the advanced directive and all that, I know Mom will be at peace as long as we can get things done…I mean she has no pain, so it is what it is, and I know after doing the advanced directive, this is what she wants, this is how she wants it done, and don’t vary from that and if it comes to that point, then it comes to that point and it is what it is…I don’t think about the end game. I know it’s coming but it’s there and I don’t have to worry about it right now…We kinda play life by goals. You know, my Mom lived long enough to see my sister get married, that was a big thing so we’ll have to see what happens after that…

“Speed bumps” of the ALS disease (Obstacles to the caregiving role).

Although Alex states that the last visit to the ALS clinic was “more of a social thing than anything else” because Rebecca has “kind of leveled out where she’s at,” Alex refers to any new physical deteriorations that have occurred in Rebecca’s condition since her diagnosis as “speed bumps” of the disease. One of the first “speed bumps” occurred when Rebecca was first diagnosed but people didn’t understand or know much about ALS.

…when mom first got diagnosed, people asked what is ALS? And then you say Lou Gehrig’s and they say, oh, okay, and granted this might be because of my age but I kind of feel that ALS is kind of like cancer was 10 years ago, that people didn’t know all the stages or what everything was and it was just one of those
things that you said cancer and people go, oh, instead of, you know, solemn sadness whatever, but now…cancer-it’s curable. Whereas ALS has been around longer quote, unquote, still not really curable and people still don’t know what it is…

Another “speed bump” occurred when Rebecca was still able to walk, but was growing weaker in her limb strength.

There were a few major speed bumps that accelerated Mom’s progression as far as I can see…We had a yard sale and Mom was going from this end of the garage and there was no handrail and she broke her upper right arm. She lost use of everything and it [ALS disease] slowly progressed everywhere else…She regained range of motion but no use of the arm…That kind of accelerated the right arm…We had some falling episodes with mom…She fell using a walker, going from the hardwood to the carpet and fell backwards and whacked her head, split it open. It didn’t crack her skull but it opened her skin…We had to run in to the hospital and get stitches and all that…There were some speed bumps that we definitely hit. That was a notable degeneration…

Because he is around his mother 24/7, Alex said it is harder for him to see each speed bump that Rebecca experiences, including the deterioration in her speech.

It’s weird because…she slowed down but I don’t notice it as much as somebody that doesn’t see her for a month…I’ve gotten use to her dialect-her change in dialect so I know what she’s saying to me…it’s something like I don’t see as much because I am the caregiver…
Another “speed bump” occurred when Alex had to change how he fixes food and had to start feeding Rebecca due to her increasing choking episodes and decreased strength in her arms and hands.

…Nutrition wise, she’s been eating less red meat because it’s harder to chew…so less meat and more starches or veggies…I’ll make a few steaks on the grill. Dad and I will have a full steak and Mom will have a half a steak because that’s really all she can handle eating…just cut smaller portions…There was the thing where she stopped being able to feed herself and not feed herself at all, so it’s getting used to what she can and can’t handle, feeding her and all that…

When the strength of her legs started to decrease and Rebecca needed help with transferring, Alex followed the suggestions of the ALS team and had a Hoyer life brought out to the house. Alex said using the Hoyer did not work well so Alex had to find another way to address this “speed bump.”

We’re looking into getting an overhead track system. I don’t know, we’ll see what happens. There’s a physical track connected to the ceiling with something. This is an older style ranch house-the Hoyer is too big. I had him bring it out…He set it up and I said would you mind if I told you it isn’t going to work and take it back.” He said “no, that’s why we set it up.” The thing was huge…something that big, it doesn’t work for a house like this. Unfortunately, the insurance will say it’s a Hoyer or nothing. So we are exploring other options…

**Resources that help him (Support that helps the caregiver).** Alex said he “doesn’t need to take any medications”, (i.e. anti-depressant or anti-anxiety medications)
or “attend support groups at this point to help him” care for his mom and instead relies on a close circle of friends for support.

I’m pretty self-supporting on everything, self-sufficient…I have some very close friends…I have a good support system with what I do with all my friends and all that…I keep them apprised of the situation…Of course there’s the guy in the wheelchair that I still see every once in a while and my partner in business…He’s been helping me out and I have a very big online presence with some Yahoo groups…and with my hobbies and all that…I have a pretty good support system that if I need something, it’s usually there within reason…

Alex said the ALS team and their caregiver’s survey has also been “helpful in expressing feelings and needs” for his as a caregiver.

It’s [ALS caregiving survey] helped me in expressing my feelings and needs when some things weren’t so great…If I have questions, I can talk to [ALS clinic team]…I can pick up the phone any day but a Wednesday and talk to somebody…

“Sleep and breathe trains” (Caregiver respite). Although it does not happen frequently, Alex does get brief periods of time for himself from other family members. “I called and talked to my aunt and my grandmother and they came out…they took care of mom while we [Alex and dad] were in [city in nearby state]”…When Alex does have free time; he spends it with his model trains. He said, “I basically sleep and breathe trains. I model. I do a little history and I’m working on building a short line railroad. It’s something I grew up with and I have fun doing it.” Alex has an associate degree in drafting and he has applied this to his love of trains. He also showed me an article that he
had recently written and had accepted in a Model Train magazine. This was Alex’s second publication about model trains.

I worked for basically 3 years as a professional model builder down in [city]…Working for the model builder, I learned some certain software and now I do graphics for making lettering for models (trains). I have a small side business doing that…I just finished another art proof about an hour ago and sent it off for the guys to look at and bless it and say it’s good to go. I get a lot of pleasure from it (model trains)…

Alex stated he “is not hesitant to take time” for himself, especially when it comes to his model train activities. He said he “recognizes the value of taking care of myself and tries to take regular breaks” from his caregiving duties.

I tease people, when I play, I play to win and even if that means stacking the cards in my favor, I’ll do it. I kinda look at it as the lone ranger perspective, that I am self-sufficient and I do what I need to do to survive…If I need to step away [for respite time] I’ll let people know I need to step away and do it and unfortunately, if they don’t like it, I’m sorry but it’s for my own good…I hate to make it sound this way, but I’ve kind of gotten desensitized… Like back in March I went to a modelers meet for the weekend and while I was there I said you can call me but there’s nothing I can do if you call me cuz I’m in [nearby town]…It’s kind of a damned if you do and damned if you don’t that I can take a break, and if I’m far away and something happens, there’s nothing I can do, so I just kinda like don’t think about it…
“Desensitization” and strategies (Strategies aiding the caregiving role). Alex also used the idea of “desensitization” as a strategy to help him in other aspects of the caregiving role.

After doing over a year’s worth of the survey [ALS caregiving survey completed at each clinic visit] for her [Rebecca] and me, I grew desensitized cuz we always joke, the last page of the ALS survey is your sex life. It’s okay, at this point, skip this question, skip this question, and did you want sexual intercourse even though you didn’t get any…

Alex has used the strategy of “expect and plan for the worst”, as well as “learn about ALS”, and said this could help any new ALS caregiver:

   Expect the worst and plan for the worst…not only every day, but the long term too. Just so you know what to expect and what’s coming, cause then when it does happen, you’re prepared for it…Once I knew what the disease did…what to expect and the progression and all that…knowing what the disease does…You know what you have with this disease…It is what it is…You take one day at a time and go from there. You have to set small goals and just keep on moving…If you’re doing anything, you have to think ahead and it’s also a mental thing, knowing that one day Mom will die. I mean, you know, hell if you go out tonight and get t-boned by a guy in a car crash, it’s just the way life is…

Drawing upon his past personal experiences, which Alex says have become “part of his personality” is also a strategy Alex has utilized. “Being an optimist” and “accepting whatever comes” has also helped him care for his mom.
I’ve had some issues in the past. I’ve learned to deal with things. I’ve had some very eye-opening personal experiences too… I had an NSA top-secret clearance done on me by the Army and it was a very eye-opening experience too. The guy that did the whole background check and then sit down [interview]…I did the lie detector test, the whole 9 yards and sit down with an NSA psychologist and discussed absolutely everything. I mean it’s NSA, you can’t hide anything anyway, so I went into it with an open eye and learned some stuff about myself… I’m an optimist, my mom’s more of a pessimist… I’ve gone through enough in my life, even in 27 years to look on the bright stuff and forget about the bad stuff and just let it go…cause I can’t change it… I’ve had some defining moments and it’s helped me to become a better person. It’s opened my eyes to things, because it’s not just a friend, it’s a family member… I’ve felt that way since before Mom got diagnosed and I’ve just applied it to what’s happened… I know if I have a problem, I know how I can deal with it that it won’t affect anybody around me. It’s my issue so I know how to deal with it on my own… If something goes wrong, and I have to fix it, I have to fix it…

Alex has also relied on knowledge from the Internet to learn about the disease as well as what his chances of inheriting the disease might be. It has also made him more health conscious as a result of this caregiving experience.

…With the Internet age, it was okay, Mom had this and you get online and see Mom’s the median age with statistics…the median age for diagnosis, again the statistics. It was just explaining to my friends, Mom has 5 or 10 years. I’ll be lucky if by the time I’m 45 years old, she’s still alive kind of deal… I just hope
that she’ll beat the statistics to a degree and push beyond those 5-10 years…I understand the slight statistical chance I’d have it [ALS] but it’s very small. I have a 10-15% chance of being diagnosed because my Mom has it…I’d say it does make you a slight bit more health conscious. I mean as far as what you do every day…It’s one of those things where you see stuff online…

Laughter has also played an important role in helping ALS caregiver 2 deal with caregiving.

We always try and make each other laugh. It doesn’t matter how raunchy it gets. If Mom laughs, she laughs…We did it before she was diagnosed, somewhat, but more so now. You know it can be as simple as Mom passing gas. ‘I heard that, you farted!’ And Mom will start laughing, you know…

“Speed bumps” of his caregiving (Obstacles to the caregiving role). In addition to Rebecca having “speed bumps” as her disease has progressed, Alex stated there have been “speed bumps” in some of the caregiving jobs he does for his mother.

There are still some things that are still a little tough…like cutting toe nails and shaving armpit hair and that kind of thing…There are some things that I know I don’t do that should be done…Mom and I don’t do much physical therapy…it’s one of those things that just doesn’t get done and it’s partially that I don’t feel comfortable trying to basically play Gumby with my Mom cuz she always thinks PT stand for “please torture”…It’s like let’s bend Mom until she bends and stops screaming…Mom, I joke is my ALS Barbie…I get her dressed, shower and feed her and all that stuff…
Lack of health care insurance for himself has been a “big concern” for Alex. Recognizing that he needs to stay healthy himself to care for Rebecca has reinforced his belief that “all caregivers should have health care insurance” for themselves.

…I didn’t have insurance anyway, and I really haven’t seen my own GP for a while just because of lack of insurance…I had no health insurance to at least provide a yearly physical…just to make sure that you’re in good physical shape and even equipped mentally…I mean I know ever 3 months we do the survey thing [at the ALS clinic visit]. We even do a complete mental eval just to make sure we can handle it. I’m not saying I can’t and I am 99% health most of the time with everything I have, but it’s something to consider…and you know some of the just general health stuff. They ask Mom about a flu shot. I didn’t get a flu shot. They tell her you should get a flu shot, swine vaccine and I’m sitting there like, great, I have no health insurance so if I get sick, Mom’s screwed! I can’t afford health insurance to keep myself healthy…Then what’s the point? I have put myself on the back burner on a few things I probably shouldn’t have. I need to get checked out…If you can’t care for the caregivers, you gotta make sure they’re healthy enough to care for the patient or otherwise the whole system goes to pot…All caregivers should have health insurance…

Focus is on his mom (Focus of others). Alex stated one difficult aspect of caring for his mom has been the realization that the attention of others, including family members is “solely” on her and does not include Alex or “the impact” caregiving has had on him.
When I started caregiving and after the first year, I kinda grew desensitized and the biggest thing to get used to and I hate to say, ignore was people would always say, how’s your mom doing…Always how’s your mom doing; not how are you doing…They think of solely of Mom because she has a condition whereas they don’t think this is a family disease, just like cancer and AIDS and all that other fun stuff. Mom may be the affected one but everybody is affected in some way…Being a caregiver doing this…It’s hard to quantify it more than just saying that it affects everybody not just the person having it…It impacts you…the joke, you know…she wiped my butt from some umpteen years growing up and now it’s my turn to return the favor. That’s fine and good but the joke gets old after you tell it for months…

Passing on his caregiving to others (Looking toward the future). Alex will soon be making another life change when he relinquishes his full-time caregiving role to fulfill a six-year dream of being a co-owner of a small business. He will be working about 15-20 minutes away but plans on living at home until he can financially afford to move out. Alex was initially “really nervous” about telling his immediate family about his new career plans, but found his family was “very supportive”.

I’m starting a business with a friend of mine and I’ve been trying to make this work for 6 years…we’re finally making this work…So now all the immediate family knows [about him starting a new job and relinquishing the caregiving role]… I was really nervous about telling my family about doing this. I told my grandmother and she was happy as all get out-very supportive. Because she knows I’ve been doing this a couple years [caring for his mom full-time] and to
do this for 2 years is a long time…It’s slightly bittersweet that now I finally get the job I want, and it’s just the way it is now…With returning to work, the stress level will be reduced as far as ALS related with my mother…. Taking on this new job has meant that a paid caregiver will need to replace Alex during the day and that his father will need to assume Alex’s duties after the paid caregiver leaves each day.

It’s mysterious how God works. The church I grew up in, the pastor’s son just got married and his new wife has been an in-home caregiver for a guy with multiple sclerosis. She didn’t have a job and we heard through one of my Mom’s friends at church that she was looking for a job. We interviewed her last week and she’s gonna come in next week and shadow me for a day and step into my role…I feel comfortable with the girl who’s going to be taking over for me…Dad and I talked about this when we started looking for somebody that I cannot guarantee when I will be home or not so we need somebody to replace me in whole…I don’t like playing hardball with my family but that’s the way it is…He [Dad] worked out the whole schedule that when he’s home, he’ll take care of it [the caregiving] and when he’s done, she’ll [paid caregiver] take care of it [the caregiving].

**Disappointment in support (Support can make caregiving more difficult).**

Unfortunately, at the time of the second interview, the paid caregiver they had hoped to hire had not worked out and this was creating a new situation that they would have to work out since Alex planned to start his new job in two to three weeks. He was “disappointed” in this situation because the girl they were to hire had been a support to him in the past by staying with Rebecca while Alex would take some time for himself.
According to Alex, she had appeared “really excited” to get this new paid position with Rebecca.

We have an issue with the person that was going to take over with Mom. That’s why I’ve gotta email some things out. We interviewed her and we haven’t heard anything back since. She’s our pastor’s daughter-in-law. She’s also come over here and stayed with mom when dad and I went to a model train weekend away. Mom loves her and she is really good with mom. She was really excited to get this job too and we can’t understand what is going on with her because she won’t return our calls or get back to us. It’s really disappointing and something I didn’t expect at all. I really thought more of her than this… I don’t know, we’re going to see what happens. We’ll have to figure out what’s going on and then go from there. I’m kind of at the exact phase that I really can’t [back out of his work commitments]. I can back down somewhat but there’s stuff that I have to do now [with his new job commitments].
Alex started at the lowest stress event in his pattern diagram, which he identified as the experience of caregiving for his wheelchair bound friend. Alex stated,

He’s pretty much self-sufficient. Just get him up in the chair and he does his own thing…It’s funny, we’re great friends, but we did a trip back in ’05…we didn’t get a handicapped accessible room, cuz we didn’t want to share the bed, so you know I said, “Dude, I got to see you naked, and I still go to therapy because of it!”

[Laughing]

Alex identified being a caregiver for his mom as being the most stressful event and said “just taking on the caregiving role, in general, can put a lot of stress on somebody…”
Along the same lines, having to stay home and the impact that had on his social life ranked higher than Rebecca’s actual ALS diagnosis.

I think it was just the caregiving role. I mean the diagnosis was there for maybe a little but until I figured out what the disease did and all that…Don’t take this wrong. It’d be like if you told me you had cancer. To me, I mean, I’d feel sorry for you, but it’s not stressful but if I would have to take care of you it would be a totally different stress level…to realize and get used to doing it on a daily basis…the next few months after knowing what the full responsibility is, figuring out stress management for yourself and all that and then by then it should level off, but still there’s that every day constant of what you have to do for that day to take care of that person…

Returning to work and relinquishing his caregiving role ranked 4th but very closely to Rebecca being diagnosed with ALS. “I know we’ll be ingrained in a high stress project, but the money and the name recognition behind it once it’s done and over with will be simply awesome.” Miscommunication with his father and working with his mother on the Advanced Directive were ranked 5th and 6th because they “were just part of the caregiving deal.” Being laid off of work ranked 7th because Alex said he “just kinda fell into the role [of being a caregiver].”

**Transformations/Insights.** When I asked Alex whether talking with me had brought forth any new insights or given him anything new to think about, he stated that he now realizes that he needs to stop feeling guilty about embarking on a new career, something that he has had problems with prior to our discussions. He stated:
It’s really hard to give up the care of my mom. I mean I’m ready to start a new chapter in my life, but I’ve felt a lot of guilt over this decision, even though everyone else seems to be doing ok with it. I really need to stop feeling guilty and just be happy and I think I’m there. I’ll still be living here for a while till I see how this works out and it will be a relief to go to work, come home and just live my life, not as a caregiver, but as a young person. I’ll still be here to see my mom, but it will be a way different scene here for me and I’m ready for that. I love my mom, don’t doubt that but I’m a young guy and now it’s time for someone else to help out and that’s what’s going to be happening…

Alex is at the De-Centering Stage of Young’s Stage of Evolution (Newman, 1984). He has made the choice to discontinue his caregiving role and is moving towards growth and higher levels of freedom by starting a new job and relinquishing the role of being his mom’s main caregiver. His young age and the desire to begin this new way of life in a job he has been planning and desiring for the past six years shows his awareness of extending beyond his current caregiving role (De-Centering Stage-Occurs once a choice is made and awareness goes beyond current physical boundaries). He has also been sharing this energy with others as he has told his extended family and friends and after receiving their approval is now quite eager and excited to begin this new stage in his life. By his relinquishing being his mom’s main caregiver, he is also experiencing freedom from the bounds of time in his caregiving journey and is very present in the moment of planning his future (Unbinding Stage-Freed from the bounds of time and able to be more fully present in that moment). Therefore he is spiraling between the De-Centering and Unbinding Stage of Young’s Stages of Evolution of Consciousness.
Narrative Summary: ALS Caregiver 3 (Andy)

ALS caregiver 3 (Andy) is a 65+ year-old man, who has been married to his similarly aged wife (Emma) for 48 years. They have 3 grown children who live in close proximity to them. Although the children will help with the care of Emma, who is the ALS patient, Andy is the primary caregiver. Emma is one of <5% -10% (ALS Association, 2010) of all ALS patients with familial ALS; her father died of ALS when she was 29 years of age. Emma’s ALS diagnosis is further complicated by a diagnosis of frontal lobe dementia (FLD), which is secondary to a closed head injury as a result of being a pedestrian accident victim with a pickup truck in 1992. Emma’s sister, who is estranged, also has a history of dementia. Emma’s initial symptoms were bulbar in nature but have now progressed to include limb presentation as well. Andy reported that Emma’s most current Forced Vital Capacity (FVC) value at the time of the interviews was 66%. Her current symptoms/adaptations include: (a) increasing choking episodes, (b) loss of fifteen pounds in the past 3 months, (c) equilibrium problems with increasing falling episodes, (d) slowing of body movements, (e) use of a walker/wheelchair for mobility, (f) short-term memory loss, (g) hand spasms, (h) intermittent non-recognition of family and friends, and (i) unintelligible speech. Emma also has osteoporosis and arthritis, which gives her increased amounts of back, hand, finger, and joint pain. Andy’s caregiving is complicated by his diagnosis of non-insulin dependent diabetes as well as requiring oxygen 24 hours/7 days a week secondary to emphysema. His main caregiving duties include: (a) cooking; (b) cleaning; (c) laundry (d) transportation (e) providing for home modifications, such as walk-in shower; (f) medication management; and (g) staying close to home to ensure his wife’s safety. Andy has had to perform the Heimlich
procedure on Emma during one choking episode. Andy is retired from a small business and a career associated with providing services to the military.

**Thematic representation of emerging pattern of the whole for Andy**

“Something’s happening” (Suspicions emerge but ALS diagnosis is delayed). Andy “could tell long ago that something was happening…it was probably a year or two before Emma was diagnosed with ALS, she started losing her voice.” Andy took Emma to different doctors “trying to find out what the problem was” and Emma had been seeing a neurologist on a regular basis since 1992 when she was hit by a pickup truck while crossing the highway and thrown 15 feet, sustaining closed head injuries. Even though Emma continued to see a neurologist from the time of the accident, “she kept losing her voice… her voice was getting funny…It was mainly softness of her voice or slurring of her speech…You couldn’t understand some of the stuff…She was always…coughing and like that…”

Andy said, “He [the neurologist] had no idea” what was wrong and “he [the neurologist] was batting his head, I think, against the wall too” when she started having speech problems. Their neurologist, whom they had been seeing since her pedestrian/car accident, then referred them to an ALS neurologist, who ran further tests. After reviewing the tests, the ALS neurologist sat down with them at the ALS clinic and even though there was Emma’s family history of ALS, Andy said both he and Emma were “totally shocked” when they received her ALS diagnosis.

…the way we were told about it was very shocking. He [ALS neurologist] just come right out and told her, you have ALS, Lou Gehrig’s…just that quickly. We were in there and he’s running these tests and you don’t know what he’s doing
and the next thing you know, he’s telling you she has ALS and I said, Whoa-
That was bad to take…Didn’t try to prep or anything…We were shocked…
They were “not considering that Emma could have ALS”, even with her family history
of the disease because Emma’s “symptoms were so different than her father’s”. Andy
said, “Her dad wasn’t losing his voice. Her dad could talk…He could walk and
everything…” Andy reported that Emma’s father reportedly “committed suicide about
two years after his diagnosis”.

He [his father-in-law] developed pneumonia so I had to take him to [medical
center] and that’s when they did the trach…He had to hold his finger over it so he
could talk…He was supposed to be on 24/7 nursing to watch him cuz they had to
pump his lungs out and everything else…I guess during the night he just ripped it
out and the nurse wasn’t there so…

**Roadblocks put up by his wife (Obstacles to the caregiving role).** Andy said
Emma is very “old fashioned, hardheaded and won’t change her mind” about several
aspects of her disease. First, “she does not want a feeding tube…when that time comes
that she can’t eat, it’s going to be the end for her.” Andy said this decision is based on
her experience of “seeing her father when he had ALS”.

She wanted that in the living will, that she does not want a feeding tube. I would
love to see her change her mind but that’s something that is fixed in her head.
Yeah, because they [ALS team] said that PEG’s are so much better now and we
tried to convince her but she’s hard headed-a hard headed Irishman!

Just getting Emma to go the ALS clinic for the first time was “very difficult” for Andy.
“We had a hard time getting her to go to the clinic. It was very difficult. She didn’t want
to go. She kept saying, I don’t have it- Ya know, I don’t have ALS.” Andy stated, “She was always, you know, coughing and she always blamed it on nasal drip. That’s why she couldn’t talk right. She was making excuses up.” Also when she was diagnosed with ALS, she didn’t want to take Rilutek (the only FDA drug approved for ALS). “At first she didn’t want it the first visit, but then, I think it was the second or third time over there, she finally asked [ALS neurologist] for it.” Because the ALS clinical visits are every three months, this would have been six to nine months after her ALS diagnosis before she agreed to take Rilutek, which is commonly prescribed at the first clinical appointment (Z. Simmons, personal communication, August 2010).

One of the hardest things or “roadblocks” that Andy encountered with Emma was “getting her to stop driving.” Emma “fought” giving up her license for three to four years.

The local neurologist ran some testing on her and her reaction time and everything else was getting slow and her memory and that ... She should [the neurologist recommended] give her driver’s license up...The doctor put a recommendation into the Department of Motor Vehicles about seeing if she is capable of driving so they gave her the option of taking the driving test all over...It took her three times to pass the written test...Finally I got her to stop driving...I had to take the keys from her. She really fought it...

Andy was worried about Emma’s safety if she continued to drive. When her car was sold, “she took that license plate and bent it to heck and threw it” and Emma still misses driving and will try to persuade him to let her drive by saying to him, “come on, I miss
driving… I miss it.” It is “very hard” for Andy to hear this and although he knows he cannot let her drive, it is “very hard” for him to hear Emma beg him to let her drive.

It has been “very hard” for Andy to get Emma to use a communication device or any new kind of technology that would help them communicate better. “Technology is hard for her to comprehend” despite his family’s best efforts to help her.

New stuff is hard for her. She will get on the phone or either my Galaxy pad and play games. She has games on her own IPod and music. But come to that thing there [communication device] my daughter programmed it up for her. All she had to do was hit a thing and say, my name is [name of wife]…had it all set up and she won’t do it. Won’t use it cuz it’s too hard. She has to change different areas and that there… I got a Prologic for her-bought her an IPod for her and she couldn’t use that. She tried but she always goofs up on it…now with her dementia and her memory and that there she’s slow to pick up on learning with electronic devices…she’s kind of hard headed and doesn’t want to use that stuff.

Emma also “doesn’t like having anyone help her bathe” as Andy describes:

She doesn’t get in the shower. She hand washes herself but she does not want [paid caregiver] to help her one bit, which she can do when she’s here…She wants to do everything herself…she just sponges herself off…like I said, she’s hard headed…She’s a stubborn person. She doesn’t want anyone to help her.

**Adapting to her changing health (Adaptations from ALS).** Andy started to “lose” the woman he married when Emma was hit by the pickup truck and her subsequent ALS and FLD diagnosis has “made it worse”. He stated:
I almost figured that accident there, I lost my wife, you know, because she’s not
the same person. She’s never been the same person. She’s never been the same
person and now with this ALS, it’s, you know, it’s worse, you know, cuz, it’s
rough seeing your wife die in front of ya, you know….She is not the happy, joyful
person that I married… that accident, the head injury…things was getting worse.
She used to be the biggest clean freak in the world. Now she doesn’t do that
laundry, I do it all…Her personality changed. She didn’t want to do things and go
do a lot…She was hooked on work. Work was more important than anything
[She worked at McDonald’s for 17 years]…After the accident she was diagnosed
as having a mind of a five year old…I don’t have the same woman I married.

Andy now has power of attorney over Emma, “out of necessity”. This was not something
Andy ever thought he would need to be thinking about prior to Emma’s accident and
ALS diagnosis. “When we retired we expected to go do some traveling and everything
else and, with her condition and my condition, it’s hard…cuz I have to lug oxygen tanks
around…” When Emma’s condition deteriorated after her UTI, Andy expressed how the
ALS disease has forced him to change:

We’re trying to work it [his wife’s care] out because we thought if this continues
I’m going to have to put her in a home, cuz she was wearing me down and
yesterday, I was at wit’s end…it was the first time I had to think about putting her
in a home…I don’t have the funds to do it but I’ll find it somehow…I had a guy
years ago try and get me to take long term insurance out. I wish I would have…
Their three grown children have all explored the possibilities that they might inherit ALS from their mother and ultimately all three children decided they would “take their chances” and were “put off” by the cost of the testing.

They all thought about it and there’s on the computer checking pros and cons about it and there’s no real proof [they’ll inherit ALS]…We went down to [medical center] for [his wife] wanted a 2nd opinion…They [medical center personnel] wanted to know if we wanted to have the test to see if it was transferrable. The test runs $3000-$4000 and insurance doesn’t cover it. That really put them off-the cost. Then it’s not proof…it’s not a proven thing so they said they just don’t wanna know.

When asking Andy about what has changed in his life since Emma was diagnosed with ALS, Andy said the following:

…but being tied down, not being able to go to…softball, high school, I like high school sports…I can’t go to the baseball games…I like to go over there and watch them games, ya know… Even though we don’t have many social friends, as a couple we don’t go out as much as we used to…We can’t go traveling, go visit people and see things like I have friends in Hawaii and we can’t go over there and she’d like to go back. We lived there for four years.

Andy stated he has “altered his daily routine” and now “stays close to the house” and Emma. He said “I will go for short stints but not for any time…If I need to go to the store…I just go for a few minutes and back…and be back home in 10-15 minutes…even that is becoming harder to do.”
Not being able to understand what Emma is trying to tell him has been “extremely hard” for this Andy. He expressed the following:

The hardest thing is communications…It’s been extremely hard because she keeps saying something over until I finally catch it or I’ll put a tablet down and say tell me what you want and now her mind is getting that bad, like when she spells things, she spells it the way it’s pronounced not the way, ya know [it’s spelled]…besides having to try and understand what’s she’s saying you have to sometimes figure out what she’s writing.

At the time of the first interview, Emma was having trouble with picking up her feet and legs to get into the van. Andy had to sell his pick-up truck “because she couldn’t get into it.” He is also “thinking ahead” about Emma’s future physical/mental decline when planning family outings/vacations. He and Emma used to “love” visiting a lighthouse in a nearby state that is currently being renovated. It is a four-hour drive, but Emma “does well with it” and “has enjoyed watching it be restored” over the years. Andy and his daughters took Emma for her birthday down to the lighthouse because “we didn’t know if she was going to be able to get up the steps to go inside again [in the future]…she just loved it…I try and keep her as happy as I can.”

At the time of his first interview, Andy said Emma could use a walker around the house but used a wheelchair only when she was out of the house. This had changed by the second interview when Emma had just been diagnosed with a urinary tract infection (UTI) and her condition had “really gone downhill”.

We noticed the movements of her legs and that were getting a little slower and Saturday morning [two days prior] she had to go to the bathroom and she couldn’t
walk. We had to get the wheelchair for her and oh, it broke her heart. She cried and cried and cried. She was getting worse and my daughter’s been calling over to [ALS nurse manager] and everything else to try and find out about different things…Here, she had a urinary tract infection and that really threw her bad. Yesterday she was at the point that she wouldn’t recognize anybody and you know she just wiped out and looked around and if you asked her what her problem was she couldn’t answer you…It was rough trying to understand what her problem was and that phone call was a lifesaver [when the doctor’s office told him she had a UTI]…They phoned in a prescription for her and I gave her a pill last night and I gave her one this morning. Today is different. Yesterday she couldn’t even feed herself… missing [her mouth] and everything else…She was really getting under my skin and I’m on Lexapro and it was getting to me.

With the UTI, Emma also experienced constipation and then incontinence of her bowels for the first time.

She went in her pants, oh, what a mess that was. When we got her into the bathroom my son holding her up . I pulled her pants down and it falls on the floor…The smell: uh! God! [Son] was gagging. I thought he was going to throw up. I had to clean that up and then get her washed and everything else…She’s been wearing Poise pads for a couple months, we might have to change her over to diapers… Apparently she wasn’t doing a good job [washing herself] and that’s how she probably got the UTI. She has not taken a shower in, I’d say at least four months…
Loss of communication with Emma has been a “challenge” for Andy. At the time of the interviews, Emma was using a dry erase board, or pen and paper to communicate.

Recently they sought an outside consultation to see if anything else could be done to help Emma speak better or slow the progression of her speech loss.

There was a lady at one of the eye, ear, nose and throat clinic, she put a television camera down there and had [wife] say things and her right vocal cord was not working in the same as the left one…so it was not closing right to make the voices. They didn’t say [if it was due to ALS]…then they sent us down to like a cleft palate clinic where this old doctor could put some kind of a spacer in there to make her palate close, so she could talk and he checked her out and he says, nah, he says it won’t help her…so, ya know, we’ve been trying all ways to get her speech but, ya know…

**Resources that help (Support that helps the caregiver).** Andy goes to three different caregiver support groups each month. The first is a general caregivers group and Andy is “one of two caregivers with a spouse that has ALS.” He said “it makes me feel good when we get out of that.” Andy also attends a frontal lobe dementia (FLD) caregivers meeting and finds it “helpful” because “just letting others know what…problems we’re having with our family and everything” and attends this support group with his oldest daughter. At this support group Andy has made friends with two hospice nurses who have been “very supportive” of him as a caregiver.

The hospice nurse said ‘you have my numbers…If you need anything you have my cell phone number. Call me. Don’t hesitate to call me.’ In fact when I was in
the hospital with my pneumonia, she came to visit me in the hospital. Both she and the other nurse have been very supportive to me…

Andy also attends the ALS support group and says “they are wonderful…I am picking up some things from these groups, ya know. The groups are helping me deal…watching her, the alarm system and that there…learning about those things there.” He said family “caregivers should get involved with a support group right away, immediately after diagnosis” because “they help yourself get adjusted for the lifestyle of a caregiver.” “The only hard thing about attending these support groups is when someone dies” and Andy stated,

…It’s rough going over there and seeing how the other people are progressing in the disease compared to her…the thing that does bother me is probably when one of them will pass away, cuz in the last two months, we’ve lost two of them [ALS patients from support group]…and then to see that young guy [new patient] come in cuz his wife broke down crying there in the group, but like everybody says, we’re here for each other ya know…

Andy says Emma “will not go with me.” Because she will not accompany him to any of these support groups, Andy has just started using a medical emergency alert button with Emma that she can push if she has any problems. This is due to Andy’s “fear for her safety with falling” while he is gone. Also, because his son and daughter-in-law live with him, they are often with her while he is at these support group meetings and Andy stated that she is safe “because that’s only an hour.”

At the time of the first interview, Andy had a paid caregiver that came twice a week, who performed range of motion exercises (ROM) with Emma. Emma refuses to
do ROM exercises with Andy and he thinks “maybe she gets away with it with me” (i.e. Andy doesn’t make Emma work very hard at her ROM exercises) but “she does not get away with this” when the paid caregiver performs her ROM exercises. By the second interview when Emma had been diagnosed with a UTI, the paid caregiver’s hours were going to be increased to 10 hours a week. Andy stated “She will feed her…and it gives me a break to get out of the house for two hours. She is also working with her on bathing and started out washing just her feet and legs but told his wife that we’ll wash up further [on her body]…so she’s getting her comfortable.”

Andy has used many sources for information about ALS and frontal lobe dementia (FLD). “MDA [Muscular Dystrophy Association] gives out those books for the caregiver and for the person. They are very good ones…I’ve read both of them.” In addition, Andy utilizes the Internet and said, “I get a lot of the ALS chapter stuff on my Facebook” and thinks Facebook “is a marvelous resource and a lot of people don’t realize it’s out there.”

The ALS team provided Andy with the opportunity to attend a weekend retreat on ALS and FLD. While at the retreat, Andy’s “sister-in-law’s going to stay [with Emma].” Andy had attended one other retreat that was sponsored by the ALS association and said:

Some of the stuff that we did in there was very helpful for when [wife] fell one time. Cuz I had to call the fire department. She fell in our bathroom and she fell up against the door. I couldn’t get the door open, so I called just the local fire department and 3 men came out and they got her out…They said if I ever needed them to call them anytime and so, I got that good rapport with them…I also had our neighbors help me out one time she fell too.
Andy also relies on his three grown children to help him with Emma. All three children and live within a nine miles radius from Andy and his son and daughter-in-law and their toddler just moved into Andy’s home “due to financial concerns”. His oldest daughter “does her mom’s hair” and Andy refers to this daughter as “his right hand. She is the one that will call and get somebody out in a heartbeat.” Both daughters “take her [Emma] out every Friday night for dinner and then they go shopping.” His oldest daughter also accompanies Andy to caregiver meetings and some doctor’s appointments. He said, “I don’t even have to ask. They are right there [to help him when needed]”

**What makes his caregiving harder (Obstacles to the caregiving role).** Andy “frequently sacrifices sleep” due to the caregiving demands of Emma and at the time of the second interview stated:

We went to bed at 11:30 and it was 3:30- she had to go to the bathroom. We got her up, onto the porta-potty and she went. We put her back in bed and we didn’t get up until 8:00…I probably look tired, but I feel it too…last night was a decent night’s sleep for a change.

Caring for Emma is “made harder” by Andy’s own medical problems. He has been on oxygen 24/7 “for about 6 years” and he has ‘‘emphysema caused from too many cigarettes when I [ALS caregiver 3] was younger.” In addition to emphysema, Andy stated:

I have had diabetes for about 2 years…because of my weight…and with the oxygen it’s hard to do exercise. About the only thing I can do is walk and I can’t walk very much because when I’m sitting here [in interview] I’m on 4 liters [of oxygen] but when I get up and start doing things, ya know, I have to crank it all
the way up to 6 liters…That gets me because there’s flower beds need weeding and everything else and she was the one that did it all the time. Now I can’t do it because when I start leaning over, my chest starts hurting me. My lungs too… It makes it harder for me to care for her…

Andy is like 90% of ALS family caregivers who at some point in their caregiving experience (ALS Association, 2010) rely on medications (i.e. anti-anxiety, anti-depressives) to help him care for his wife. He said he “listened to his daughter’s advice” and it’s really “helped me not get so worked up all the time.”

I used to always get worked up. I’d get excited and that when she would fall and hurt herself. My daughter kept saying, ‘Dad, you got to get the doctor to give you something,’ so I talked to our doctor and he put me on Lexapro, and it’s helped…at one of the FTD meetings, they had a lady from one of the day cares or nursing homes and one thing she said really toyed on me…she said that the statistics show that 63% of the caregivers die before the patient and I thought, oh my God! I don’t like that…it woke me up some…yeah, as far as taking care of myself…

**Relying on past life experiences to guide his current caregiving (Strategies aiding the caregiving role).** Andy said he relies on three experiences to help him in his current caregiving role: (a) his past nursing home experiences, (b) his hospice experience with his mother-in-law, and (c) his counseling experience through the military.

She [his wife] had a very bad lung infecting back in ’07 and they had to cut her open and clean her lung…they moved her out of the hospital into a nursing rehab place. That was the worst place in the world. I think they only had one nurse for
the whole place and she had a feeding tube in her…they [the nurse at the rehab] put the antibiotic on her and then she would leave and the machine was empty…You couldn’t get a nurse to come back to disconnect it…Before she left the hospital they said they’d have her medications-everything that she needs over there [rehab]…well, when we got there…they didn’t have her meds…they didn’t have a doctor. We were blowing up and the food was terrible…She swore she’d never go back to another nursing home…That was bad memories for everybody…It’s put a bad taste in all of us for nursing homes…

When talking about his past experience with hospice Andy said, “I’ve seen hospice with my mother-in-law…it was a good experience. Yeah, the hospice people were real nice to her. Yeah, I would not be afraid to do it [use hospice with his wife]”

While Andy and Emma lived in Hawaii, he provided services for the military. One service was with counseling women who had experienced domestic violence. Andy said this experience gave him a “bigger picture” of what families go through.

We did a lot of role playing and a lot of counseling and you’d have these women that would come in that their husband’s would beat the daylights out of them. Had this one lady…she had arm prints, black and blue on her, then I got her set up at a place to stay away from her husband and she calls him up and he goes over there and then she comes back into me again and I told her-‘lady look, if you want to get help, you got to cooperate with me’…I got all kinds of different things so I had a lot of counseling experience. It helps, yeah. Hey, your whole life helps.

**Respite time (Caregiver respite).** The ALS team has also talked with Andy about respite time and he revealed:
If I ya know, needed it, yeah, I think I would, yeah…It probably would [be a good thing]…when the girls [his daughters] left to take her the first time, I thought, here I had this time, what am I to do with myself?

Andy was unsure what he’d like to do with this free time but decided he might like to “go visit people…I will go do some grocery shopping or I will try and schedule stuff…probably take a ride down to [nearby town] see my old boss and sit and shoot the bull with him…yeah go and talk to somebody; it just gets a load off you…” Andy had not utilized respite time at the time of the interviews, but instead likes to talk with his brother because “he’s going through about the same stuff as I am right now. His wife has lupus.” Andy also likes talking to others in the support groups. He “gets ideas of what’s going to come…you have the idea of what, you know to expect…”

**Family support can be a disappointment (Support can make caregiving more difficult).** When Andy helped his son and his family by inviting them to live in his home, Andy said he “expected” both his son and daughter-in-law would be able to help him take care of Emma. These expectations did not come to fruition and Andy’s “disappointment” was compounded by the fact that the “support” he expected to be there was not.

They ran in to some financial problems and, uh, to help them out… I thought they would be a help for us here. I told them they could move in here and they sold their house before they lost it…They really don’t do much around here for us. She (daughter-in-law) is a schoolteacher. They’re out of school right now, so, she (daughter-in-law) just took the dog to the vets but she helps some but not what I would like her to do. I’d like both of them to help me more. I thought they’d be a
good support for me. It’s been a disappointment. I thought when they came to live here that they could help with [wife] but that just hasn’t happened. They do their own thing and don’t really go out of their way to do much to help me. I didn’t expect that when they moved in. They live here free of charge. They ran into some mortgage problems and we helped them out. They just don’t seem to see what needs done here or what I need help with. I didn’t see that happening once they moved in and now that’s the way it is…

**Difficult decisions for the future (Looking toward the future).** Andy faced an “unpleasant decision” concerning his wife’s sister, whom he refers to as “the black sheep” of the family. He said:

She was a very good person and the bottle killed her...we don’t keep in contact with her…they [group home] wanted us to take care of her cuz she has dementia, from the bottle, from boozing and that and she’s really messed up from the drinking…I said, ‘I can’t do that. I have one person I have to take care of.’ I could not do two of them...I’d shoot myself if I had to do two of them.

Thinking about the future, Andy said for right now they are going to keep Emma in the portable wheelchair while she’s here at the house. He said, “I have no choice. It’s the only way she can get around right now. If her strength comes back, that will be a Godsend, I’m praying for it, but in the meantime, we’re dealing with it.” Andy also revealed he was “concerned about when she has to be in an automatic wheelchair [all the time]…that’s going to be the big factor, ya know, as far as getting around the house here cuz I don’t know how she’s going to be able to control an automatic wheelchair.” He is also planning ahead and stated,
I’m waiting for Bath Fitters to put a walk in shower in…She’ll use that because there’s gonna be only a little lip to get in. It’s also going to be a built in seat that folds up and down for her to use…the guy told me he put it in as a medical emergency so they would put us up on the list…

Andy said he is “going to try to keep Emma at home as much as possible…for as long as possible…I don’t know what I’m going to do whenever something happens…It’s hard to think about that kind of stuff…after 48 years, what do you think?”

When asked about how he makes decisions about Emma and her future disease progression, Andy said, “I probably let it go as it is until the time comes, then I’ll start thinking more about it…ya know it’s all the learning curve. Learn as you go”… His family “tries to make decisions as a family…it’s better for more heads together than one trying because not always what I think is right…I’m open with whatever they think and if their decision is better than mine, why I would probably go with it.” Emma is not included in these family meetings.

There’s a lot of things she doesn’t even know what you’re talking about…before she always said, if I ever get dementia, I’m going to shoot myself, so we kept the word dementia away from her for a very long time. Now you can say it all you want and it doesn’t bother her…that’s how far her mind has gone…Short term [memory] is losing it. She did have long-term but right now, I don’t know how her long term is…Things on TV and if somebody important dies, she doesn’t remember who it is. Going to the movies, comedies we go to, she doesn’t even laugh. She just sits there and watches. The funny parts don’t phase her one bit…
Others focus on how his wife is doing (Focus of others). When discussing whether most people think about him as a caregiver and his needs, Andy said, “I think it’s more focused on her [Emma], but people say that they’re praying for her and all that there.” Andy stated “people always forget about you [the caregiver] …they don’t realize how much of a load or burden it is on you [the caregiver].”

Figure 4.5. Chronological Pattern Diagram: ALS caregiver 3 (Andy)

Chronological pattern diagram narrative: Andy

When I reviewed the chronological pattern diagram with Andy, he immediately indicated the ALS and dementia diagnosis had the most impact on him. Loss of communication was 2<sup>nd</sup> and his going on oxygen was 3<sup>rd</sup> because “it limits what I can do.” Losing her voice (4<sup>th</sup>) was followed by Emma’s weight loss (5<sup>th</sup>) because losing 15 pounds in 3 months was ‘not a good sign.” Andy then paused and identified when Emma lost the ability to drive as the lowest in stress (10<sup>th</sup>) followed by when he was diagnosed...
with diabetes (9th) saying, “I’m only on the pills. I’m not on insulin” so it is not very stressful. Andy then identified when Emma was hit by the pick-up truck as being 6th in ranking. Andy then stated being tied down to the house would be 7th followed by when Emma fell and he had to call the fire department (8th).

Reviewing the pattern diagram not only gave Andy the chance to verify my interpretation from the first interview, but it led into a discussion of whether it’s harder for him to be a caregiver for Emma’s ALS symptoms or for the FLD. He replied: “Both. They pretty well intersect. It’s hard to detect which is which. I think the FLD on the memory and that is progressed worse than the ALS.” It also led to Andy telling me what caregiving means to him.

It’s a big job. It’s rewarding in a way because you’re keeping her going, you know. That’s the one thing about being a caregiver. I’m here to keep her going as long as I can. I’m going to do my best.

**Transformations/Insights.** When I asked Andy if talking with me had brought forth any new insights or made him think about anything he hadn’t before, he replied:

Yeah, it’s the thinking of what to do with her in the future and that. It’s got me thinking more…It’s not scary, it’s hard to describe what it is…It’s just the thought of what you’re going to lose. It’s the friendship of 40 some years that I’m going to lose, you know….It’s rough to see her die in front of you…

Andy was at the Choice Stage of Young’s Stage of Evolution (Newman, 1984). He was aware that old rules that had previously worked for Emma, such as letting her perform her own bathing and hygiene care were no longer applicable and hiring someone to help her, despite her protests, was what needed to be done in the best interest of his wife. Even
though he relies on input from his children and will go along with their decisions if he thinks they are better than his own, Andy will make the final decision, not his children, as he faces the current choice point (turning point that is a destabilization of established order) about her paid caregiving assistance with hygiene. Andy still prefers to face choice points one at a time and faces them as they occur before him, but through this Choice Stage (old rules don’t apply and a need arises to be more reflective in response to situations), he has shown movement toward the expansion of consciousness (Picard & Jones, 2005).

**Narrative Summary: ALS Caregiver 4 (Hannah)**

ALS caregiver 4 (Hannah) is a woman in her mid forties who has been the primary caregiver for her similarly aged husband (Tony) since he was diagnosed in September 2008. Tony’s initial ALS presentation was limb but has now progressed to include bulbar symptoms as well. He was one of the first ALS patients in this region to receive a diaphragm pacemaker for his diagnosis of ALS. His ALS diagnosis was further complicated by being diagnosed with thyroid cancer at the same time he received his ALS diagnosis. Hannah and Tony have been married for 23 years but have what she refers to as an “unconventional marriage” where she is the breadwinner and Tony is the stay at home dad. They have an eight-year old daughter (Laura) who also helps with her dad’s care through activities such as handing things to him, or helping him put on his BIPAP mask. Laura does not participate in any toileting or bathing activities with Tony.

Tony’s current symptoms/adaptations include the following: (a) wheelchair bound with no function of his arms or legs, (b) limited use of thumbs, (c) BIPAP machine usage for 14-15 hours/day, (d) feeding (PEG) tube, (e) diaphragm pacemaker assistance device,
(f) rapidly declining FVC values (decrease from 50% to 34% in three months time period), (g) eye gaze device, (h) slowing, slurred, soft speech, (i) Hoyer lift for all transfers, (j) implanted vascular access port, and (k) difficulty breathing when sitting up. He is currently participating in a clinical trial with the drug ceftriaxone and has no mental changes at the time of the interviews. Hannah’s main caregiving duties include: (a) feeding, (b) toileting, (c) all activities of daily living (ADL’s), (d) transportation, and (e) bathing. These caregiving duties are in addition to working full time, often putting in 60 hours/week at her job as a project manager. For the past six months, Hannah has received help during the workweek from her mother and aunt with Tony’s care. They are now exploring hiring someone to help with daily care while Hannah is at work. Tony’s latest FVC value was 34%, which was done prior to his diaphragm pacemaker surgery.

**Thematic representation of emerging pattern of the whole for Hannah**

**Vague symptoms and unnecessary surgery (Suspicions emerge but ALS diagnosis is delayed).** Hannah and Tony “initially dismissed” the vague symptoms he was having, but when they grew more severe Tony sought medical advice. This resulted in an “unnecessary spinal surgery”, after which his symptoms got worse. Tony was finally referred to the ALS clinic and was simultaneously diagnosed with ALS as well as thyroid cancer.

…He was having a heck of a time with terrible cramping. Like jump out of bed cramping, in his thighs. And then he was kind of stumbling going up the stairs. And I’m like, you’re just getting to be an old man, so we just kid of chalked it up to that. Then he had an incident where he was helping a friend move and he was carrying a couch and walking up the stairs backwards and he couldn’t do it. He’s
like-I’m trying to lift my leg and it just doesn’t want to so he fumbled…He went and saw his primary physician and then got referred to neuro-somebody for his back and they told him that they thought that he had an issue with his spine. They wanted to do a lumbar, lumbarectomy kind of thing. So he had surgery scheduled for June and after the surgery he got worse. So they said, “okay [Tony] you really shouldn’t be getting worse.” Did a couple scans. No, the surgery worked fine. They said I want you to have an EMG…and from that they referred him to [ALS clinic] and he saw [ALS neurologist] and then he got the diagnosis just shortly thereafter. He was also diagnosed with thyroid cancer so he had his right thyroid removed four days after the other diagnosis so there was a lot going on…

Support that helps her (Support that helps the caregiver). Because Hannah “works long hours” at her job, she has “relied on my mother and aunt to help” with watching Tony during the day. Hannah will “get up an hour and a half before leaving for work” so that she can bathe, dress and feed Tony, which leaves her Mom and Aunt to “just keep him safe during the day.” Because they are Canadian citizens, her Mom and Aunt are limited in the number of days they can stay in the United States to help her. Hannah also relies on “support from other family members”, especially her sister, who is “a great listener” for Hannah. There is also a “close family friend” whose “presence helps more” than any of Hannah’s other friends.

…For the past year and a half, I have altered between my Mom and my Aunt, who can spend 181 days in the country, being here with us…I still do 80% of it (caregiving) so they would be there to make sure that he was okay. They’d get him something. [Aunt] will help him get something where he was still able to get
things in the refrigerator. Help him open something…My Aunt, she does laundry for me; she gets dinner ready; she does the dishes. She’ll do those kinds of things so if I had to do that on top of everything else, forget it. I would have hit the nut house already so at least I have people doing what I call more home care things…I talk to my mom, my dad, my sister. My parents are divorced so I can talk to them separately…I talk to my sister a lot or I text her, blackberry her…She knows I’m just venting. Sometimes I need to just vent…my sister’s very good at that (listening and letting her vent) She’s a great listener…We have a friend, our best friend. He comes up at least once a week to spend time with [Tony]. He calls [Tony] every day. He’s been up to clean out the gutters, move some furniture…

Support is sometimes more work (Support can make caregiving more difficult). Hannah has several support systems that can help her as a caregiver and although her company and friends “can be very helpful, they can also make caregiving harder” for her.

… He (Tony) is a stay at home Dad. I’m the one who worked and I do travel. He helped me by doing all the home stuff and I brought in the money…I’m a partner in a firm and they’re good…I’m trying to educate them but they kind of see it (ALS), I think, as this temporary period of time when I need to be fixing things as opposed to this is a longer term thing here. They’re being great, flexible, and letting me set my own hours as long as you get your stuff done kind of thing, but at some point, you know I’ll need more…All our friends live away from here. The problem with them is that they (friends) are always telling me what I should do. I don’t really want you (friends) to tell me what to do. I don’t need to hear,
“well [Hannah] you should be setting your time up and you should be going to somewhere,” I just need you (friends) to listen… I find my friends are not real helpful because they want to tell me what to do as opposed to helping me figure out what to do. They want to just tell you what to do. “[Hannah] you know you should, we should go out shopping,” and I’ll say, “well, that’s not going to be relaxing for me if I don’t have things set up at home.” They don’t see it… The other thing I’ve had difficulty at being able to articulate to people… People saying, “well what can I do to help you? Would it be helpful if I came over and did blah, blah, blah?” I’m not so great at being able to figure that one out. It appears to be that it’s more work for me to figure that out…I have no issues with asking for help around those kinds of, like a project. Help with the walk stuff (ALS annual walk). Get the letters out, so no issues with asking for help around that kind of stuff but the more day-to-day things. I find that hard to compartmentalize… Most of our friends live about 40 minutes away so… you know that it’s almost better to just kind of drop in and if there’s something going on, well, then let’s just do it than to figure out how to plan it all… My situation is a little different sometimes, I think, than my friends. My friends have always challenged that life that I’ve had…

Even though her “Mom and Aunt are a great support” to Hannah, “they can sometimes create more work by not making Tony do the things he needs to do. “ In addition Tony can make more work for Hannah by “his refusal to let others help him with toileting issues during the day” while she is at work.
…But now, he can’t even take his meds. He can’t go to the bathroom…He doesn’t want it (Mom and Aunt’s help with toileting); not because they’re not willing to do it…But they don’t want to cross the line…[Tony] used to take his meds at 4. “Well, [Tony] was sleeping. [Mom and Aunt said]. I didn’t want to wake him up.” “No you wake him up. He needs to stay on his pain and medication regimen.” Or I’ll say, “[Tony] do you want lunch?” “No, I don’t want lunch.” Well somebody needs to be strong enough to say, “no [Tony] you have to have lunch”…In defense of them, who wants to be the bad guy? He said “no” and then I’ll get so I’ll say to him, “[Tony] stop, you know you have to have lunch. Figure out something then that doesn’t require somebody to school you. Eat the power bars or pour the can (tube feedings)”…then I feel like I’m scolding and I don’t want to be like that but you know the end of a day when I’ve been at work for 12 hours already or whatever, sometimes it’s scolding…

Even the ALS support group, which Hannah and Tony attend regularly, can be “helpful but lacking in some areas”, especially because “so few of them in the support group have young kids to take care of on top of caring for their spouses.”

…The support groups I find that they, up to this point, they’ve been very helpful with tools and aids and things to think about, be prepared for…The age group of the people is a lot older so finding out what have other people done has been. There’s been less support for people who have young children…I think that could be helpful; having somebody who’s in the same situation as me and then trying to kind of come up with or getting advice is a little different than the person sitting over here who’s not kind of living your life…
Hannah talked with me about spirituality. In contrast to her husband, Hannah “does not turn to her spiritual beliefs to help her” in caring for Tony or “dealing with the difficult decisions she will have to make in the future.”

[Tony] would tell you otherwise. [Tony] would tell you that that’s (spirituality) been very important to him but that’s a personality thing for me. It’s not a support system for me because it doesn’t give me answers so it doesn’t help me in my quest for solving things. Therefore it’s not helpful. That’s a very black and white answer but [Tony] would tell you that it’s very important to his journey.

Whereas I just ask lots of questions and get no answers but I’ve always been like that so that’s not new for me. I think it’s important for people and I strive to be better in my faith but I’ve always been like that because that’s who I am. I’m a want the answer kind of gal…

A new “stage”: A new “hurdle” (Obstacles to the caregiving role). With each new development of Tony’s disease, Hannah has dealt with each new “stage” or “hurdle” through “extensive planning”. Not only does she plan on how to deal with each current “stage” or “hurdle,” but she likes to “plan ahead and develop strategies for hurdles that will occur in their future” as her husband’s disease progresses.

ALS is very unique because there’s the things we go through and maybe I think that compared to some of the others I think there’s some uniqueness to this staying one step ahead because it’s so long. The journey is long… We’re going under the hurdle, a new stage, a new hurdle, and what do we need to do to get past it…So I think that what keeps me going is I put stuff out there so that we have to get to it and I gotta figure out how do we get to it, whatever it is…I’m always
planning ahead something so there’s something out there to work for because you work for things and there’s a goal. Whatever the goal is. I figure if we don’t have those then we’re gonna give up…I think it’s helped him, I think. Then I get to the when it doesn’t happen I get very disappointed so I gotta work on that because I think there’ll be more of that than less of that going forward…

Hannah often contacts the ALS team, especially the ALS nurse manager to help her “plan ahead for what could be coming” as Tony’s disease progresses. Immediately facing her are decisions about hiring a paid caregiver and making a decision regarding extending Tony’s life through use of a ventilator. Hannah often refers to these new “hurdles” as new “brick walls” that appear before them and tries to “plan as a strategy to deal with each “brick wall” as they occur.

…I’m trying to draw myself a picture of what does the worse case look like? I’m not sure I know what that is yet. [ALS nurse manager] is helping me with it. We’re going to get together again. She gave me the next wall. What’s the next brick wall I’m going to hit. What are we doing with this communication and his breathing thing (ventilator)...Figuring out...How we can improve this piece...I need to know...I think just understanding what happens in the next phase...I still can’t get my arms around what is the day gonna be like with this machinery (ventilator)? That video (ventilator video) made the machinery look so onerous and I don’t understand this machine...Is that a 24/7 thing and is somebody gonna have to be standing there and I just don’t get it...The mechanics...I think I gotta probe more...I need to go back to [ALS nurse manager] and say, I watched this video and there are these big things and such and machines and it’s like I still
don’t see it…and then this caregiving piece (hiring a paid caregiver). If I can’t get this through a personal channel (friend recommendations) then I’m definitely gonna need some help from [ALS social worker] or somebody to navigate the waters here…I feel like because of the role that I have in my job…My expectations of people are that they won’t come to me asking for help if they can’t articulate what that help is so I believe if I’m gonna go ask somebody for help, I need to know what that help is and I’m not sure I know what that help is yet…I asked the questions before, still don’t have the answers so therefore, I believe I’m not asking the question right…I’m assuming I’m having difficulty articulating what it is that I think I need…

During interview two, Hannah spoke about what she would be discussing with the ALS team at their clinic visit later that week. “Proactive planning” regarding Tony’s communication device as well as “planning for interviewing agency caregivers” are at the top of her planning list. “Setting goals around Tony’s disease progression” also is part of her “planning strategy.”

…We’re going to talk about how he’s declined even since he’s had the surgeries. We want to look at what does that mean and where are we going or what are some things we need to be doing proactively…We’re trying to get [Tony] ready for trying to qualify for the AAC technology…We’re still waiting to hear from them. We haven’t heard back so upon my follow up this week. I’m gonna say, okay, where are we at? We’ve been through 2 personal people trying to do the caregiving. They’ve both turned us down…they were through people that we knew who said, “Oh let me ask so and so”…They came out, spent some time and
then saw that it would be more work than they had thought so my goal is by the end of this week to see where I’m at so I kind of gave [Tony] a goal that says by the end of this week we’re done with our personal hunt and I need to go to the agencies but I need to get time during the business hours to do that so that’ll be my goal by the end of this week because we’re not getting where I think we need to be fast enough...

**Many different roles of her life (Adaptations from ALS).** Hannah has “really struggled” to fulfill what she refers to as “the many different roles I am expected to be; mother, caregiver, wife, and provider” since Tony’s diagnosis of ALS. She also distinguished between the “varying roles that a caregiver implies” and “has not figured out clear distinct lines separating those caregiving roles.”

…I kind of teeter on the when am I just being this drill sergeant versus trying to keep being the wife and not the drill sergeant caregiver…because I am such a planner. I like things to be here’s what we’re going to do for dinner tonight, here’s your work, you know…I know some of the burden I put on myself but it’s the way I can fit it in to feel like I’m still being the 3 people. 3 different people I need to be that we choose to be and you know [Tony] and I talk about that. You chose to be a parent, now be a parent…I know that clinic gives us good advice about trying to separate…but it’s very difficult to separate…Back to the binary question of well you should really be a spouse and not a caregiver, but as a spouse you are a caregiver so where do you draw the line at caregiving? I think that’s the key…Sure I can find somebody to give him a bath but who’s gonna help deal with these other things…The loss of whatever. You’re still the caregiver for that.
You’re the caregiver of your partner. That’s what marriage is. You signed up for that so you can’t abdicate that responsibility…Never did “it wasn’t in my job description.”…The hardest thing for me is saying, “can I continue to do this job and take on these other responsibilities?” I haven’t answered that question yet. I keep thinking that I can make this work…and keep my sanity… So I think there’s that realization of there are 2 different kinds of caregiver and separating those things and I’m not sure…You gotta think about that. That’s a thinking thing.

Yeah, I think it’s a big area…

Hannah shared that “central to the many roles ALS has forced me to adapt to have been decisions relating to my young daughter (Laura).” Hannah and Tony were only one of two husband/wife couples in this study with a young child still living at home. Their consideration of Laura and the impact Tony’s ALS has on her life “has been a major concern” and Hannah “has tried to strike a balance in letting Laura participate in Tony’s care and still be an eight year old girl without too much pressure on her.” Realization that “her dad will eventually die is a reality”, but “not exposing Laura to facts about his condition until they are necessary” is advice that Hannah has “received and utilized from the ALS nurse counselor.”

…She will give him his meds, like his treatments…Because they’re sorted and so she can just pop the lid and then put them in for him and give him his coffee and she’ll make his coffee for him…She will put on the BIPAP machine and turn it on and off for him. She will give him his beverages. She helps sometimes feed him dinner…She will, of recent, help him in the bathroom. Kind of give him the urinal, take it away because he can’t lift his arm up. Pull his shirt down after he’s
finished. She’ll scratch for him…I will say there isn’t really anything she
wouldn’t do. We don’t let her do any of the true medical kind of things…I just
try and balance how much responsibility I give her. More with asking her so I
don’t kind of task her with it; like her chores. I try to separate those two things so
that taking care of Daddy isn’t a chore…Since we went on the breathing machine
(BIPAP), we’ve now given her more details, so she knows basically everything
now. We kind of follow [ALS nurse counselor’s] advice and told her what she
needed to know, or asked as things went along. Now she knows the whole
picture. The unfortunate part of knowing the whole picture is, we don’t know
what really the whole picture is. We know that the end stage is that daddy will
die but we don’t know when…It could be tomorrow so we’re working on the no,
it’s not going to be tomorrow. That’s how she interprets it- I don’t know, could
be tomorrow so we don’t want to leave Dad’s side. Other than going to school we
don’t go anywhere unless Dad’s with her because she needs to make sure that he’s
okay. She’ll do things in the house, but we need to be within eye shot of
checking…She’ll run up, “Dad, are you okay? Do you need something?”
…We didn’t have her watch the video (ventilator video). Well, first of all
because I didn’t know what the video was gonna say so I’m glad that she didn’t
watch the video but I’ll work with [ALS counselor]. She’s very good about
giving me advice to kind of broach the subject with [Laura]…She’s always told
me ‘make it timely’ so if we don’t think the vent is yet, then…I mean given the
trajectory he’s going, unless things change, I’m not sure it’s far off…That’s my
worry…
Separation from her dad, especially when she had to go to a summer camp proved to be “especially difficult” for Laura “due to her fear about her father dying while she was away from him.” Hannah made Laura attend this summer camp because in her role as mother, Hannah said she “tries to maintain as much normalcy in Laura’s life” as she can and “having separation from her father, even as his health declines, is something that is important, both for Laura and Tony as well.”

…We (Laura) had the runs, we (Laura) threw up 3 times (when preparing to go to camp). I sent her in the car with a bag but I said, “You’re going to go. It’s only 2 hours a day.” I think she needs some separation and then she spends the afternoon with him so I’m trying to balance the, given his voice and his breathing, what if this is the last summer they’re spending time? Quality time, talking or doing things together, so I kinda say, well maybe it isn’t such a bad thing, you know? The pool party at the friend’s house, well, okay that’ll be there later, and if she doesn’t want to go, I don’t want to force her. I’m kinda working with her principal, who’s a psychiatrist, so I’ve been working with her and she talks to her on a weekly basis until school finishes. She’s done art therapy with her…

Spending enough “quality time” with Laura away from her job and caregiving duties is a “high priority” for Hannah. “Maintaining daily routines, especially since Tony’s ALS diagnosis” is one way that Hannah says she “can spend quality time with Laura and make her feel like she is a high priority in an otherwise busy life.”

…We have routines in the house and we go by that. I’ll say “why don’t I get Daddy to bed first and Mom will come upstairs and get you into bed” and sometimes we read, sometimes we cuddle, sometimes we just talk, sometimes we
just fart around. And then my routine in the morning, this is a good example for people who say, “just don’t do it (morning routine with Laura). Let your Aunt go get her up” and I’m like, “but it’s quality time that I spend with her.” I get into bed with her in the morning…I help her get dressed…I get her in her uniform. I talk to her while she’s brushing her teeth, get her some breakfast. Sure, can somebody else do all that for me? Yes they can, but I felt like that was the Mom stuff I was doing. It wasn’t related to [Tony] and it wasn’t related to my job. It was Mom and daughter time…

“Locked in”: The future is before them (Looking toward the future). Hannah reported Tony’s FVC values have been “steadily declining by 10% at each clinic visit (3 months apart) for the past year, but at their last ALS clinic visit, his FVC value decreased from 50% to 34% in just a 3 month time period.” This rapid decline prompted Hannah and Tony to face the decision about whether they would like to extend his life by being on a ventilator. The ALS team gave them a video on ventilators that introduced the concept of “locked in” which refers to the fact that once a person is placed on a ventilator, there is no turning back. The machine will provide that person with life that otherwise would not be possible. It also includes the loss of the ability to communicate (via voice) while on a ventilator. “Locked in” is a loss that those involved must come to terms with. Making the decision about a ventilator is one that “instead of doing jointly”, Hannah is “letting Tony take the lead, even though it is upsetting for him to think about, or discuss.”

…I’m not sure this is one that we can come to a decision together…I’m not sure I can weigh in the same way that he will weigh in. Because of his age, I feel selfish
asking him to compromise what he deems to be quality of life from my definition of quality of life. I’m trying to be very cognizant of that because I know how independent a person he is so this understanding of the concept of “locked in” was new for me. They describe when at some point, and it may not be just the ventilator…I keep going down the whole decision path and looking for the if [Tony] became, was in a stage where he was what they call locked in…he cannot communicate. We’re already almost at that stage and cannot communicate; that wouldn’t be something that would be I think happy with so I need to hear him say that he has changed to be okay with that and maybe his hope or his drive to see [Laura] grow up is enough for that. I don’t know… We’ve kinda broached the subject. He gets very upset about it so I know him well enough to know he needs to be ready to talk about it. He’s the one that needs to think about things. He doesn’t make risky fast off-the-cuff kind of decisions whereas I do. I’m a lot quicker to just act; I can weigh the pros and cons a lot faster about something and then get to a decision and then if I know that if it’s a mistake, okay then we’re gonna fix it. I mean I’m okay with that. He’s-even to purchase something we go to consumer’s best reports; we go to 3 websites. He needs a lot of facts in order to make a decision. I’m letting him take the lead on this one a bit. This was a little more of a different decision making process I’m not sure that we’ve gone through before, the two of us…I’ll see what his mood is like after we have discussions (at upcoming ALS clinic visit). It may be that we need another visit…I’m hoping we don’t need to make that decision right now so I’m hoping we get more information…This last loss of independence has made him think
more about how he wants to live the rest of his life…What’s your definition of happy? [Tony] needs to define that for us. What makes it so that he wants to get up every day and be part of what we’re doing. So we keep talking about that…We’re trying to be logical but emotion obviously comes into it…Maybe it isn’t the right thing to spend the next 14 years on a machine with somebody here and you get to run in and look at me and I can’t say anything…

When I asked her if there was a best-case scenario that she was hoping for when she thought about what her husband would be facing at the end of his ALS disease journey Hannah had the following response:

I’m at the we need to get on the vent (discussion) and understand what that means, I don’t know what happens between then and the end, Okay, so then I jump a whole span of time because I don’t know what happens here and I don’t know what that time looks like yet,.. Then I get to the okay, so [Hannah]’s already planned out what the end should be so in my mind, I’ve already got to, but what I can’t judge with that is when is it? So, I’ve got to the okay, conversations like, am I going to stay here or am I not? I’ve already planned out probably not. Again, based on time, if that in the next 5 years, then probably the answer to that is no because of [Laura]’s age. If [Laura] was a lot older because [Tony] decides he wants to stay on the vent, so some of this is around timing but I’ve given the 2 scenarios of how we’ll go back to [town]. I will do something here with friends. I’ve talked to my Dad and said how would I arrange to get [Tony] from here to there; what does that look like? I don’t want to be doing those kinds of things when I’m in an emotional state not to do those things the way I think they should
be done so I want to plan them out. Not so that [Tony] knows, but in my brain I want to communicate what I think those things are. I’ve not had those conversations with him. He’s (Tony) not a person who deals well with death…Anybody…Culturally it’s a very distressing thing whereas I wasn’t necessarily raised that way. We have definitely differing opinions on what I’ll call death ritual traditions; very basic traditions his family. His sister-in-law was down to visit us and she talked about, “well, what is [Tony] gonna do about this, this, and this” and I said, “I don’t know. We don’t talk about it. He doesn’t want to talk about it” so we’ve got some work if I’m to do things that I believe would be things he would want. I don’t necessarily know the answers to them. When I talked to him about it once he was kinda like I think I don’t really want to know. Maybe it’s best if we don’t talk about it. You just do whatever you think is best…So, in the back of my mind it’s there…

**The “new us” (Adaptations from ALS).** Hannah shared that partnership between herself and Tony “has always been an important part of their marriage” and maintaining that partnership has meant the development of what Hannah calls the “new us.” She said “it is still a partnership, but one that has evolved to include adaptations to ALS and how that disease has impacted their time together.” For example, because it takes her an hour and a half to give her husband his bath and get him dressed before going to work in the morning, Hannah “had to work hard to convince Tony to take his bath at night instead, a move, which he initially resisted. It has also required Tony to not lie about how he is doing during the day while she is at work,” which Tony would do to “try and protect Hannah from worrying when he was having a bad day.”
…I think it still gives us time to have conversation and you know, [Laura]’s not running into the bathroom…so it’s 15 minutes of just conversation you can have…you know quality time that you’re spending that’s quiet and can be a little more than the morning where you’re grumpy and being rushed. The evenings…You can make your own time as opposed to you don’t have the clock in front of you. Then I think the only clock in front of you is you want to go to sleep. I felt good that he made that big jump…He’s not been doing that well the last couple weeks…I was in the office working all day and I called about 2:00 just to kind of check in. “I’m fine, everything’s okay, it’s good.” …When I got home around 10:30, he said, “Aww, today was awful.” I said “why did you tell me it was okay?” “Well, I don’t want you to worry…the rest of your day would have been crap.” “Okay, now I’m just going to believe you lie every time I call you. I’m not sure that’s much better, but thank you for trying to make me feel better”…He sees that I’m not doing great with the worrying about him while I’m trying to get my job done so he’s being very sensitive to that and trying to do as much as he can…That’s a good thing. I think he’s stepped over a little line meaning he’s crossed over to understanding that this is the new us…

Throughout their marriage, they have maintained “separate but equal roles.” However, with the advent of his disease, Hannah shared that role has “greatly shifted,” with Hannah “assuming the responsibilities of home, caregiver, as well as home provider.” Both have “actively worked to maintain a partnership with each other, which has proven to be very difficult as Tony’s communication skills have declined” and Hannah has “taken over many of the responsibilities that were previously Tony’s.” Both partners have “had to
adapt to maintain a bond of communication with each other,” which has also resulted in a “new us.”

We’ve been married, this year will be 23 years…We are both, I think even to now, we’re both very independent people; he more than I. He is very comfortable with being by himself and managing his day. I on the other hand am very planned and I like to be with people…It would be no big deal for me to be gone all day and all night and he’d think nothing of it and he’d be fine with it. He’s very good at amusing himself or making work or keeping himself occupied. As he says, “I like my own company,” whereas I’d be like, “God, what time are you gonna be back?”…I actually like some solitude but then, just in terms of who we were, we equally divided up what were our roles and responsibilities and took those pretty serious and acted on them. I think we had a really good partnership for what each other did in the marriage, did for the marriage…We clearly separated the things that we did…That’s been one of the hardest thing for him…He felt like before we had a partnership. Now we don’t have that partnership anymore. He can’t do those things and now I have to do them. I have to find time to do them…I would say that’s changed. The roles and responsibilities have changed and that’s been a bit of a struggle since diagnosis because we both felt that we were contributing, being in what I would call a nontraditional marriage where I was the one working and bringing home money and he was home and taking care of the child. We wanted to make sure that neither of us lost our identity or our role. That was important for us when we went down the path several years ago; we talked about this…One thing that hasn’t changed before or now is we communicate every day
so even if I’m at work all hours of the day, we touch base several times a day. We always talk on the drives so that we keep what happened today because there’s so many people in our house but even when there wasn’t we still would use that time to catch up on stuff because when you got home, things just start pulling at you—the mail the whatever…It’s a little harder now because his communication is difficult so I would say I miss that…Now it might be 5 minutes and he’s labored or he’s got the breathing machine on (BIPAP) or it’s hard for me to hear him…He this weekend ordered a voice amplifier…It probably won’t work but we’re going to try a new gadget…New boy toy…He’s trying to make sure that we don’t lose that (partnership)...I can tell when he’s getting tired and then I’ll just say, “okay, I’ll talk to you when I get home” kind of thing but at least he’s trying…We don’t want to lose that too because we talked about this whole caregiver role. We don’t want to be just about that. We want it to be about who we’ve always been and not lose that for as long as we can…

“Setting limits,” especially with Tony’s family, “has been an important adaptation in maintaining a partnership and family time together.” These “limits” have included “not only retiring earlier than the rest of the family for some quiet private time,” but also “setting limits to ensure Tony’s privacy in toileting and bathing routines now that they have moved downstairs” and Hannah must transfer him via Hoyer Lift to a bathroom down the hall from their converted first floor bedroom.

I’ll say we’ve set parameters or limits with people that say okay at 9:00 we’re going into our room so if we are home, we’re going to our room. They’ll be like, “Are you tired?” “No, we’re just going to our room.” We might just watch TV
together…we’ve set parameters for people to say, “If you want to get up before we get up, which you can hear, then get a coffee or something. We’d appreciate you taking that back upstairs because I want to be able to get [Tony] ready without having him having to worry because I have to take him from our room to the bathroom.”…Set limits for other people in order to maintain our privacy and dignity and those kinds of things…Me getting less worried about where people sleep or what time they go to bed or making sure that they’ve got coffees and that kind of stuff has been a big shift for us…We’ve had to unify and say we were going to do that for people coming to visit us…

Hannah used the noun “we” instead of “he” throughout the interviews when talking about Tony’s progression because she said she “feels they have a true unity or partnership in this disease journey.” Some examples include the following:

I know the numbers are less than where we were at before… At least where we are now… We want it to be about who we’ve always been… We’re already almost at that stage… I figure if we don’t have those then we’re gonna give up… We were transferring and then I would say last Christmas we stopped being able to transfer… We’ve lost use of our arms… Now we can use our thumbs. We pretty much have lost the use of our fingers. We’re at our thumbs now…

Hannah has faced the reality that with the “new us” there are no more “one days” in their future and even though it “saddens” her, she utilizes her energy on “concentrating on the things they still can do and not the things that are no longer possible.”

…Always the tomorrow. There’s always something tomorrow. Not that I live for the tomorrow but I’m always planning something. We’ve always done that
even the old [Tony and Hannah]...Every year on our anniversary and then typically 2 other points during the year we have our two lists. We have out what are we gonna do this year, 5 years? What are we gonna do one day... One day we will, or one day you will have blah blah blah car. You know, those wish lists. He’s always like, sometimes we’d start out, well I don’t know if I’ll ever do that...never say that. One day is always out there. We don’t say one day anymore. He doesn’t say one day ever. I don’t ask him that because I think it’s one of those subjects that’s related to the diagnosis. We don’t talk about one day because now there is no one day...I probably should ask the question but it’s almost like a no happen thing that there is not one day anymore. You know, the one day we’re gonna do the X trip. Well, that’s probably done now...I don’t like to give up on that but I mean it’s the reality. There’s certain things we’re not gonna do so I just keep trying to find things we will do...What keeps me going is that there has to be still things that we can do. We just gotta find them...

The “definition of hope” (Strategies aiding the caregiving role). Since Tony’s ALS diagnosis, Hannah said she has changed her mind about what hope means to her. She tries “to plan out everything in her life,” including her caregiving efforts and tries “to stay positive in all aspects of life”, yet she shared “hope is something that is not addressed by healthcare providers or support groups.” Participation in the annual ALS walk is something that Hannah has done “to help find answers/treatments or even a cure for ALS.” At this year’s ALS walk, Hannah revealed the team she organized was “the top money earner among all family teams participating.”
I wouldn’t say that I was Miss Butter Sunshine. I’m never the cup half deep girl or if I am I quickly get away from that but I’ve always been like that. I might see the cup as half empty for 10 minutes and then I’m okay, how am I gonna fill it? I quickly go to the how am I going to fill it. But I think that’s what people need to look at because maybe that needs to be the spin that people have…We’ve never had a conversation at the clinic or with anybody who’s been helping us, with hope; the definition of hope other than hope for a cure…You know how everybody gets hope and I see it with some of the other people in our support group…There’s a couple there…Their son has ALS and he won’t come to support group because he just doesn’t want to…He hasn’t accepted it yet. I think that’s important. It’s almost like that you need to hit rock bottom so that you can get better…[Tony] hit rock bottom and so I’m hoping that what I’m seeing in terms of him contributing again, contributing to where we’re going and how we’re going there means that he’s past mourning. I don’t know if that’s the case…His (Tony’s) hope was always he didn’t have it (ALS) and I think that was the wrong hope to have. You always use that but even then, the likelihood of that happening…A cure means it never happens, which I didn’t know that. I always assumed a cure meant that [husband] would get something that would make him better. Fix it. There is no fixing it. It might stop it. We might get to something that stops where he is but [Tony’s] never gonna go back and be who [Tony] was no matter what happens…We’ll never get to an answer if we don’t do something about it. I don’t wanna sit back and let others solve my problem. I’ve never been that kind of person so it is a bigger problem but I wanted to be part of saying, hey,
I contributed to this never happening to other people because I believe there is a smart mind out there. Somebody’s gonna figure this out…

“Keeping my husband independent” (Strategies aiding the caregiving role).

“Keeping my husband (Tony) independent for as long as possible is a top priority” according to Hannah. She has stressed, “although he may have physical limitations, Tony has no mental limitations” and Hannah does “insist that he remain in charge of the duties he can around the house. The only difference now is that Tony may need someone else’s hands to accomplish what he previously did by himself.”

I said to him, “You know what? You’re physically helpless but you’re not mentally helpless…You’ve got to be responsible here. You gotta say yes, we’re doing this or no.” This guy shows up…He’s going to fix the garage…We do the “it’s your job” to determine whether the guy can do whatever he’s supposed to do. My Aunt shouldn’t have to call me at work, which she did the other day. I said, “I don’t know, ask [Tony].” “Well, he’s sleeping.” “Go wake him up and ask him whether he wants that done with the garage guy”…I’m still trying to push, he still has that role. Though he physically can’t do it, he can mentally be responsible. “[Tony] you can’t open the mail but you can tell me, [Hannah] Thursday nights we’re going to open the mail so a bill doesn’t get missed. You know, you [Tony] can still be responsible without doing it and I’m trying to show there’s a difference between being responsible and doing. Be the boss. You [Tony] are the boss of this house. I bring home a paycheck”…That’s what I’m trying to convince him…Especially where I get to the point where I need to do, you know…”Where’s all of our bank accounts and where’s all of our stuff and
write it all down and put all the passwords and all…It’s like you (Tony) like to do that stuff so keep doing what you like to do. Just use my hands or somebody else’s hands to do it…You’re not helpless. You’re physically helpless but you’re not mentally helpless…You are in control of this house…”

Even in adding modifications to their home or new adaptive equipment, Hannah stated she has “really strived to keep Tony as independent as possible for as long as possible.”

She shared “relying on his technological strengths may be one area that can give him added independence through the use of an eye gaze device.”

…He has been one that has to the last minute that he could keep his independence, so that’s what we’re trying to do. We did an accessible bathroom. We put in one of those bidet toilets…We’ve done little things to keep him independent…He’s technologically very savvy so we’re right now waiting for [local hospital] to call us about the Eye Gaze Technology…He’s finding it difficult to change the TV. He had somebody come over last Sunday. They programmed his wheelchair so he’d be able to change the channel but this whole Mother May I (asking Hannah for assistance) every 5 seconds it’s getting bothersome to him…

Keeping his independence as a goal, Hannah said she and Tony “often turn to the ALS clinic team for strategies/advice on various issues concerning his care.” Although they will start with the ALS team as a resource, Hannah shared “they have found that often the team’s advice sometimes gives the shortest and easiest solution but not a solution that encourages independence, leaving them to figure out adaptation that will work for them.”
They also have “frequently learned from others in similar situations to learn what worked best,” and then Hannah and Tony “have adapted these ideas to their own situation.”

I start with the team to get ideas and then [Tony] and I typically take that conversation and say, “well, what’s going to work for us?” I will say that we’ve come up with a lot of adaptive things on our own. Then we take them, like as an example, I’ll take him to support group (to share ideas)...I think [ALS nurse manager and nurse counselor] are very helpful. I find that some of the other (team members)...They don’t come up with ideas that help you be independent...They’ll be, the answer would be like [Tony]’s toileting is a good example. They would say, “well Tony you just need to get your wife to do it and you just get your wife to wipe it for you or you need to start using catheters.” [Tony] would be like, “No, I’m not ready to do that so we’re going to go out and get the bidet so that I can wash. We’re going to get the one where the remote comes off the wall because I know I’m not going to be able to reach soon and I can hold it.” So we sit down and figure out and maybe we’re just the type because he is so strong willed and I think that other people we’ve met, and I don’t know if it’s an age thing, but a lot of people in our support groups in their 70’s. They’re receptive to people helping them because [Tony]’s been less receptive to people helping him. We’ve had to think hard about how he can keep doing something so...He’s determined to get dressed without lying on the bed so we got those poles at our house and I would take the wheelchair right up to the pole. We would lift his wheelchair up, we would like push him from here, he’d stand and hold, pull up his underwear really quick and then he’d sit back down. Now we
use the lift (Hoyer)... We’ve been creative with the lift. We’ve got the hygiene sling, put it around him I hoist him up long enough that I can pull both up so that he’s not lying, trying to struggle...With the eating, I went out and got hospital tables...I can lift them up as high as I could so that [Tony] doesn’t have to do it when he started having difficulty doing this, okay we’ll do this. But we didn’t get that kind of advice. We got that “[Tony] let your wife feed you” (from some members of ALS team). It was more you really need to get a caregiver versus caring for yourself. Because he’s been so stubborn, we’ve been very adaptive at trying to figure out how can we be minimally providing the care...They’re (ALS team) trying to make it easy. They’re trying to make it safe. They’re telling you all the right things but in our situation, that just wasn’t good enough...He had a terrible time in his chair...So we finally went and found somebody who’s in a wheelchair and has been in a wheelchair for 15 years to give us some ideas about some seats...These people are giving you stuff out of a textbook...[Tony] wanted to figure out how he could get in that shower. They’re answer is “[Tony] you can’t get in the shower. You need to get a shower chair. Your wife needs to help you get bathed.” “No I’m getting in that damn shower.” We went to meet people who’ve been in these, not ALS but have been in other like quadriplegic, to get what have they done. In some cases they had use of their arms and stuff, so we’ve had to adapt. But I think it was more about the independence that drove those things than anything else. So the team would give you ideas places to go look for stuff...We definitely adapt like ran with stuff more...
Hannah said “I’ve used many strategies to keep Tony independent as long as I can, but the process of getting him to be receptive to others providing care to him has been particularly difficult.” Having a paid caregiver come into the home is something Hannah said she “realizes as a necessity but Tony has shown reluctance.” Her mother and aunt currently trade off the care of him because as Canadian citizens, they are limited in the number of days they can be in this country. Hannah gave the following example, “We (Tony) were being stubborn with I don’t want to eat. I don’t want somebody to feed me and if anybody’s going to feed me, I want it to be my wife… It’s taken us (Tony) a while to get to he’ll accept help from somebody other than me…” She shared “his refusal has transferred to other aspects of caregiving as well, especially to the idea of having a paid caregiver assist him with the more private aspects of bathing and toileting.”

…Other than it being forced, I’m not sure that’s the right approach but it’s kind of the one, the path I’m taking since the suggested one stopped working. We talked about it; we talked about it, my dad talked about it. I said “let me pick the people I know he trusts to talk about it” and it was always, “Yeah, I know”…I finally about a month ago…I kind of had a “[Tony] I can’t do this conversation. I cannot do this 3 hours in the morning before I go to work, spend all day at work, come home, do homework, do more things for you, and then do a whole hour and a half bed routine. This isn’t going to work long term”…I sat down and said, “you deserve better care than you looking at what time it is because I gotta get to a meeting. You deserve now somebody to massage your hands so they don’t go to; rotate your ankles at nighttime. Not, okay, Tuesday night I got an extra half an hour so [Tony] why don’t we do that?”…I’m focusing on getting [Tony] to that
answer…I’m working on it but I really want him to be part of the deciding that rather than forcing it because I think he’s going to deem his quality of life to be less if I force him. If I just say, I’m not doing it and she’s showing up. Then I feel like he will give up and I don’t want him to give up…

“Brain throwers” (Obstacles to the caregiving role). Hannah refers to events that make caregiving more difficult for her as “brain throwers.” One of the events that has been “really difficult” for Hannah is the hiring of a paid caregiver to help her take care of Tony while she is at work. She revealed “I would love to take care of Tony full-time herself, but I need my job for the income and benefits since I am the sole breadwinner for the family.”

Since I work in [city] and live an hour away…and my current job is not a 9-5 job, it’s a two-fold issue for me when I still have an 8 year old, so what am I going to do about her? What if I can’t get home when this person needs to leave? …We have to have a solution in place by [date aunt leaves]. I’ve been requested to travel. I really don’t want to say no. We need this job. We need these health benefits…I’m gonna need to figure out (paid caregiving situation). He’s (Tony) like, “oh [Hannah] you can’t give up your job, you know, you work, our lives financially, medically. You can’t just walk and walk away.” Some of our circumstances are that we’ve only been in this house 4 years. I mean we just built it. We don’t have enough equity in it yet to turn around and sell it. [Laura’s] still going to school. You know there’s lots of things that you can’t just say, well, just quit the job and stay home or get a new one. Where am I gonna get a new one, you know the economy. So there’s lots of brain throwers.
Another “brain thrower” that Hannah says “makes caregiving difficult” has been that “Tony’s family has not offered to help at all with his caregiving.” Hannah also says “our cultural beliefs have made caregiving more difficult as well.”

…I get resentful of them sometimes that my family’s been the one who’s been here for 6 months taking care of him. The rotating 6-month schedule and nobody in his family has offered to do that. I’m not sure I would have taken them up on it, because I’m obviously comfortable with my own family, but the ask would be nice. Nobody’s asked us yet, “what are you gonna do (about ventilator decision)?” Maybe they don’t want to know the answer either…I don’t really spend a lot of time thinking about it but sometimes I’ll say, “Oh well, sure it’s great to just pop in and out for the week”…They come and stay for days…You gotta plan meals. You gotta feed people. You gotta clean up after them…Like [Tony] will be tuckered out. He’s done. He just goes into his room or whatever so the last 2 visits, I did that, “okay guys, I’m sorry, the hostess days are over.” [Tony] comes from a European family where you are much more of a hosting place…His brothers and sisters are a lot older. There are 15 years between him and his next sibling…Everybody is a lot older. His oldest brother is like 66. Very old fashioned. Comes from a home where his wife does everything for him so we have a little family dynamic there…Sometimes they’ve even actually been a little resentful like at the fact of what my family’s doing… They just show up…They’ve had a real eye opening these last 6 months with how quickly he’s declined…I’ve said to them “get up, you know guys, I’m not getting your coffee. You can get your own coffee. You can make your own food.” We’ll all make
dinner together. You know that kind of thing… Culturally… When people come to your home and their traditions are… It’s bearable… You treat them almost to the point that if you went to his family’s house or something, they would give up their rooms for you and sleep on the floor. That’s a very European, very European tradition that they, if they made the visit to come see you, that’s very special… It’s hard to educate people on this when they live so far away…

Hannah shared “one of the biggest brain throwers occurred when Tony had his diaphragm pacemaker and feeding tube surgery done. The rapid pace which decisions were made and the surgery completed did not allow me to plan enough so that I was prepared for the caregiving load I faced when I brought Tony home from his surgery.”

…I found that I was very ill prepared when we got back from [medical center that did pacer surgery]. I had not planned out what was going to happen in those 2 weeks… We didn’t get what was going to happen. We made the decision very quickly to go to [pacemaker medical center] like it happened very quickly. As an example [ALS neurologist] was like, “Well I didn’t know you were getting a feeding tube.” We found out we were getting a feeding tube the day before because one of the things that has happened, there’s only been one other one done from [ALS clinic] but other people have gone out for the test, then just went back (home). They found out the test to see if he qualified, got all the data, and then you go back for the surgery. They found out that was hard for patients who had to commute so we had to drive 6 ½ hours, stay overnight somewhere in a hotel… So they said, how about if you decide you want to do it, we’re just going to do it the next morning so that happened way too quickly for me to plan. I was able to plan
the week that I was there. We took our friends. I had my mother. We had 3 hotel rooms; used my points; brought things for the bed. We took our lift; we took our shower chair…You know what I mean? I had a little project planned, little chicklets. I knew what was in what car…But then I came home and Oh my God, I don’t know what to do with this feeding tube. What was going to come out of that? So there wasn’t enough for me. The hospital gave me data before I left but they give you in the perfect world, this is what’s supposed to happen and well now we’re in the real world. So I needed a little more of that…

**Her “own form of relaxation” (Caregiver respite).** Relaxation time for Hannah often means “setting limits around Tony’s care because getting adequate sleep is a high priority” and enables her to “function in her many roles in life; mother, caregiver, wife, and working professional.” When I asked her about whether she gets any relaxation time at all, Hannah had the following response:

…I’m just not sure how to fit it in…I’m just still struggling here with the work thing. I’m not sure I’m going to achieve the work-life balance and I don’t know what that means…My job is almost as important as my home, balancing that is more important than me getting social time…I don’t get alone time, but I try and make it so that I put boundaries around, okay [Tony] we’re going to start the bed routine at X time so that I’m getting at least 7 hours of sleep a night. It’s my own form of relaxation. I’m using something to help me sleep so that I get my 7 hours of sleep at night…I do a little more sleeping on the weekends. [Tony’s] a little better. He’s good about that about staying in bed. He wakes me up early but
we’ll sleep in…Sundays are a good day where I can sometimes go sit on the deck for an hour and read my magazine. I do those kinds of things.

Hannah revealed “It is very difficult to take a couple of hours when somebody’s taking care of Tony to do something for myself.” She “struggles to balance time with her daughter, husband and her job and finding down time is not a possibility” because even when she has free time while someone else is caring for him, Hannah feels “the need to be checking on him to make sure he doesn’t need anything.”

If I’m not doing something for him, I’m trying to do something for her. My job is very busy and so I try and make it where I get home from work to spend at least 2 to 3 hours with them in case I have to go back to work…It’s hard to turn it off. It’ll always turn into okay I should go check to see (if Tony is okay). Should I get him a drink? I mean I’m always trying to make sure that he’s okay. Even though there’s somebody, somebody besides myself…I’ll finish reading this article and then I’ll go back in and check him and then I’ll walk in and say, okay, because I like to sit outside because he finds the heat a bit harder some days so I wouldn’t say I do nothing for myself but probably not as much as has been told to me that I should be doing…

**Others ask about her (Focus of others).** Hannah revealed she “feels very supported in her role as a caregiver” and finds that Tony’s family in particular, will ask how she’s doing. She expressed “They appreciate how hard caregiving is because they all took turns caring for Tony’s mother before she passed away.”

People ask me how I am doing. [Tony’s] brother was just here and brought me a gift and said, “Thanks for taking good care of my brother.”…People in the last 6
months especially that he’s gotten so much worse, they’ll say, “how are you hanging in there?”…I think we’re fortunate because we have people as a result of [Tony’s] family being so much older; his Mom having gone through the stuff (recent illness). She just passed away and they’ve each taken turns taking care of her. She’s lived in all of our houses. There’s a natural understanding of what it means to be a caregiver. Different context but I think the principal of caregiving is understood.
Figure 4.6. Chronological Pattern Diagram: ALS Caregiver 4 (Hannah)
Figure 4.7. Chronological Emotional Pattern Diagram: ALS caregiver 4 (Hannah)

Husband = Patient with ALS

Denotes time of disruption/crisis
Figure 4.8. Chronological Physical Pattern Diagram: ALS caregiver 4 (Hannah)

Chronic pattern diagram narrative: Hannah

When I showed Hannah the original pattern diagram I had made based on our first interview, she initially started out numbering them as all the other caregivers had done in our interview process, but then she said she didn’t believe the pattern diagram was accurate for her because there were really two different types of caregiving that she performed and representing them on the same pattern diagram was inaccurate. The first type of caregiving Hannah labeled as physical and the second type was designated emotional and she even drew a picture of the shape of the two (see Figure 4.7 above). Physical caregiving is much easier in her opinion and is represented by peaks and valleys
because it is mechanical in nature. Physical caregiving needs planning and involves the caregiver figuring out how he/she is going to solve a problem and once that’s solved, the caregiver can move onto the next challenge. Hannah also said the peaks and valleys were level across and even though some were harder, such as the intense caregiving following Tony’s surgery, they were still horizontal in nature and did not picture them being higher or lower on a page (like the other caregiving pattern diagrams) but bigger stars on the same horizontal plane.

Emotional caregiving was much more difficult for her as a caregiver and represented events that she still has to deal with and isn’t sure how to deal with them, such as Tony losing his voice strength because it represented a threat to their communication together, or using the Hoyer lift exclusively because it represented the loss of her husband’s independence. Hannah again pictured the emotional caregiving events graphed on the same horizontal plane and said they are constant with each other but knows that in the future they will increase, as end-of-life decisions are imminent. She said that health care providers could help her most with the physical caregiving events but thought she would need to seek out counseling for the emotional caregiving events, but said she was not yet at that point in her life to seek out a counselor due to her busy life style. By making this distinction, Hannah was the only caregiver interviewed to break the chronological pattern diagram into two distinct patterns representing her caregiving journey.

It’s almost like there’s for me 2 categories of these stressors. I know that may be more complicated than it needs to be, but it’s like the emotional stress versus… more the mechanical…so (pointing to the physical diagram) how am I going to
get all this stuff done and what is it that you do and how am I gonna fit this all into my day versus this (pointing to emotional pattern)…I’m not past these (emotional pattern). One is emotional; one is physical for lack of a better word. I don’t know if there’s better terminology for it…I’m dealing with these (physical) because I can do something about these and these (emotional) I don’t know what to do with…Go get counseling…So they’re in the background. There’s so many other things to do first so they’re probably the most important…I can typically get answer to some of these (physical). The stress goes up and down…My emotional stress now isn’t dipping…Now this 2011 has been like we’re at the max whereas the caregiving, this other stuff (physical) is like solve that problem, move on…Next problem so it’s different…based on whatever occurrence is happening so this is kinda stage driven (physical); this is very personal (emotional)…I haven’t done anything with this (emotional). I’m assuming it’s gonna go higher which is why I’m trying to prep myself. What is going to happen when we can’t communicate?…It’s (emotional) at what I would deem a max right now and not going down…It’s (emotional) a constant. I wouldn’t use the word plateau because I know we haven’t plateaued, but it’s a constant. As far as these other ones (physical) are concerned, in and out…Health care providers can help with this (physical)…Counselors can help with those (emotional). I haven’t done anything with that. I’ve worked on everybody else’s but my own…If I could find a counselor who I could drop in on whenever, which I know is unrealistic but my thing is about the flexibility of it…I know it’s important but I don’t feel it’s important enough that I would give up other things to schedule it in my day
yet…I would hope I would know when I’ve got to the point where I can’t deal
with it by myself anymore…

Hannah had the following insights about the emotional chronological pattern
congering Tony’s loss of voice strength, Hoyer life exclusive usage, and use of BIPAP
machine, which she ranked #1, #2, and #3 respectively.

The hardest thing to deal with and I haven’t dealt with it yet, is the lack of talking.
That has been the hardest. I have not found the other things as hard because I
think they’ve been more progressive so because my nature is to plan, I try to step
ahead…It’s harder now (communication with Tony) because his communication
is difficult. I would say I miss that. We would talk a good 30 minutes
(previously) and now it might be 5 minutes and he’s labored or he’s got the
breathing machine on. It’s hard for me to hear him…I’m trying to prep myself.
What is going to happen when we can’t communicate?…I haven’t figured that one
out yet…

…then December of ’10 we had to use the lift exclusively so up until this point
we were back and forth where he could still stand so that was another big
milestone…I mean this was okay, now we got to figure out how I’m going to get
you dressed…That (Hoyer lift usage) was a big one because he had to relinquish
control now…Till the person can’t do things anymore, it wasn’t very real. The
fact that he was still independent…This I can’t stand that we had to go to this. It
meant he wasn’t independent anymore. When he went on BIPAP I was like, okay
this is real now. Once we can’t…The BIPAP, the arms…boom, boom, boom…
Hannah ranked the intense caregiving following Tony’s diaphragm pacemaker and peg tube surgery as the top event in physical caregiving followed by having to move downstairs as Tony’s condition deteriorated. Number 3 was the loss of partnership with Tony and #4 was Tony’s belief that he had ALS. All other events on the physical pattern diagram she ranked as being equal in stress levels to her role as a caregiver.

…I anticipated when I got back (following Tony’s surgery) that I’d be able to work from home. I took almost 3 weeks off work with very little communication. That’s how stressful it was. I couldn’t…There was no balance. He was 120% of my day…I mean it happened, I wasn’t prepared for it and so hence, my lesson learned. I won’t go into the next situation not being prepared…I would say the other big major thing was we had to move to downstairs. That was September of ’10…We’ve now taken our mornings to a longer kind of thing (takes longer to get him ready in morning) and that was after we moved downstairs. That was a big stressor for me to move downstairs. I was very unhappy with that. I was more unhappy with moving into my office and not building out of the house than I was really truthfully moving downstairs because moving into this cramped little room without having what I deemed a proper bedroom and bathroom. I have to take him out in the hallway (to toilet him)…I hate that…

…He felt like before we had a partnership. Now we don’t have that partnership anymore. He can’t do those things and now I have to do them. I have to find time to do them…

…I’ve seen signs of him since we were in [medical center where pacemaker was done] and we saw the third set of doctors who told [patient] that he had ALS, he is
now convinced that he has ALS. Up till now, I think he had that spark, glimmer at the back of his mind, maybe I don’t…He didn’t believe that (ALS diagnosis) and [ALS nurse manager] and I underestimated that. Looking back now, I think we should have made sure that [husband] really thought he had ALS because his hanging on…his hope was never for a cure or him getting better. His hope was always he didn’t have it and I think that was the wrong hope to have…

Transformations/Insights. When I asked this caregiver if talking with me had brought forth any new insights or made her think about anything she hadn’t before, Hannah said it helped her see the “bigger picture of caregiving” and compared our interviews to the experience gained by completing the caregiver questionnaire at each ALS clinic visit.

I think it’s (our interviews) helped build the picture (bigger picture) because I’ve never sat down and talked about being a caregiver with anybody. We still have that questionnaire (completed at each ALS visit) and I stopped filling out that questionnaire. I told them (ALS team), I think this questionnaire is useless. You’re not getting out of it what you want…from a research perspective. I’d be curious to know what you’re (ALS team) finding, but me clicking a box isn’t telling this picture (caregiving). But sitting here doing this conversation (our interviews) helped articulate this better…Plotting it out, seeing what I said and saying now that’s not really what happened or oh well yes. I’m a very visual person…most adults are visual learners and need something. The (ALS) questionnaire isn’t a visual learning aid. It’s a circle and it’s very black and white…Do you feel depressed (one of the ALS questionnaire questions)? Well I don’t know. Okay well it’s (ALS questionnaire) thought provoking and then you
go, well that’s depressing to think about… You know, do you resent your care (another question on ALS questionnaire)…the questions were harsh and the answers were black and white. There was a scale (on ALS questionnaire)…maybe you need the dialogue with somebody (like our interviews) to interpret back…A questionnaire doesn’t guide you through that process…Like one of the questions, are you feeling depressed? Well, I may not be depressed but I may feel sad today. That’s different than being depressed so it’s key words in the survey. It seems clinical and what I’m going through isn’t. I feeling like being a caregiver is not clinical. It’s an emotional roller coaster…It’s (ALS questionnaire) very binary…You never see any results for that. I don’t look at that because it’s part of a study but this (our interviews) is results oriented. We’re having a conversation which results in the end something…I just keep filling out something every 3 months (ALS questionnaire) that by the way results in me saying things get worse, which I already know…There’s data analytics, I appreciate that. I do that for my own clients…but I think that questionnaire by itself isn’t it…We (caregivers) need the personal touch…

Hannah is alternating between Choice and De-Centering Stage of Young’s Stage of Evolution (Newman, 1984). She is in charge of her own decision making process and works actively to plan ahead so that every new situation that occurs with Tony’s ALS physical deterioration is made well ahead of time and she can more onto the next hurdle (De-Centering Stage). She shares her decisions with others and plans ahead to make sure all choices made are carried out in the manner she desires and demands. With the next hurdle of a ventilator decision with her husband, Hannah has not made a choice yet
(Choice Stage) but realizes that old ways of caring for Tony will soon be inadequate as his FVC continues to decline and BIPAP is no longer enough to sustain his oxygen requirements. For this reason, Hannah is currently at a Choice Stage, but once this decision is made, based on her past history of decisions made for her husband, I anticipate that she will accept this ventilator decision (for or against), make the appropriate care modifications for Tony. This will continue her growth toward higher levels of freedom as she extends past her current caregiving boundaries and has paid help either to give 24/7 care to her husband on a ventilator, or extended help in the form of hospice if he decides not to be put on a ventilator.

**Narrative Summary: ALS Caregiver 5 (Brittany)**

ALS caregiver 5 (Brittany) is a woman in her early 40’s who cares for her husband (Jacob) of similar age. They have been married for 14 years and have a 13-year-old daughter (Anna). Jacob was diagnosed with ALS in September 2009 and continues to work full-time from home as an engineer for a federal government firm. Brittany used to work as a manager in a group home for people with disabilities but quit that job 4 years ago to home-school Anna full-time. Brittany’s not only provides caregiving to Jacob, but also to Anna who is diagnosed with high functioning autism (diagnosed in 2005) and has severe food allergies as well as a severe allergy to sunlight exposure. For the past 3.5 years, the family has a service dog (Maxie) that lives with the family full-time and helps with socialization and safety of Anna. Brittany’s caregiving duties are complicated by her 24 various health care conditions, ranging from diagnoses of (a) fibromyalgia, (b) bipolar, (c) myasthenia gravis, (d) Barrett’s Esophagus, (e) rheumatoid arthritis, (f) Reynaud’s disease, (g) skin cancer, and (h) rosacea to name of few of the most prominent
health problems. Brittany’s health has seriously deteriorated over the past 2.5 years. All three family members are on different diets and their kitchen is equipped with 3 different refrigerators, 2 toasters and 2 microwaves due to Anna’s severe food allergies. This family has a coordinated team of volunteers (numbering 55-60) who come into the home to help with caring for Jacob, caring for Anna, arranging medications, fixing food, and caring for Maxie (their service dog). The family has their own website that details the kind of help needed along with 3 coordinators of care who handle scheduling of volunteers and assignment of caregiving duties.

Jacob has limb presentation ALS but has started showing some swallowing problems in the past few months. At the time of these interviews, he was not experiencing any speech problems. Jacob has exhibited cognitive changes, making it hard for him to work in a productive manner. His current symptoms/adaptions include: (a) fasciculations of the chest and back; (b) air gulping, especially at night; (c) little upper body strength; (d) thick mucus production, causing increasing coughing/choking episodes; (e) increasing pain medication usage; (f) constipation issues from the pain medications; (g) drop foot; requiring ankle/leg braces; (h) ambulation with a walker or wheelchair; (i) inability to feed self or perform any self-care; (j) increased sweating episodes, which makes him feel “hot” all the time; (k) C-Pap usage; (l) inability to hold head up for long periods; resulting in wearing a neck brace for most of the day; (m) use of a Stair glide, raised toilets, and seat assists in the home; (n) shuffling gait; and (o) fatiguing easily. He takes Rilutek and Brittany reported his most recent FVC value was 85%.
Brittany’s caregiving duties for Jacob include: (a) all self care, including toileting, bathing, feeding, grooming, and dressing; (b) coordination of volunteers to help with his care; (c) transportation; (d) assisting with his job responsibilities; and (e) medication management.

**Thematic representation of emerging pattern of the whole for Brittany**

**Unrecognized symptoms and misdiagnosis (Suspicions emerge but ALS diagnosis is delayed).** From the start of his hand symptoms, Brittany said “there was a delay in over 2 years before Jacob was diagnosed with ALS by the ALS neurologist.” First, “his primary care doctor misdiagnosed him and then a neurologist, who ran numerous tests, did not diagnose Jacob,” but rather spent time telling Jacob and Brittany “what medical conditions it was not.” Brittany said “I am unsure whether the neurologist knew or suspected Jacob had ALS, but he referred us to the ALS clinic neurologist, without informing us of about what kind of neurologist we would be seeing.”

He was diagnosed 2 years ago. It was around Labor Day, 2009, however he was symptomatic for 2 years prior and misdiagnosed. At first, it was hurting his left hand and a primary care doctor, who we are no longer with…he thought he had trigger finger…It started with his fingers not being able to do their job. He was losing some of his fine motor skills…Even though he’s right-handed. It was left (hand) so it wasn’t as noticeable. He does do some things left-handed…Did he go through a period where he didn’t feel well? Maybe. It was so hard to tell during this time frame but it seemed like it was just fatigue as opposed to like my daughter had a very severe case of mono for quite some time but he didn’t have anything like that…So you’ve got the finger going funny and then he complained
of the fatigue and that is how the chronic Epstein Barr Virus got diagnosed and the physician was a pill pusher in a lot of ways...Jacob got put on some really good medications that really wasn’t doing a thing for him...I forget what he prescribed at the beginning but the thing was, my husband wasn’t improving and the right medications, right doctor, right therapy for me is a life changer and he’s just kept getting worse...What really stunk is we did see the neurologist and more tests were done. The neurologist called us back for results and he went over everything that it wasn’t. We had to sit and look at brain scans and it wasn’t cancer and there’s no tumors and it’s not MS because there’s no lesion and we learned everything that it wasn’t and then he said so I’m going to send you to a neuromuscular specialist and that’s how it was stated, who will help you. We think that this is a neuromuscular disorder...I remember going, “okay” and he goes, “well he’s from [name] medical center and our office will set up the appointment and they’ll contact you” and we were warned they were backed up and it could be 30 days...They didn’t tell us it was an ALS clinic...

Due to her heavy caregiving role with Anna, Brittany said “I did not place Jacob’s complaints ahead of the care I was providing to my autistic daughter.” Brittany asserted “this shift in priorities also delayed Jacob’s diagnosis of ALS.” She stated, “I have to say that my daughter was placed first and those 2 years, I was placing her first and I was not paying enough attention (to his symptoms)...I wasn’t making appointments for him...She’s (Anna) a lot of work...”

During the 2-year delay in diagnosis time frame, Brittany also “grew very frustrated with Jacob to the point of contemplating divorce” until she realized that “there
was something very physically wrong with him” and then “started to work actively to
find an accurate diagnosis.”

During that time frame, there was frustration because I didn’t feel like he was
pursuing getting a doctor for himself. There was also, I started not recognizing
my husband and I felt like in some way, I don’t know he wasn’t the same
guy…Slowly it became many personality changes…He did complain of pain and
my answer was, “well what are you doing about it. Complain all you want;
what’s the action plan?”…He was not himself because he was starting to gain
weight. He couldn’t work out like he used to. He didn’t understand why even
with the chronic Epstein Barr, he rested and why didn’t he feel better? Why
couldn’t he work it out? … I’m not very nice to my husband at this point… I was
so ready to divorce my husband. I didn’t recognize him… He was in pain. I was
not being very supportive and I think everything was too much… At a funeral I
was sitting on his left side and I was holding his hand…I couldn’t believe the
amount of twitching. It wasn’t just his fingers anymore. It never stopped on the
left side from shoulder to hand and there was every now and then in his leg and I
never said anything. I had watched him dress and I had watched him try to
button. I watched him struggling and I didn’t say a word…suddenly I saw him in
a whole new different way…

Changes since her husband’s ALS diagnosis (Adaptations from ALS).

Brittany’s social life has “greatly changed”, along with her “expectations of what is
enjoyable, because of the isolation caused by Jacob’s illness.” She stated she “misses her
friends and especially entertaining with those friends,” but realizes that there is a “season
to friendship” and “our season ended when our friends could no longer relate to what our life had become.” Theirs was “a lifestyle that their friends did not understand.”

What used to be enjoyable to me to what’s enjoyable now, I guess that really changed…I still yearn for, I miss my girlfriends…My friends would come to me, we had a lot of friends who say, I’d watch your kid so you could go out and then you’d watch theirs…somebody would watch mine just so I could sleep…There was this beautiful network but that also was a time period where we did, every week if not more often, I loved hosting. I loved cooking. I like cooking for a lot of people. I love feeding people and making them fat and full and I love when everybody leaved the table so happy. I loved the mess and the chaos and the kids running around having fun…We had so many friends who were dear…and while we still hold them near and dear to our hearts, there’s a season to friendship…Suddenly we became isolated…Even when we started getting names for everything (diagnoses), they didn’t believe us and they didn’t understand it. It wasn’t mainstream…They’re still friends. They just can’t handle my husband and daughter’s situation…

As Jacob’s disease has progressed, Brittany has “opened up to others” and shared “I allow myself to ask for help.” This involved Brittany “sharing my family’s story with others and allowing others to help me in the caregiving role, which was very difficult” for her.

I used to be a person, many years ago that held my cards very closely. I only wanted people to know the good stuff and only ever see the outside and I lived in a home where you didn’t tell what happened behind your doors. You didn’t tell
people those things. And I’ve realized that doesn’t really work. Once I decided to start sharing…Realizing that it’s okay to talk about this stuff…I have to laugh. Because of living other places, I know people who don’t want you to know that they’re suffering or know that they’re ill…Caregivers who also try to do it on their own because we might have the person we’re caring for won’t tell anybody. You know, don’t tell anyone. It’s hard to be a good receiver…It’s humbling. It’s exhausting, and it’s hard to receive…

Brittany expressed, “accepting help from others was an even harder adaptation, especially when Jacob had to watch others perform home improvements that he formerly would have done.”

It was okay with him if it was to help me get something done. It got much harder. He was happy to comply when it was for her (Anna) but when men were here helping with construction, when men were doing the things he did. He had a hard time looking at them. He had a hard time being around others helping to fix up the house.

Another adaptation faced by this family involved “adjusting to having volunteers in the house from early morning until late at night.” This adaptation is going to be “tested further” in the upcoming months as Brittany addresses “the need to hire a paid caregiver for the evening hours with Jacob.” She said, “I am concerned about finding a good caregiver, but also worry about my family’s safety.” She shared, “getting used to having someone who is paid to be a caregiver instead of having a volunteer who is a caregiver out of a sense of friendship and love” is another adaptation in what Brittany calls “an already complex caregiving situation.”
At the very beginning of volunteers, it was stressful because my daughter was freaking out. She’s doing so much better but the first month to 2 month it was a horrible roller coaster ride…and volunteers now actually, it’s so second nature. The house opens by 9. We can expect the last person maybe through by 8…They might still be here till 9 at night. We’re used to it. The next big thing is paid staff and it’s my mental block. Paid staff means forever and now it’s having somebody who has a job and it’s not because they love us and want to help us. I hope they do but there’s a whole level of will my possessions be okay? Will our safety be okay? What happens when somebody I don’t know finds out my doors unlocked most of the day? When they see how we run this house, will it be okay? ...I just pray that the right person or people will be the ones to walk into this house…

“Financial ruin” (Obstacles to the caregiving role). Brittany revealed “as Jacob’s mental confusion began to impact his job performance, I had to find ways to help him while dealing with the financial ruin his actions had caused for our family.” Not only did she have to “adapt to providing care for his physical needs,” but she also had to “find a way to help him maintain his job,” which is done at home, so “further financial problems did not compound an already distressed financial scene.” Dealing with this financial situation was in addition to what she called an “already overloaded caregiving role in caring for Anna” and her own health concerns.

I did have to take care of everything and I tell you how bad his thinking had to be. It took me probably a good year and I’m still behind to reconstruct the files. Everything was misfiled. We were seeing bills and he didn’t even know who they were. We had a 2nd mortgage and I didn’t even know we had that. I actually was
trying to sell the house because I was trying to get us out of debt to find out I couldn’t at that point and it wasn’t till his diagnosis you know you have a 2nd mortgage and I was cleaning up this disastrous mess…He was tired. He was disoriented…I feel like he went back to, I say infantile, that’s way too dramatic of a word but he needed taking care of…It wasn’t until May that I found out how much trouble he was in at his job…His production goes from October to October and so his October 2009 ended with, he’s got this diagnosis and it wasn’t his best year so things were horrible, only I didn’t know it…He was so in the hole…During that time frame it was disorientation and I remember reading through all of his emails for work. He was so in trouble because he wasn’t getting back to people. He was losing track of how much time; to him it just didn’t seem like that much time could have passed…I went through a year’s archive of his emails and I couldn’t do his job if I tried…but I was able to administratively do a game plan and it required and sometimes it still requires me saying, “Did you receive any phone calls today? Okay, did you call them back? If not, that’s what you have to do first thing tomorrow morning. So tomorrow morning I am going to make sure you make those phone calls. Who emailed you today? Do you have answers for their questions?” That’s another thing; if he didn’t have an answer, he just never responded…This was a man who’s received cash bonus awards for his job…It was mind blowing…

“What helps me” (Support that helps the caregiver). Hannah disclosed “my own health experiences and job as a manager in a long-term care facility really helped me prepare to be a caregiver to Jacob.”
I can do every bit of direct care. Ain’t nothing I haven’t touched, seen, or done. I can do every med except intravenous and I’ve been asked to do it all…I’ve learned a lot of things and I’ve cleaned up a lot of things. I can eat a sandwich and change a diaper and I’m good to go…That’s the part that none of this shocks me. It is so hard when it’s your husband…I hope I’m more empathetic to my husband in some senses because I knew what it was like to be ill. I knew what it was like to be in pain and I knew what it was like to be hurt and I knew what it was like to be scared and yet, it can’t even compare to the diagnosis of ALS…

*Share the Care* (Capossela & Warnock, 2004) is a book that describes how to organize a large group of volunteers to help care for someone who is critically ill. *Share the Care* is not specifically aimed at just ALS, but instead all diseases that can be considered critically or terminally ill status. Brittany along with 3 of her female church friends “decided to use the guidelines given in this book to help build a team of volunteers who could help me in not only caring for Jacob and Anna, but also help with the maintenance and running of my household.” The four women presented this idea to their local church community, and Brittany said she “never expected the huge outpouring of support that occurred and still exists.”

I became aware of *Share the Care*. Other people have done the journey before us and so this book came to my attention…All I know is that we had to come up with a way to deal because so many people helped. We were so behind in our lives…There’s 3 other ladies and they are my dear friends now but they were 3 women who had volunteered with my daughter and had the time in some senses and I asked if they were interested. It thought it was only going to work if I had
volunteer coordinators and we do not follow the *Share the Care* way of doing things totally but it opened the idea of creating a group…How can friends come in and not step on families? How does the family work with all these volunteers? It’s an amazing resource. It’s a great guideline to mobilize a group of people to help…We asked if the church would do it with us and our church is beyond phenomenal…That our church didn’t do this for anybody up until this point but because I asked and what I’m learning, if you ask, if you tell somebody and if you ask, you’ll never know. You’ll never know and you just are going to get sucked down into the well of all this…What happened then was people started finding out that [Jacob] had ALS and going you couldn’t just have somebody come in the home and think that, I’m here for [Jacob]. He has ALS and wonder why am I laying on the couch and I’m not helping my husband or why is that girl over there acting like that? We are home with 3 people with way too many issues. As people were ready to volunteer, they needed to know what they were walking into. It was out of that… these three women saying, it’s important for me (Brittany). Not because I need pity and I have to feel worse for our situation, but it might be difficult to understand why that lady I see on Wednesday nights, who is just full of energy, why in the world does she need any help?…We advertised it at church and it was an informational meeting mainly about ALS. We had the chaplain from the ALS clinic who spoke. [Jacob] and I did not attend…We did this whole presentation. It was multimedia and what people had to learn was the issue…We even own the T-Mobil. We have a website…What we do is every 2 weeks we take turns being volunteer coordinator and we have a dedicated phone
that they trade off. It’s not their own phone they have to use. It’s not their email address they have to use. They take 2 weeks at a time so they’re off for 6 weeks at a time…We did email invitations…I think we’re in the 50’s to 60’s (volunteers) but some of those include families.

The 50 to 60 friends and church members that make up the team of volunteers that help Brittany in her caregiving role “do a variety of jobs for the family; from meal preparation, tax preparation, medication management, to caring for the pets in their home, there are very few caregiving jobs that they do not perform for us.” At the point of these interviews, a volunteer would feed Jacob, but “all toileting and bathing and dressing caregiving duties” were still done by Brittany. With her own health concerns and the care required for her autistic daughter, “the volunteer support of taking care of all the household chores has been a huge blessing” and something she has “come to lean heavily upon.”

Everything has to be made here. We have separate refrigerators. We have somebody who helps preset my husband and my daughter’s meds every week…Somebody feeds [Jacob]. Someone entertains my child. Somebody was doing typing for me…We have a volunteer who comes over and helps my daughter prepare meds, things for the dog…The cats hadn’t been taken to a vet in over 2 years and a friend uses a mobile vet and she had a mobile vet come here and she paid for their appointment…Our counselor calls the house so we don’t have to leave. He (Jacob) gets to talk. I just try to make sure no one’s in listening range because he doesn’t have as much privacy as I get to have…Our church actually helps foot the bills…I am so blessed and I couldn’t do all this without
them…I’m so grateful for the community. I’m just so grateful for the friends that we’ve cultivated and grateful for the place we chose to go to church and each and every day I am surprised at the outpouring. This place is a miracle every single day. There’s just stuff here all the time…

Brittany prepared a brochure that is handed out to all existing volunteers or new volunteer recruits. It is a six page colored brochure that has (a) a map to their home; (b) information about [Jacob], [Anna], and Brittany; (c) six candid pictures of the family, including one with [Anna] and her service dog, Maxie, and (d) service opportunities, which contain a detailed list of tasks to be done in their home. These specific tasks are listed below in Table 4.3.

Table 4.3. Tasks to be done in the ALS Caregiver 5’s (Brittany) Home

<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Food Preparation</strong></td>
<td>Because of food allergies, all meals must be prepared with the recipes and</td>
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<td></td>
<td>ingredients provided by the family in the family home. Ideally the</td>
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<td></td>
<td>preparation of three meals would be done twice a week. Goal: Team of</td>
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<tr>
<td></td>
<td>eight people so each volunteer needs to cook only once a month.</td>
</tr>
<tr>
<td><strong>Laundry</strong></td>
<td>Because of allergies, all laundry must be completed in the family home</td>
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<tr>
<td></td>
<td>utilizing a special detergent. This task needs to be done twice a week.</td>
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<tr>
<td></td>
<td>Goal: Team of eight people so each volunteer needs to do laundry only once</td>
</tr>
<tr>
<td></td>
<td>a month.</td>
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<tr>
<td><strong>Ironing</strong></td>
<td>This job would be done on an as needed basis. The current need is minimal.</td>
</tr>
<tr>
<td><strong>Grocery Companion</strong></td>
<td>Twice a month, Brittany needs help unloading groceries at home. Because of</td>
</tr>
<tr>
<td></td>
<td>food allergies and other special needs, the family as a large number of</td>
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<td></td>
<td>groceries and assistance with transporting the groceries into the home</td>
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<td></td>
<td>would be helpful. Another possible task would be for a volunteer to help</td>
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<tr>
<td></td>
<td>Brittany push her multiple carts at the grocery store.</td>
</tr>
<tr>
<td><strong>Trash Disposal</strong></td>
<td>All trash needs to be taken to the curb on Thursday evening.</td>
</tr>
<tr>
<td><strong>Refill Home Supplies</strong></td>
<td>Household supplies such as soap, batteries, tissues, etc. need to be</td>
</tr>
<tr>
<td></td>
<td>refilled once a week.</td>
</tr>
<tr>
<td><strong>Empty Kitty Litter Box</strong></td>
<td>This job should be performed twice a week and could be combined with another</td>
</tr>
<tr>
<td></td>
<td>at home task.</td>
</tr>
<tr>
<td><strong>Home Maintenance</strong></td>
<td>Handyman jobs such as installing deadbolts, weather stripping around doors,</td>
</tr>
<tr>
<td></td>
<td>hanging shelves, installing cable boxes, painting</td>
</tr>
<tr>
<td><strong>Construction</strong></td>
<td>Help is needed to construct a temporary bedroom on the first floor. Eventually the garage will be converted to a permanent bedroom for Jacob.</td>
</tr>
<tr>
<td><strong>Friday Game Night</strong></td>
<td>Jacob, Anna, and Brittany welcome families to their home on certain Friday evenings to play family games. It’s a great time to relax and visit.</td>
</tr>
<tr>
<td><strong>Feeding Meals to Jacob</strong></td>
<td>Volunteers are needed to feed meals to Jacob. Some food will be prepared but may need to be heated. Other minimal preparation may be needed, such as making sandwiches. Because of Jacob’s medication, breakfast must be served by 8:00 a.m., lunch is served around noon and dinner is served around 6:00 p.m. All meals must be completed within a 35-minute time frame.</td>
</tr>
<tr>
<td><strong>Companion for Jacob</strong></td>
<td>Jacob needs a companion to stay with him when Brittany and Anna have necessary appointments outside the home.</td>
</tr>
<tr>
<td><strong>Companion for Anna</strong></td>
<td>Anna needs a companion to stay with her when Brittany and Jacob have necessary appointments outside the home.</td>
</tr>
<tr>
<td><strong>School Aide</strong></td>
<td>A school aide would be helpful in guiding Anna through her homeschool studies when Brittany must be away during the day. This person would not be responsible for teaching new material but simply guiding her studies.</td>
</tr>
<tr>
<td><strong>Exercise Partner for Brittany</strong></td>
<td>This volunteer would be an early riser who would be willing to exercise with Brittany at her home. You could arrive between 5:30 a.m. – 6:30 a.m. and exercise for an hour.</td>
</tr>
<tr>
<td><strong>Anna’s Activities</strong></td>
<td>At times help will be needed to transport Anna and her service dog Maxie to various activities.</td>
</tr>
<tr>
<td><strong>Travel Companion</strong></td>
<td>Traveling to doctor’s appointments can be difficult with the extra responsibilities created by ALS and the other challenges facing the family. Thus, a travel companion is requested to help Brittany at some doctor visits for both Jacob and Anna.</td>
</tr>
<tr>
<td><strong>Snow Removal</strong></td>
<td>Volunteers are needed to help shovel snow from the driveway and sidewalks.</td>
</tr>
<tr>
<td><strong>Yard Work</strong></td>
<td>Yard and flowerbed clean up will be necessary this spring.</td>
</tr>
<tr>
<td><strong>Coupon Clipping Coordinator</strong></td>
<td>Brittany must purchase many specialty items and searches the Internet for specific coupons. This individual would frequently check Brittany’s favorite coupon websites and notify the coupon clippers of download opportunities.</td>
</tr>
<tr>
<td><strong>Coupon Clipping</strong></td>
<td>Brittany must purchase many specialty items and websites often limit the number of coupons she can download. A team of people who are willing to download coupons from their computer would be very beneficial. The coupon clipping coordinator will provide a list of websites and coupons needed.</td>
</tr>
<tr>
<td><strong>Sewing</strong></td>
<td>Some occasional mending is necessary and in the future Jacob’s clothes may need to be tailored.</td>
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</tbody>
</table>
Brittany revealed “I rely heavily on my faith and spiritual beliefs to get through each day,” not only in her caregiving role to her husband and child, but in also dealing with her own medical conditions and the “uphill climb that each day can bring.”

The Lord doesn’t give us more than we can handle and honestly, even if that is your belief system, you will be questioning and screaming and crying and saying, bull crap because I can’t handle all this and here’s my beautiful petite answer and it took me a long time to get to this point. God believes in us way more than we’ll ever believe in ourselves. He loves us bigger if he knows us to be stronger. He believes in us so much more. If you truly believe in the God that I choose to believe in, I believe he has seen it already done. He has seen. He knows our future. He’s already seen me through it. He’s already seen me do all of this so apparently, I can, so apparently, I am capable of doing it and I continue to have to believe in myself that God has entrusted me with this. But in my human, limited earthly state, sometimes it’s hard to believe in myself as big as he does. I have to walk in his boots. We are more than we can imagine. We believe all of those things. If he can love us more than we can imagine, obviously he can believe in us more than we can imagine. We have to walk in that belief of ourself if we want to truly believe in a God that loves us more than we can imagine. We have to walk in the belief that he does love us…

Support from others can add more work (Support can make caregiving more difficult). Have a large volunteer team to help with the many facets of caregiving present in the home is a “wonderful asset” to Brittany; yet all those people coming in and out of the house presents “challenges and a definite lack of privacy”, which is something that
“has proven to be an added stressor” to Brittany in the midst of the “wonderful support by the volunteers.” Also “trying to get my own work done while volunteers try to socialize with me is something that has been difficult” according Brittany. She said “this often occurs at the cost of me completing my own work or resting while others are caregiving to my family.”

It’s just putting ourselves out there…To have everybody know that they could walk in and we could be feeling any sort of way, but lets be real. While we all know that that can be true, there still is a bit of like you have to put on. I don’t feel like I have to put on a happy face but it is generally who I am but yet, would I be at that moment if the world wasn’t witnessing it? …They’re here and they’re trying to help but they wanna catch up with me and I wanna go do something I should be doing but I have a huge need for socialization and it’s been fleeting in getting that need met. Unfortunately I think more often than not because they didn’t get done what they want to do and now they feel bad and I feel bad because I should have been doing this. I really needed to catch up…

Having volunteers and family help with caregiving has “brought about a lack of privacy, not only in dressing and bathing, but also interferes with intimate times with Jacob.”

Having to “explicitly set limits with family and volunteers has been necessary,” especially when it concerns private time between Brittany and Jacob.

…Somebody walking in and I better make sure I am completely dressed. There’s a few silly things, not remembering to take my clothes because now I live down the hall to a bathroom when I got showered and hello, there are people in the house. Or because it’s such a free house in some senses…All the sex stuff. It’s
just that it takes a lot of time and planning to have any type of intimate relations.

We have something like 15 different key holders to our house and it is immediate family. It is coordinators and having a few moments where I’ve now had to explicitly say to volunteer coordinators if there weren’t other people parked outside the house and the doors are actually locked, you might want to call and if we don’t answer the phone, you might not want to walk in my door. Actually how embarrassing to also tell his (Jacob) own parents that. If you also know that [Anna] is at her aunt and uncle’s house; if you find out all these things don’t assume you can use the key and walk into my house…

**She does “try to relax” (Caregiver respite).** Brittany said, “I don’t have much time to relax in my crazy life.” She shared “my physical limitations at times can also make it difficult for me to enjoy walking, which I love to do early in the morning before the rest of my family is up and about.”

When I am feeling well, I love to go for early morning walks. I even listed that on our volunteer brochure because I love to walk and having a walking partner early in the mornings is so enjoyable to me. I also like to do yoga when my body will allow me to do so, but lately that hasn’t been as often as I would like it to be. I also like to cook and when I can, I still like to cook meals for us. That can be very difficult with our different diets, but I still enjoy being in the kitchen and seeing what develops when I try out a new recipe we might like. It’s just hard getting the time or feeling well enough but I do try. I do try to relax…

**“My needs matter too” (Focus of others).** Brittany said she “has such a large network of volunteers that provide assistance to not only Jacob and Anna, but to me as
well” and “with the exception of his family, there is an equal emphasis on my needs.”

She shared “I think this is most likely due to my putting in writing for the volunteers what I need and why I need assistance.”

With all the volunteer teams we have, I think they all know I need help. Why else would they be here helping and I have been very specific about what I need and they know why I need it too. Not all the details, but they know that I have a lot of health problems of my own and I need help as much as [Jacob] does at times. But his family, I think they always think about [Jacob] first and I’m just sort of here. They really are focused on him and that’s okay. He’s their son and should be their primary concern. I rely on others to help me and they do. I’ve got a lot of people pulling for me and helping me daily.

**Looking to the future (Looking toward the future).** One of the “biggest hurdles” that is facing Brittany and Jacob “concerns his current job and the uncertainty that ALS may have on his job status.” Brittany revealed, “his current employers do not know about his ALS diagnosis and because Jacob works from home, I have been able to hide his illness from them. He has used sick time and holiday time to avoid traveling to Washington DC, where the main office is, but we are concerned about what will happen when his company discovers his diagnosis and have hired a lawyer to advise us.”

He is supposed to be required to go there and he’s been using sick time for certain things. He’s used sick leave. He’s used vacation time because we’re trying to stretch it out. Nobody there knows. If he had to go to a meeting right now, he would need me to take him and he is getting ready for his wheelchair evaluation in August…He fatigues so quickly…His job does not know. We are working
with a specific lawyer for federal disability law out of DC…He’s determined to do his job and I think it’s a very good thing. I don’t know what we’d be doing if he wasn’t keeping his brain active. Give him goals and he feels contributory and I’m not going to lie. I’m scared to death for the day that job ends because this house only stands by the grace of his work. I don’t know how it’s all going to work. It’s going to be a mystery and it will but it’s scary but yet, if he needed to stop now, we’d figure it out…

Brittany stated Jacob participated in a research study at the ALS clinic on advanced directives and completed an advanced directive for himself as a result of that study. Brittany said that she “disagreed with Jacob’s wishes about life extending measures when they occur and challenges Jacob’s desire to extend his life on a ventilator,” but said she “felt guilt over this,” but “they were opposite” to her own view of death.

The [ALS clinic] did an advanced directive care study. Jacob did it. I’m the one who entered the answers into the thing. Then they give you the program to bring home and I feel awful that I’m going to say this. While he did it, I said nothing about the answers he was putting in. I was absolutely appalled…It’s been on our list to redo but I guess I was very quiet on the way home. I did want it to be his answers and then they go over the answers and they put it in that (research study) and they read them off to you and I said nothing because that’s the point of the study. We were on the way home and he opened the door by asking me and I couldn’t believe everything that came out of my mouth! Pretty much for Jacob, it (his desire) was do every possible type of intervention if his mind was still working. I mean it could be a car accident tomorrow and revive him, bring him
back, do everything and I was appalled because I’m like you want to come back to have the demise that you’re going to have? It’s because my own self. I don’t know. I don’t find it to be a blessing of anything else happening before you have to almost decide something horrible…Jacob knows my biggest strength has always been, Jesus can come down and I’m good. Let me off. Can we have that rapture thing happen? Do we still have to be doing this stuff? Maybe because I’ve faced a lot more illnesses way earlier. I also don’t think because I’ve also faced other people’s illnesses, I’ve faced what I sort of call them indignities. I said I hope I do things for my clients or for my husband with dignity and yet there’s just bottom line, invasive. You’ve got literally no control and I think it would be more excruciating to have your mind there and have every single day of the rest of you completely out of your control and at times not be able to convey your own wishes. I think that is hell on earth to me in so many ways and I guess I like got red. Sort of vomited up my answer at him. I actually found that I was angry because I was saying; in some ways you know the bottom line. If that’s what he wants and he wants to sign that paper and have it end, I guess I don’t have a choice. I was angry because God forbid he got into a car accident and is totally disabled, because to me it felt very selfish. Then I felt selfish for me and my daughter for me thinking that way and how dare I tell my husband what to do. It’s such a double edged sword but when they go through these scenarios that were very real, okay I understand that you’re just wanting to cling onto every bit of life that you have and it’s just my own belief is, I’m good to go…But I do believe that after Jacob passes my world will change completely. Not because
I’m looking bleakly. Just because I know my daughter can be taken care of and because it’s not my own belief system to have to do all of that…

Brittany knows that “there are practical matters that will greatly impact” her family in the future that she “needs to have in place before Jacob’s illness deteriorates much further,” but with all the other responsibilities she has in her life, “making time for these matters can be very overwhelming, regardless of their importance” to her family’s future.

There’s still some components that I’m aware of and actually need to be on my plate but I still need him to show me… I have this really weird date of September in my head because to me this is the summer to try and get the ducks in a row by then. Maybe because I’m actually not having to start my daughter’s home school till October but because September I need to get my daughter to a bunch of specialist appointments that I’ve been putting off and before I start opening the next can of worms, I’m trying to fix this can of worms. Everything from insurance, retirement and I’m still not quite sure how all this works together when his job does say, “You’re done” or he has to say, “I’m done.”… We’re fortunate that we have the things that need to be there. I still don’t get how the whole thing’s going to all come together and that’s kind of stressful. That’s why I actually try not to think about it too hard at the moment because it’s all immobilizing and I have become immobilized too many days… The stinky thing about as they occur is that there are things that are coming down the road in the future, anywhere from a week to two weeks to a month. Anything from an appointment that you have scheduled out because you’re aware of a time you didn’t prepare yourself for…but it isn’t anybody else’s world…
Attitudes: She is “not alone” and “gifts” (Strategies aiding the caregiving role). “Despite all the challenges that caring for an autistic child, a husband with ALS, and my own medical issues,” Brittany said “I have the attitude that I am not alone in my problems and that everyone has family issues of some kind.” This feeling of not being the only family with problems is one way that she keeps her “positive attitude,” which she applies to her “caregiving journey.” Also, she views the volunteering that is done for her family as “a gift” that she can do for other people. She has been told that this is a “true gift” that she “can give to others.”

I don’t know if every family has maybe so much on their plate but I don’t think; I think we’re interesting but I don’t think we’re the worst family in the world. I’m not silly enough to think our life is more horrible than anybody else’s. I don’t believe that whatsoever but there is an awful lot…I never believed life to be fair to begin with. And that whole fair thing or that we’re all supposed to live to be 105, I know it’s not true and it’s okay and I’m okay with anybody’s life journey and cycle and time frame. Not that it’s not sad when you see a 3-year-old pass away or my friend who lost a 7-year-old son. You know, it’s not right. It’s not the way parents in particular want it to happen…but everyone has something. Everybody has crap. Everybody has their closet. Everybody has skeletons. Everybody has had death somewhere in their family at some point in time. Some may have experienced sickness. You are no different; no better; no worse. Allow others and we have been told and even though it’s hard in the middle of it, we have been told over and over that the true gift has been us allowing others to be a part of it. We have been thanked repeatedly and it is hard to believe it when
you’re in it. It is hard to believe that anybody wants to come in here and help; that they’re only doing it out of pity and they’re not. They really, really aren’t… Despite all the pressures and responsibilities placed upon Brittany, she said “I am able to find blessings and beautiful gifts in an otherwise tragic disease.” “ALS is not changeable, but my attitude toward caregiving is” and this “positive attitude” is what she “tries to concentrate” her efforts on.

It’s a weight that I put on myself that’s how dare I be sad? You know I’m weighed down on a daily basis. I’m exhausted beyond belief and yet I’m blessed and how dare I complain… I resolved it would be okay. Intellectually I know that…If you ever want to make your marriage right, just shorten a life span because you’re either gonna find out right then and there, how do you want to spend you time and who do you want to spend it with? We get to fast track our marriage and that’s the beautiful gift. There’s beautiful gifts in this if you can find them and there’s perfect tragedy but it is what it is and you can’t change it, but I’m grateful. I’m so grateful…I looked at the obituaries today and the average age was probably in the early 70’s. There was a couple at the different ends but at the same time there’s stuff that you’ve lived a life. And I get that we’re so fortunate because [Jacob] did not do manual labor. We’re so fortunate that what he’s able to do for his job, he’s capable of doing it sitting in that bed in the next room. That I can’t imagine for so many others, that a lot of them can’t even do their job by the time they might have found out that they even had ALS…I know we’re lucky.
Brittany ended our second interview by telling me the “story of Holland” which I was unfamiliar with. She stated “I heard one my her co-workers tell it to a family who had an autistic child, but it applies to families with an ALS patient as well.”

Do you know the story of Holland? This is so used for families, especially with kids with autism that I think it’s been used a billion ways for anybody. The story is that I planned a trip to Holland. I got the guidebook. I learned the language. I researched it. We were excited about it. Spent 9 months being excited about it and then we finally got in the plane. We took the trip and we landed in, we’ll say Italy and we’re scared. You don’t know the language. You don’t have the maps. You didn’t get the guidebook for here and you’re lost and you don’t know what to do. This isn’t what you planned for. Here’s the thing, given time and education and given resources, you can learn to love Italy. You’ll learn the language. You’ll learn the customs. You’ll learn about the place. You’ll get the road maps and you will learn to love the place that you land. But you can’t expect it…I planned on Holland. I personally think I landed somewhere in South Africa! I don’t know but they weren’t English speaking. It was in the middle of a tribe somewhere. They were aboriginal. I don’t know! They weren’t wearing any clothes. There was no written language and they had never seen a white person. I don’t know! I didn’t even land in Italy. I felt like I got dropped in the middle of a jungle of a tribe somewhere. And just, it applies to somebody with ALS, even though the journey is still potentially going to suck till it’s all said and done, it doesn’t mean there aren’t going to be beautiful things that come out of this journey but you’ve got to allow for the family to learn the language and to get the
road map and you know you can’t keep saying, well I hate this Italy thing. Well, you’re in Italy and this is what happens in Italy and you know, according to other Italians this is great! Well, according to people that planned for Holland this isn’t what you expected, but it can be beautiful…

“My advice for new ALS caregivers” (Strategies aiding the caregiving role). Brittany said she had “definite advice for a new ALS caregiver.” She was eager to share her experiences and what had helped her “in the hopes it could help a new caregiver as well.”

My advice is first of all, the two of you need to sit down and know every in and out of finances. The two of you need to know every single password, If you take care of the finances and your husband doesn’t, every single password, every single account needs to be written out. Do not wait…Don’t take for granted you have the rest of time to figure out your life and I’m sure we all live in some sort of credit problems to this day. My biggest advice is learn how to live with less. Try not to extend yourselves. It’s just knowing the ins and outs even though you might not like to do the checkbook or whatever; you yourself need to know what bank accounts you have. It would be also to do a will. At least have a starting point before you’re even sick because a sickness will change what you might like to do. Educate yourselves about the starting point to begin with so by the time the sickness rolls around, you’re not going, what???

Brittany shared she “had specific advice about being on the same page as Jacob because of difficulties faced with in-laws,” especially her mother-in-law “about Jacob’s treatment and future medical care.”
Here’s an ALS thing I did from the beginning too, especially if you’ve got living parents of a spouse. You and your spouse need to know from the beginning, you do need to have a set game plan recognizing your game plan might have to change but the two of you better be on the same page when it comes to health information being disseminated. If you’re not on the same page with your spouse, don’t discuss it with family because you could have family taking sides of the two of you and that can also rip the two of you apart.

“Learning to accept help when it is offered is something that was hard” for Brittany to do, but ultimately she “had to do it.” Also learning to “give herself some grace” and “not be so hard” on herself when her caregiver role became “very frustrating and demanding” and she would “become emotional about the physical demands of caregiving” is “advice all new caregivers could use.”

The biggest one is I learned to ask for help and actually learned to accept help. That’s harder than I think anything and I think a big hurdle is so many people offer and my best phrase is, I need to know if you really mean that because I will take you up on it. I actually learned that back when I was diagnosed with lupus when we moved to [town] and it was very hard back then at the very beginning. Even for me because I was a person who enjoyed the fact that people thought I could be Martha Stewart and do it all and I wouldn’t want people to think I was anything less than perfect and when I realized my husband couldn’t do everything…He couldn’t work a full time job and watch my child all day too…I’ll never forget trying to put dishes away from the dishwasher at a time period where my hands weren’t working very well. I tended to drop things and it
took longer…I had a very well meaning friends grab the silverware tray out of my hand an gently pushed me aside and said, “I’ll just do that” and I started screaming at the top of my lungs that I can still do something…I’m still here and I’m still living and yet I made the same mistakes with my husband many times over where I had found I needed to step back and sometimes it was really scary when he had a knife…Cut yourself some grace when you do it because sometimes when you just experienced the fact that he set the kitchen on fire and the day before that you’d already cleaned up 3 broken glasses and you’re really tired and feeling like you’re flying around cleaning up mess after mess. When you do get frustrated, you can scream and yell about it…Give yourself some grace…Brittany’s last bit of advice was really about “the changing role of being a caregiver of an ALS patient” and how “so many of the decisions a caregiver has to enforce are difficult for the loved one they are caring for.”

I found it more frustrating early because he was still struggling to stay as independent as possible but literally creating messes from morning to night. I felt like I was either running after him or if I had to walk away I’d come back, rejected, my shoulders sagging and I’d be so exhausted. I’d look at the mess that got left so he could still be independent and at some point, having to come up with a game plan that works for both of you. Know that as a caregiver you get the best and the worst and you’re going to get to be the person to try and make it okay. You should be the person that makes it as funny as possible when you have to start wearing braces and start using all this equipment that’s just so upsetting to the person you’re caring for. If you can keep a sense of humor about it, make it
funny and tell them that they’re sexy when they’re wearing it, then you actually will start believing it to be true. Do it and at the same time know you get to be the person most likely that’s going to say, “I need to take your driver’s license away. The doctor might not have, but I will not put my child in a car with you and I will not endanger every other person on the road today because you’re insisting you’re going to drive. I will not allow you to potentially kill another family because you want to be independent.” Know that you get to be the bad person. You get to say, “I’m sorry, I think today’s the last time you should do that. It’s now too dangerous” and be ready to be hated and be ready to be loathed and somebody to be sad with you and angry with you. You get to bring the worst news. You get to enforce goals. It’s sucky. So much of it sucks. You get to be the one if they’re crying and they’re coming to terms and you get to be the person that might not have anybody there…
Figure 4.9. Chronological Pattern Diagram: ALS caregiver 5 (Brittany)

Husband = ALS patient

Caregiver Perceived of Stress

- Caregiver Diagnosed With Lupus
- Daughter Diagnosed With Autism (Auditory/Sensory Processing Problems)
- Daughter Very Ill
- Caregiver Home Schooling Daughter
- Husband Experiencing Left Finger Locking/Fine Motor Loss in Hands
- Husband Diagnosed With Chronic Epstein-Barr Syndrome
- Caregiver Not Recognize Husband (Personality Changes)
- Caregiver "Consumed" With Daughter's Care
- Husband Having Short-Term Memory Loss

Denotes time of disruption/crisis
Caregiver Perception of Stress

- **June 2009**
  - Husband Having Hand/Shoulder/Leg Twitching
- **July 2009**
  - Daughter Developed Severe Food Allergies
  - Caregiver Handling Finances of Family
  - Husband Experiencing Depression Symptoms
- **September 2009**
  - Daughter Allergy to Sun Diagnosed
  - Caregiver Aware that Husband Not Able to Multi-Task Anymore
  - Husband Fatigues Very Easily
- **May 2010**
  - Husband = ALS patient
- **September 2010**
  - Caregiver Mealtime Difficulties with Rheumatoid Arthritis
- **February 2011**
  - Husband Falling Frequently
  - Husband Having Decreased Work Productivity
- **Spring 2011**
  - Volunteers Coming into the Home
- **June 2011**
  - Husband's Company Will Learn of ALS Diagnosis
- **Fall 2011**
  - Paid Staff Employed for Husband

Denotes time of disruption/crisis
**Chronological pattern diagram narrative: Brittany**

Due to the complex health issues of all three members of Brittany’s family, the chronological pattern diagram took three pages to complete. We started by numbering the chronological events from high to low, but because these three diagrams had so many events listed, Brittany decided to group events together in level of caregiver stress when ranking the events on her pattern diagram. Reviewing this chronological diagram with Brittany provided the opportunity to unravel and clarify this complex caregiving experience.

There were three events in Brittany’s chronological pattern diagram that she rated as being the most stressful (#1). These were (a) the caregiver’s diagnosis with lupus, (b) her husband’s diagnosis of ALS, and (c) family financial concerns. She ranked her diagnosis of lupus in this #1 category because of all of her diagnoses, lupus has been the most complicated and the most difficult to control, even currently. When I asked about including her diagnosis of bipolar disease, she did not want it included because she revealed it is well controlled now and since she was diagnosed at age 13, being bipolar is just part of her “normal personality” that she doesn’t even think about it. Unlike some other caregivers in this study, Brittany ranked Jacob’s diagnosis of ALS as a #1 event because Brittany diagnosed him herself through Internet searches prior to his actual diagnosis by the ALS neurologist, and she was extremely knowledgeable about the diagnosis, treatment, life expectancy, and presentation of ALS prior to Jacob’s official diagnosis. Therefore, she knew what that ALS diagnosis would mean in her already complicated caregiving journey with Anna. Lastly, she ranked the financial concerns of her family as a #1 stressor stating her family was facing “financial ruin” due to her
husband’s confused mental state while making financial decisions for the family. Brittany was faced with selling their house as an option to improve their financial situation but could not due to the second mortgage on the house. These financial concerns still continue to the present.

The second grouping of events, which were ranked #2, concerned three categories: (a) Anna, (b) finances, and (c) volunteers. From 2005-2008, Brittany was “consumed with her daughter” starting first when Anna was diagnosed with autism through her daughter’s “many associated illnesses” until Brittany had to quit her job to home school Anna full-time.

I wasn’t making appointments for him (Jacob) and while there was complaining going on (by Jacob), I was also working through a daughter who I home schooled who has medical issues…He was complaining a lot and I’m going, “I’ve got a kid, I’m working on it” and we did divide and conquer. [Jacob] took care of everything so I could focus on her and at this point, we did home schooling.

She’s a lot of work. She’s had a lot of medical challenges… Financially, her family was in a bad situation. “[Jacob] had done a lot of things that I didn’t know. We were financially bereft and I didn’t know. He doesn’t remember taking loans out. He doesn’t know where the money went.” Lastly, having volunteers come into the home is a vital resource for Brittany, but having to coordinate this volunteer effort is very stressful. “The bottom line is I keep this place floating every day with other people (volunteers).”

The third cluster of stressful events (ranked #3) started chronologically with Jacob having short-term memory loss and continued with her husband’s mental confusion state
resulting in his inability to multi-task. This ability to multi-task was one Jacob had always had with his demanding engineering job. She stated, “He’s an electrical engineer…that knowledge hasn’t left him whatsoever. However, one of the struggles the very first year after diagnosis was he can’t multi-task.” On the same day as his diagnosis of ALS, Jacob discovered he was being accused by a fellow employee of having an affair at his workplace.

He was accused of having an affair with a woman at work and that came in a few hours after his diagnosis; the same day. She had gotten someone else fired before…She had a reputation for doing this. He swears to me to this day nothing ever happened but it was a very hard thing…

The last event Brittany listed for the #3 group ranking was having to have a paid caregiver come into help her with her husband. This has “proven to be a stressful event for Jacob, which results in it being stressful for me too” said Brittany. She states that Jacob is “very modest” and “there are certain caregiving duties that have been hard for him to allow his wife to perform let alone a stranger.”

The fourth grouping of stressful events (ranked #4) contains two events revolving around her Anna; her daughter’s severe food allergy problems and sun allergy. Both of these events “caused changes in their lifestyle” (i.e. gluten free diet, special food preparation equipment, change to indoor activities, vitamin deficiency replacement) for Brittany. In addition, two events concerning Jacob, Epstein-Barr syndrome diagnosis and his personality changes were included in this category (#4). At that time they did not know about precautions to take after Anna contracted Epstein-Barr and as a result, Jacob contracted the virus. “He was starting to show cognitive changes a year before his ALS
diagnosis,” which Brittany did not realize and as a result, he turned into “someone she didn’t know or recognize.” This was “very frustrating and confusing” for Brittany.

The fifth category (#5) concerns events that occurred with Jacob after his diagnosis of ALS. These events included: (a) Jacob’s fatiguing easily, (b) sleeping in separate bedrooms, (c) awareness of Jacob’s decreased work productivity, and (d) Jacob’s frequent falls. All these events resulted from her husband’s declining physical and mental abilities. Brittany stated:

He (Jacob) couldn’t stay awake for long. He was sleeping. There was a lot of fatigue…it was disorientation and I remember reading through all of his emails for work. He was so in trouble because he wasn’t getting back to people…

Brittany’s last identified category of events (#6) were the lowest in stress level for her and involved three more symptoms of Jacob’s ALS progression (i.e. loss of fine motor skill in hands, body twitching, and depression symptoms) and her own health condition impacting her caregiving duties (i.e. mealtime difficulties due to her rheumatoid arthritis). She communicated the following:

…he (Jacob) needs his food chopped smaller but my daughter also is hypotonic and she can’t cut things and I have rheumatoid arthritis and mine has affected my hands so till I get the 3 of us fed in an evening, it’s like one person is done, and I get….here, they’re done eating by the time I get the next one and I’m having a problem now…

Transformations/Insights

When I asked Brittany if talking with me had brought forth any new insights or made her think about anything she hadn’t before, she said
I’m finally getting a chance to talk…It’s very cathartic because for me, this is my personality and talking is cathartic…When you asked me what I’d do with an hour (of respite time), I now don’t think I’d want to be social. I did have that desire. The reason I don’t want to be social now is because everything centers around, “Well, how’s it going? Well, what’s happening with you? How do you feel? How’s [Jacob] feel?” Nobody wants to share with me the reality of their life because theirs can’t compare to ours and I’m so tired of so many of my friends going, “nothing, fine, nothing’s new with us” and it actually makes me sad and I probably would do it to somebody in my situation too. But it’s not what I want and while I can sit here and it sounds great while I talk about me forever, one of my favorite phrases is, “I’m really sick of me. I am sick of us. I am sick of talking about us. I’m sick of dealing with us.” So that hour, I do need to do something just for me. I do love movies and yet there’s always a feeling of guilt that of all the other things I could be doing…

Brittany was at the De-Centering Stage of Young’s Stage of Evolution (Newman, 1984). She had made the choice of having teams of volunteers come into her home to help with caring for her husband, daughter, home, and herself and she stated one of the best results of allowing people into their lives was that they were “giving a gift” to others who so desperately wanted to help. Her energy at this stage (De-Centering) came from truly sharing with others. Her awareness went beyond her physical boundaries and thus showed growth to higher levels of consciousness.
Narrative Summary: ALS Caregiver 6 (Aaron)

ALS caregiver 6 (Aaron) is a male in his mid-sixties who has been caring for his similarly aged wife (Ashley) since she was diagnosed with ALS in April 2011. At the time of these interviews, Aaron and Ashley had just attended their first clinical visit with the ALS medical team. Ashley was the newest diagnosed ALS patient participating in this research study. Aaron is a retired high school teacher and Ashley is retired from working for the state of Pennsylvania. They have been married for 43 years. They have three grown children, two daughters and a son. Their two daughters live over an hour away and their son lives in the same town as Aaron and Ashley.

Ashley’s symptoms are limb in presentation and she has no mental changes. Current symptoms/adaptations include: (a) use of a walker around the house and a wheelchair when out of the home, (b) difficulty going from a sitting to standing position (get up and go), (c) use of a stair lift in the home, (d) use of a shower chair, (e) loss of gross and fine motor movements of the hands, (f) incontinence of bowel and bladder, (g) limited strength in legs, (h) increasing body weakness, (i) extreme overall body fatigue, and (j) frequent stumbling and falls. She was started on Rilutek one week prior to these interviews and she has just agreed to participate in a medication research clinical trial at the ALS clinic that will begin in approximately one month. Ashley attends rehab sessions twice a week for limb strength. Aaron reported Ashley’s first (and only) FVC value is 82%.

Aaron’s main caregiving duties include: (a) assistance with bathing and dressing, (b) cooking, (c) cleaning, (d) assistance with toileting, (e) transportation, (f) washing and
ironing, and (g) assistance with change of positions. Aaron does not leave Ashley alone at anytime due to his fear of her falling.

**Thematic representation of emerging pattern of the whole for Aaron**

**Misdiagnosis and “vague symptoms” (Suspicions emerge but ALS diagnosis is delayed).** Aaron reported that early symptoms with his wife were “vague” in nature and although they “thought something was wrong,” said “our family physician misdiagnosing her problems as being a back problem.” He shared, “We were referred to a neurologist, who also did not initially diagnose ALS, but said she had a nerve problem in her leg. Even after Ashley was referred to the neurology department where we go to the ALS clinic, she was evaluated for Multiple Sclerosis and only when that was ruled out was she referred to the ALS neurologist.”

…about last summer, she fell coming down the steps once and then she had trouble with her legs, moving around. She went to the shore and she was in a wave and it kind of knocked her over too and she had trouble getting up and then we went to [location] in October. When we were up there, she had trouble walking and then we went to some basketball games over at [university] girl’s basketball games and she had trouble getting in and out... She just had trouble with her legs, weakness in her legs and we thought it was her back-originally. That’s what we thought was the problem but then we went to a neurologist. We went first to her doctor (family doctor) and she said she didn’t know what it was; maybe MS or whatever so we went to a neurologist and he said something about a nerve in her leg so we messed around with that for a while and finally he said it might be MS or ALS so then he referred us to [ALS clinic] and that’s how we got
that diagnosis. We saw the other, the MS doctor first (at ALS neurology department) first…We saw him first hoping that that’s what it was and then we went from there. He (MS neurologist) said no, you have ALS so we saw [ALS neurologist]…

Even though Ashley believed she had ALS from the start of her symptoms and she sought medical advice at the start of her symptoms, Aaron stated “there was a six-month delay from the start of her symptoms until Ashley was diagnosed with ALS.” He stated “This was really upsetting for her because she thought she had ALS based on her experiences with two local church members who had ALS and eventually died from it.”

That upset her…She was upset. I think we all were that it took so long to diagnose especially when she claimed way back that she knew what she had…She had two people within the last two or three years in her church that had it and died from ALS…These people were in our church and we knew them and associated with them and she had the symptoms…She believed that she had it (ALS) from the very beginning…She had these tingling sensations in her skin-arms and legs and she right away told the doctors (that she had ALS)…Because at [ALS clinic], [ALS neurologist] came in and did test and he said something to her and she said, “Yeah, I think it’s ALS” and he went on and said, “Unfortunately, yes.”…She said that when he was doing his tests. He said “but we best still do these other tests”…

Although Ashley “firmly believed she had ALS right from the start of her symptoms,” Aaron did not and shared he “was surprised when they got the diagnosis from the ALS neurologist.”
…I was surprised, first of all, that it even happened. She has been in pretty good health all her life…She hasn’t been in the hospital at all and she’s been sick here and there and she’s broken things but she hasn’t really been sick before and all of a sudden, this happened to her…She’s had an inkling a long time; before they diagnosed her because of [two friends with ALS in their town]. This is, hers is different and I don’t know. I wasn’t that close to either one of them. I saw [ALS patient friend] at the church making eggs at Easter time and he was there and I saw him go through and go down with his speech but his motor seemed like his other things. He walked and he could handle himself very well. [Other ALS friend] was the same way until the very end. He did use a wheelchair at times there at the end, but up till that period of time, he was walking and using his arms and all that. Now hers is entirely different because it’s her arms and legs are what’s going…

“Changes in my life” (Adaptations from ALS). Aaron said, “many things have changed in my life” since Ashley was diagnosed with ALS. He shared “one of the things I miss most is the traveling that we did,” both on long trips as well as around their hometown. He also disclosed “because she realizes her condition has gotten worse, she is planning a trip with all of their children and grandchildren.”

We had a good life. We did things together and we always tried to go somewhere every year. We’ve been to Alaska since she retired…We’ve been on cruises and when I was teaching, I had a sabbatical and we went across the United States; took a month…We go out once in a while but it’s hard to get her out now. I miss the traveling…Now she’d like to plan a trip for the kids; all the kids to Disney
World. Take a cruise and go to Disney World…I think it’d be good to get everybody together and get together with her right now…

Aaron expressed, “One of the biggest fears I have is that she will fall and this has changed my daily routine more than anything else.” As a result of this fear, Aaron said, “I have to have someone with her at all times. I don’t like to leave her alone.” Even when he is trying to complete housework or yard work, Aaron said, “I have to keep her close and check her frequently to make sure she’s safe.”

The roughest thing is fear of her falling…I have to be here and be near and be doing everything…She fell in the kitchen and then she got up and she was in the kitchen and she just fell backwards. We have a stone kitchen floor and she hit her head and that just kinda stops your heart. That was near when she was first diagnosed…then she fell probably about a month ago. She was in the living room pulling the blinds down and she fell backwards and she grabbed the blind, tore the blind down off the thing and fell backwards. I was out mowing grass. She tried to call and get up. She couldn’t so she laid there for about an hour till I came in and so now I take a cell phone with me…now I check about every half hour if I go out…

This fear of her falling has changed the daily routine for Aaron and Ashley. Golfing is the main way that Aaron enjoys himself and reported, “I used to golf up to five days a week. Now, I go out very early to golf, three times a week because it’s easiest for me to find someone to stay with her during those early hours instead of in the afternoon,” when he used to golf. “This change in our time schedule has changed her daily routine too.”
She’s sleeping much later than she ever did except on the days I go golfing, she has to get up. I have to get her dressed and breakfast…Our tee time is 7:30; we have a big group of guys. She gets up. I get her dressed and we get breakfast, all that and I tell her she has to sit in a chair until I get back. Then I have people come. Everybody’s offered to come stay with her. People have been great…My friends that I play golf with, their wives will come and say, “You go play golf and we’ll come stay with her.”…

Aaron shared he has “taken over all housekeeping chores now” and this has changed his daily routine, which had been “long established” since his retirement 10 years ago. Now his daily routine includes “watching over and assisting Ashley while completing the chores around the house.”

I have to do almost everything at this point. She did hire a cleaning lady for once a month and then the other 3 times a month, I clean. I dust and run the sweeper and I do more of the cooking. We’ve always shared the cooking and that so I do more of that. She does more supervision of that and helps what she can do. She does whatever she can…It may sound crazy about washing because I wash all the time. I wash clothes all the time…I do cut her meat. More and more she’s having trouble with it…She has very little feeling in her hands anymore and very little feeling in her legs. Now she does still get around with a walker but you have to help her get up. You have to help her in the bathroom, as far as getting on the commode and getting off. I hafta help her into bed. I help her in the shower but she still showers on a shower chair…I just sit there and when she’s done, she tells me she’s done and then I help her out of the shower. I’ll dry her off and get her in
her clothes and back upstairs…I have to assist her in bed…It’s physically exhausting…

He shared “Another change in our life was when Ashley had to stop driving.”

Since she was the main driver for the family, this had a “major impact” on Aaron as well as Ashley. He said the following: “I won’t let her…She wanted to but I said ‘no’…That was a hard thing for her. She was always a driver and she did most of the driving. She loved to drive…”

Aaron disclosed, “Although most of the changes in our life have been negative, there have been two positive things. First, there are more people coming to our home and many of them are church members which I never felt close to, but do now.”

…We have a lot more people coming here. I mean it’s like every day somebody’s (friends from church) here visiting…I think her church has been a support. I think you understand that I say her church because it’s her church. I don’t go to church. I do help at the church with Easter eggs and things like that but I don’t go…because I’m not a churchgoer. She’s always been a very good church person. She’s always been close to the church and the people in the church and I’ve grown closer to the people in the church. I really have. They’ve really become friends…

The second positive change involves their three grown children and Aaron shared “the family has grown closer together since the ALS diagnosis.”

They’ve been around a lot more…My daughter’s here. She’s been here most of the summer…My daughter, we’ve been pretty close always…We just haven’t seen them as much before because of the distance and because of her husband in
[southern state]. Now my son has definitely stepped up the calling. When she first got sick, I think finally my sister called him and said, “Hey, you know, your mother isn’t well. You need to call more often and find out about it.” He has done that and now with his kids being here and with his son, they’re here a lot…

**Support of friends and neighbors (Support that helps the caregiver).** Aaron and Ashley have both had the support of friends and neighbors since the beginning of her ALS diagnosis. He said, “many friends have offered to stay with her while I golf three days a week,” which along with reading is his only form of relaxation. He shared, “Ashley has always been active socially with her former high school classmates, but since joining the Red Hat Society, she has also had the support of this group as well,” which Aaron said “allows me to catch up on housework or yard work because I know that she is safe with her friends.”

…Everybody’s offered to come stay with her. People have really been great. Her church and she’s in the Red Hat Society…They’ve been great. Everybody, my friends I play golf with, their wives will come, “you go play golf and we’ll come stay with her” and people have just been great…Usually when we’ve gone out, people have helped. You know they open doors and they’ve held doors open and done what they could for us…Last week one of her friends she went to school with came up and talked to her and they went over to [park]. She has a convertible so the lady said, well tomorrow we’re going to go over to [park] and see that because she hadn’t ever seen that so they went over for 4 or 5 hours. Drove around and had a good time…She’s had a couple friends from down in [city], she worked there the last couple years when she worked for the
employment office and they’ve come up and they’ve gone out to eat…To see her and talk to her and be with her…They really take care of her and they watch. The Red Hat ladies are great with her and the neighbor up here is one of her classmates and she comes down about every day now…everybody has volunteered. I mean, I had probably 50 people, but we got a lot of people who said, “Yeah, if you want to go play golf, give me a call. We’ll come and stay.” Not only have their friends been supportive with spending time with Ashley, but Aaron said “they have given us a lot of medical equipment, which has saved us from having to buy a lot of it.”

…People have just been great. People have been giving us things, like wheelchairs and bath seats and this and that…now she has a walker…She has one upstairs and one downstairs. They were both given to use. Yeah to use and when we go somewhere, we’ve been taking those…We do have a wheelchair that was given to use to use and we just got a transport chair yesterday. Somebody gave us one of those to use…There’s a lady that called that goes to my wife’s church and she called yesterday that she had one of those lift chairs and that it was her mother’s and they didn’t need it and they were going to give it to [Ashley] so they’re supposed to bring it up tonight…That’s the kind of things that happen constantly…

One particular event “really impressed” Aaron about “the kindness of others” towards Ashley. For her recent birthday, church members held a “card day” for his wife. This really made Ashley “feel good,” which in turn made Aaron “very grateful to the church members who were so thoughtful” to his wife.
…The church, definitely the church (supports them) and in fact on her birthday they had a card day. Everybody sent her a card! …That week and that period of time she got about 60 cards from friends and people from the church. From her classmates here and there and everywhere, you know…It really bolstered her up. She really enjoyed that…

Of their three grown children, Aaron said his oldest daughter “has been the most helpful with helping me care for her. Not only helping me take care of her physical needs but she also helps transport her to rehab. She is also helping me figure out how to hire someone to help once she leaves to go home.”

She’s (Ashley) doing rehab twice a week now…My daughter’s been taking her…My daughter really, really helps and really takes a lot of burden off of me…My daughter’s here. She’s been here most of the summer and she’s going to go home now and I don’t know, a couple weeks she said. The kids have camp so then she’s going to go home and then she’ll be back for a couple of weeks…My daughter, we’ve been pretty close…I just don’t know how to go about getting the help. Now my daughter, she’s more forceful…She could get it done but I don’t know if I am equipped (to know what to ask). And I know my wife couldn’t. For help I’d have to ask her (his daughter)…

“Supported by others” (Focus of others). Aaron stated that he “feels supported by others” in his role as a caregiver. Aaron said “I don’t believe this will change as time passes and her health declines.” He said this feeling of support is “especially true with the encouragement and concern” he has received from his three grown children.
They ask me. Yeah. Definitely the family does. Definitely my daughter and son are concerned about me and like I said, we’ve had all kinds of help…I don’t think that’s going to change. I’m pretty healthy now but they all ask about me and how I’m doing with all this…

“Chaos in their everyday lives” (Support can make caregiving more difficult). Even though his daughters help with Ashley’s care, “their presence along with their children has created chaos in their everyday lives, especially at meal time. Just having all these relatives in our home has made Ashley try to stay up later every evening,” an action that has made getting his wife to bed “more difficult” for Aaron. In addition, even though their friends have been “a wonderful support system” for them, this support has “also caused added house keeping duties” to Aaron who “is required by Ashley to clean the house prior to their arrival for monthly dinners.”

…With the kids here and all that and [daughter] here, she (Ashley) likes to stay up a little later. She falls asleep, the dog and her fall asleep probably watching TV about 9:00. But if she does that, then when I have to get her up, she just, she’s foggy…She gets awake, she’s a bear…She’s really foggy and kind of stumbles around and all that. Now If I get her in bed at 9 or 10:00 and she doesn’t fall asleep, then she’s much better. I don’t know what happens…She gets kind of foggy…with the kids and with everything, it’s kind of chaotic and meals are really a problem. There’s just so much to do and you know, kids are here and kids are there and my daughter and I, she really works. My daughter’s a great worker and it’s just chaotic. Then my son usually comes up so we usually average around 9 or 10 people…We have a lot more people coming here. I mean,
every day somebody’s here visiting. They’ll call and they’ll say can we come see and they’ll come and stay for an hour or two and they’ll talk to her…Once a month her classmates, her girls in her class meet usually they go out somewhere but they’re coming here tonight so there might be like 10 or 12 people. They’re bringing all the food. We just have to straighten up the house. That’s an order!...

“Makes caregiving harder” (Obstacles to the caregiving role). Aaron shared one of the factors that “makes caregiving harder” for Aaron has been “Ashley’s attitude and her frustration with the disease.” Having Aaron take over the household chores that she has previously done “has not been easy” for Ashley. He said, “She is very specific about how her house should be maintained, which has really been a challenge for me.” Also, “Her refusal to take pain medications for the pain she has with ALS as well the knee pain she has, has made caregiving harder for me.” Ashley has also “gotten frustrated” with Aaron during the night when he has to help her get to the bathroom.

My wife’s really fussy. Yeah, even when I dust and move things, she gets upset because they’re not back in the right place. That kind of sends me up the wall because who care whether they’re back in the right places at this stage? I don’t and I never did care. She’s very particular…She’s not a good patient-No. She’s always been that way. She’s pretty much been bossy. She’s still bossy…She’s more emotional…She had pretty much things her way, which she doesn’t believe but I have. And she doesn’t suffer pain very well. Now my daughter and I would probably cut off our leg and you know, we wouldn’t say anything. So that’s hard you know. Which you realize she’s going to and it’s hard to be doing things and helping her and watch her go through this. It would be easier if she just didn’t say
anything but you know she’s going to…Right now her knee really hurts…She’s one of these people who has always been proud, which my daughter and I have just been discussing. She’s never taken any medicine. She doesn’t take medicine and now she has these pain pills and we’re trying to get her to take them and she hasn’t taken them because she doesn’t take them…she’s never been one for pain or one to push herself…A lot of times she says “I can’t do things” and that’s stressful. She’s never been a person to really push herself. I think just do a little bit more. Many times, lifting her leg or moving this or doing this or getting up, which you know she can do. She says she can’t because she’s never been one for pain or one to push herself…I have to assist her into bed and then she likes the one side to roll over on and we have to flip her over when we first get her into bed and then she gets mad…She’s fussy with her personal hygiene and she’s having problems going to the bathroom and that’s really upset her, getting to the bathroom in time before she urinates…Sleeping’s a problem (for Aaron) because she gets up quite a bit during the night going to the bathroom…Her hair bothers her because she can’t lift her arm to do her hair and that really bothers her…There’s really nothing anybody can do…

Even though he has ‘been willing to take over spring-cleaning and other household chores,’” his idea of making a chore lists at the start of each day was something that was “very difficult for Ashley to deal with.” Aaron stated, “Ashley is very frustrated with her inability to perform the chores that she had previously done and has turned this frustration instead to me” as Aaron “struggles to carry out all these tasks.”
At the beginning I made a list of things I have to do each day and she kind of got upset about that. Like I had to do houseclean down here spring clean down here, wash the windows and all that and she kinda got upset about that. I really don’t know why really she got upset. Probably because my list that I had this, this, this to do and I think that may have upset her because she couldn’t do them any longer and she felt kind of useless…She’s always made me feel like things had to be done. And it’s more and more that she’ll look at something and see this has to be done and this has to be done and I feel that if it has to be done then it has to be done and that kind of frustrated me too. It kind of wears on me…

In addition to Ashley’s “frustration with her physical limitations, her saying that she is a burden” has been “especially hard” for Aaron to hear.

Some days she unfortunately expresses that she’d just rather die. It hurts so much…That’s what gets you. She says, “I’m so much of a burden on you. You have to do everything for me.” That’s what she says and “that’s not right and you have your own life.” That’s hard on me too... I try to encourage her and it’s really difficult because she’s been her own person all her life and she’s pretty much run things. I try to encourage her but that’s all I can do. I kind of get angry, to tell you the truth. I kind of raise my voice, which I shouldn’t and that really upsets her. I shouldn’t but I don’t know, that’s me. That’s my make up. Because I’ve always been, there isn’t too much you can’t do and pain doesn’t bother me. My daughter and I, it just kind of frustrates both of us really. I do raise my voice. I do yell which I shouldn’t and I know that…I can’t stop it. I just can’t stop it. After it’s all over and done, I feel bad about it…Once in a while she starts her thing
about dying and all that you know, I’d sooner not be living life like this, and that upsets me…

Aaron stated, “Ashley is really reluctant to get out with friends and prefers to have people come to her instead, yet once she goes out she really enjoys herself. Even as a couple we don’t go out as much due to her fear of how people will respond when they see her.”

She’ll say no but then when she goes, it’s fine…We don’t go out. Usually we probably used to go out once a week but the problem is for her to get in and out of places. She’s kind of leery about doing that. I think part of it is that she feels kind oh, how do I want to say this? She feels like people watch her or look at her. We’ve all told her, you know, “be yourself. Don’t worry about it. We’re human. To heck with other people” and usually when we’ve gone out, people have helped. They open doors and they’ve held doors open and done what they could for us…

One other factor that Aaron says makes caregiving harder for him is “his location in relation to the ALS clinic.” “The distance away from the ALS clinic (1.5 hours) has prevented us from participating in the ALS support group. It’s also harder for me to transport her to the research study that will soon start at the ALS clinic.” When asked about whether he had attended any of the support groups, Aaron responded: “No, again that’s the travel aspect of it…I looked at some of those flyers and I think the closest one would be [ALS clinic], so I don’t go”…When asked about his wife’s participation in a clinical research trial, Aaron had the following response:

She’d like to do what she can for anybody in the future. She’s really concerned about that; to help somebody else in the future. The only problem we have is
[ALS clinic]’s quite a ways. I think they said they’d have to set the date and we’d have to go down there…if it’s too much we can’t do it…

Aaron shared “Another thing that has makes caregiving harder is my hesitation in asking others, friends, family, or the ALS team, for help.”

I think probably our problem is that we’ve always been people who have done things for ourselves. I think that we’re kind of hesitant about asking for help. As I said, I can have people come whenever I wanted them really to stay with her and do what I wanted to but I can’t bring myself to ask people and she can’t either. I think that’s been a problem about getting anything done or getting help that we need…We’re not people that ask for help. We never have been…I really find it hard to ask people to help me. I don’t think it’s going to be hard to come in and help me with it; I think it’s going to be hard for me to ask somebody or for her to ask somebody to come in to help us…We’ve never been to counseling…We’re probably more deal with it ourselves…

“Simple life and simple pleasures” (Caregiver respite). Aaron said, “I don’t have much time for relaxation but when I do get time, I love to golf with my friends early in the morning.” Although I can’t golf as much as I used to and probably won’t be able to do as much in the future, I still enjoy it.” Other forms of relaxation he enjoys are “reading and going out,” but said these activities are “usually done with Ashley” and not by himself, which would “give him some time away from his caregiving responsibilities.”

I do play golf sometimes and when I do, I get up; we go real early…I try to get out once a week and now with my daughter here now, I’ll be able to go probably 3 times a week…I like to work around here doing jobs around the house… we go
out every once in a while but it’s hard to get her out now…I like to read so I read a lot. She does too…That’s about it. I lead a pretty calm life. I’ve always been that way…I lead a pretty simple life and have simple pleasures.

“Easy going and laid back personality” (Strategies aiding the caregiving role). Although Ashley had only been diagnosed a few months prior to these interviews, Aaron said, “I accept that she has ALS and know what will happen with my wife.” He stated his “easy going” and “laid back” personality has “helped me come to terms with her diagnosis.”

I’m pretty easy going…I’ve always busied myself around here doing this and that and the other thing; jobs…You know things got to be done and this is the way things are gonna be and we just have to live with it and do the best you can…It’s sad. There’s really nothing anybody can do…I know things are gonna get worse and we’re gonna hafta have help and it’s gonna go downhill and there’s gonna be a time when she’s gonna be bedridden. It’s hard to look at but you realize it’s gonna happen so, like my daughter said, “That’s that’s life, unfortunately”…I’ve got to accept that…It’s what I have to do…They’ve (his children) accepted that and like [daughter] said, “it’s unfortunate, but we have to live with it and so does she.” Try to make the best of it. I think we all have that attitude…I try to encourage her but that’s all I can do…I kind of accepted it and realized that that’s the way it’s going to be. I can’t change it. It’s not like cancer. Maybe you have a chance, you know, maybe you don’t? There isn’t any that we know. You have to kind of accept that and then go day by day…We’ve been fortunate that she’s lived at least 65 years and you have to look at that aspect also, you know. People die a
lot younger and everybody has their problems and everybody has suffered and all that…

**Planning for the future (Looking toward the future).** Even though they are in the beginning phases of the ALS disease journey, Aaron said “We are already making plans for the future when her physical abilities decline.” He shared, “One of the first areas we have dealt with has been the household finances and investments,” which “until recently had been handled solely” by Ashley.

She’s always been like that, the bank and the money. She’s always been a money person and talking about the different banks and getting things consolidated. She did the books and the finances, to get me involved to take that over. I’ve been doing more and more because that was her role. She’s trying to sort of prepare a little bit for the future…

An issue of “immediate concern is the hiring of a paid caregiver” to help Aaron once his daughter leaves. Even though he said he “is convinced he will be needing help shortly with Ashley,” Aaron is “uncertain” how he should go about the process of hiring paid caregiving help. “Relying on the ALS team” as a resource, even after only one clinic visit is something that Aaron is already “prepared to do.”

We don’t really know what to do. I mean how to go about that. That’s one of the problems that we’re going to have to look into. I don’t think it’s going to be long. With my daughter here, it’s going to be different. As long as she’s here, I think we can handle it…when feeding her and bathing her…She (Ashley) said “I’m going to have to have a caregiver” because she’s always been- she worries about her hair. She can’t do her hair and she worries about smelling and things like
that…so, hopefully they (ALS team) can help us out. I don’t know what they’d do but I know what their areas are but I don’t know exactly what they can do for you and I’ll have to find that out as we go…It’s going to be difficult to have somebody here. That’s going to be stressful…Like I said before; it wouldn’t matter to me if somebody came in or not. They don’t bother me but it’s going to be emotional for her…

Even though Aaron said he and Ashley are already planning for the future, he shared, “we are planning for the immediate future, not the end stage of the disease yet.” When asked about whether he and his wife have discussed whether they would use a ventilator to extend her life, Aaron said, “No, we haven’t.” When asked about whether he thinks about his wife dying, Aaron replied, “No. I try not to.” However, he said, “I think she does (think about dying).” When asked about whether he could think of a “perfect case scenario” about what the rest of her journey would be like, Aaron had the following response:

You get both; both things go through your mind. You know like suddenly you’re long term or whatever. I think everybody would go through that sometimes you say this, suddenly and then sometimes you say no, let’s take as long as possible so you have conflicting opinions about her suffering and that…It’s just very difficult. You know, there’d be times you’d say this way and other times you’d say another but you just can’t. Hope for the best…
Chronological pattern diagram narrative: Aaron

At the time of the first interview, I had just finished completing ALS caregiver 4’s interview and she revealed that her vision of the pattern diagram should be separated into two separate pattern diagrams; emotional and physical. When I discussed this concept with Aaron, he disagreed that they needed to be in two separate diagrams and also stated that for him, “the physical aspects of caregiving are more stressful than the emotional aspects of ALS.”

Well, I think day to day is more stressful (than the emotional stress of the disease)... Just carrying out the day by day situational, that’s a high level of
stress… I think kind of after you know that you (have the disease), I kind of accepted it and realized that that’s the way it’s going to be. I can’t change it… You have to kind of accept that and then go day by day…

When we examined the pattern diagram during the second interview, Aaron did not hesitate in labeling Ashley’s diagnosis of ALS as “the highest stressor” for him. This was closely followed by Ashley saying she can’t do something (#2) and his wife falling in the living room (#3). When labeling his 4th highest stressor, caregiver mealtime preparation, Aaron noted that I should change caregiving cooking to caregiver mealtime preparation because he stated:

   It doesn’t matter whether it’s lunch or whatever; Getting meals, preparing them. I think that’s really a problem because she always helped and now she can’t really do too much of anything… It’s just the time you spend doing that after you’ve done everything else during the day by mealtime you’re kind of beat. That’s really hard…

Meeting the cleaning standards of Ashley (#5) and assuming all household chores (#6) were closely rated together by Aaron. Ashley starting to have problems walking was ranked #7 because at that time, they “did not know what was going on and were in the midst of trying to find a diagnosis.” This, according to Aaron was not stressful because he “did not believe it could be related to anything serious because Ashley had always been so healthy and had taken such good care of herself.” Being at home more was ranked next to last (#8) because it was “not much” of a lifestyle change for Aaron. He stated he was “always a homebody and liked to work around the house prior to his wife’s diagnosis.” Ranked last (#9) was Ashley starting a clinical trial at the ALS clinic. When
asked about his feelings regarding this clinical trial, Aaron stated, “I think it’s a good idea. So does she. If we can help somebody, if she can help somebody else in the future, fine.”

**Transformations/Insights**

When I asked Aaron whether talking with me had given him any added insights or things to think about that he hadn’t before, he said:

> I see that I may have to let some other people help me with her. If not now, then in the future, but it’s so hard for me to ask others for help. It’s so very hard. I’m a private man and she’s private too and we have always tried to do things on our own but that may not work anymore. Maybe my daughter can help me ask for help. That might be a place to start but even though I can handle her care now, I won’t be able to do that forever. I’ve had help all summer but that is going to end soon. It probably would have been better to talk to you then, after all the help has left me…But yeah, I’m going to have to ask for help…

Aaron is between Centering and Choice Stages of Young’s Stage of Evolution (Newman, 1984). He is new to the ALS caregiving role and Aaron is reluctant to ask others for help, preferring to rely on himself to care for his wife (Centering Stage) but admits he may have to have some other people help him with her care in the future, but he’s not ready to do that at present. Awareness that he needs to take this step, which will be a turning point for this ALS caregiver (Choice Stage), is something he will be facing when his daughter leaves and he must care for Ashley by himself.
**Narrative Summary: ALS Caregiver 7 (Karen)**

ALS caregiver 7 (Karen) is a woman in her early 60’s, who has been providing the primary care for her husband (Mark), who is in his late 60’s since he was diagnosed with ALS in September 2010. Karen works full-time in the restaurant business. Mark has not worked for the past year, following knee and wrist surgery. They have been married for 25 years and this is a second marriage for Karen and a third marriage for Mark. She has three grown children, two daughters and one son. Her two daughters and their children live in close proximity and are very close to her, but Karen’s son has been estranged from her and Mark for the past eight years. Karen is a two-time cancer survivor, having recently survived breast cancer in 2007.

Mark is one of < 5% to 10% (ALS Association, 2010) of all ALS patients with familial ALS; his sister died of ALS 25 years ago. His mother’s side has no known history of ALS, and because Mark’s died when he was three years old, Karen and Mark are uncertain if there has been any previous family members with ALS.

Current symptoms/adaptations for Mark include: (a) frequent falls, (b) inability to go from sitting to standing position (get up and go), (c) slurred speech, (d) difficulty swallowing, (e) drooling, (f) marked weakness and slowness in limbs, (g) mental confusion, (h) increasing tiredness, (i) rigidity in limbs and trunk, (j) visible fasciculations on face and chest, (k) use of a walker while in the home and motorized wheelchair when out of the home, (l) inability to roll side to side, and (m) inability to rise or roll from a lying position. Karen reported Mark’s most current FVC reading was 92%, the highest of any of the ALS patients involved in this research study. Current caregiving duties for Karen include: (a) transportation, (b) meal preparation, (c) aid with bathing and
dressing, (d) preparation of anything he will need prior to leaving for work, and (e) all household chores.

**Thematic representation of emerging pattern of the whole for Karen**

“There’s something wrong” and “unnecessary surgery” (Suspicions emerge but ALS diagnosis is delayed). Karen started to notice that “there was something going on with Mark about six months before he was diagnosed with ALS.” “He was falling a lot” and complaining of symptoms that Karen thought were “carpal tunnel or perhaps stroke” in nature. After seeking the advice of their family doctor, they were referred to a neurologist, who suspected that there was another factor contributing to Mark’s current symptoms, but recommended going ahead with the carpal tunnel surgery. This proved to be unnecessary surgery. When they received the diagnosis of ALS, Karen said, “we were surprised, even though there was a family history of ALS.”

…He (Mark) knew there was something wrong with him, I think for quite a while and he really didn’t share that with me until I saw some things…I’m basically the one that pushed him to go to the family doctor…I thought he may have had a mild stroke…He was complaining about his hands, carpal tunnel like (symptoms). He couldn’t button his buttons and zip his zippers and do things like that. I said, probably carpal tunnel because I had one operation on my hand for it, so he went to our family doctor and he said too, it’s probably carpal tunnel…He (family doctor) sent us to [neurologist name] and he said there’s something else going on here. He (neurologist) said I’m not saying you don’t have carpal tunnel, but there’s something else going on too…We went ahead with the carpal tunnel surgery. He had one hand done and then I’m going to say 2 months later, the
They were getting better at first and then they seemed like they wanted to ball up on him…then the falling started. We went to see our family doctor and he said there’s something else going on here. He sent us to a neurologist…They did all kinds of tests and then they brought us back and did some more tests and MRI’s and he said he felt that it was ALS…He (Mark) had that jumping (fasciculations) across his chest, his muscles more on one side than the other; it definitely wasn’t a stroke…Then he sent us to [ALS neurologist]…reevaluated him and he said that’s what it is (ALS)… it never crossed my mind that another member of the family or anybody would have it…I knew she (Mark’s sister) was sick and I knew she was in a wheelchair…She passed away only a few months after we were together so I didn’t know a whole lot about it…It seemed like after she passed away, no one ever really talked about it so that was it…

“A life within a life” (Strategies aiding the caregiving role). Karen shared she and Mark have had a “very troubled and complicated marriage” for the past 25 years. She stated “there have been years of lying, womanizing, verbal abuse and secrets.” These difficulties have caused Karen to lead what she refers to as a “life within a life.” While speaking about these difficulties, Karen was frequently crying and very emotional.

…He’s always been quite the womanizer. You know, he was always busy with the ladies. [long pause]. I’m sorry (crying)…We fought about that a lot over the years and he was always sorry; he wasn’t going to do it again…We were getting ready to get married in September of 1989…I had the most beautiful cards, the most beautiful notes a man could write…and in the Christmas of 1989 I went down to the mailbox to get the mail…There was this thing from the bank, a note,
that he had signed a bank note for a girl at work and she defaulted on the loan. She didn’t pay the loan and that came to our house. This was 3 months after we were married. And I asked him about it and he totally, totally lied. He said he didn’t do anything. Well, he lied but it was what it was…I found out then… because he was bugging women at work. He would ask girls to go out with him. I mean, everywhere. He said it was going to stop. “I’m not going to do it anymore, so sorry. Don’t kick me out.” Blah, blah… “I’ll straighten up. I know better. I didn’t want to hurt you.” It’s been years of it off and on…It got to be routine that I think now I can say, I have a life within a life. I made a life for myself within…

Karen is a two-time cancer survivor but stated she “did not feel supported by Mark during either event,” supporting her need to lead a “life within a life.”

…I had cervical cancer in 1981. Then in 2007 I had breast cancer. He didn’t care. He didn’t want to hear about it. Didn’t want to know about it. I went for my treatments. I went to work in the morning, went for my treatments at 11:30, came home and slept the afternoon, went to work the next day. The best part of that was I finished up my treatments in May (pause) and in August of that same year I was called down to human resources because he made a remark to a girl in the bakery…His social thing was while he was on the job when he wasn’t supposed to be doing it, being a bad boy…He was making comments, doing his things; things he shouldn’t have been doing. Going to the bank, going to the grocery store, saying things he shouldn’t have said, stuff like that…Then I’d hear about it later, but that’s him. I’ve learned over the years. I can’t be defined by
what he does. I do my own thing...He said to me already, “why don’t you just leave, why don’t you just go?” I’m not leaving my home. This is my home. I’m not leaving. I’m not going anywhere. I’ll do cooking, I’ll clean, I’ll take care of your clothes, I’ll take care of you but I’m not leaving...I really don’t care. That’s him, that’s not me. I’m so used to it, I really don’t care...Even now when I cook for him, he tells me, “This is really good. You could always put a nice meal together” and I’m here thinking, how grateful were you for that?...That man that came to see me (when they were first dating), he disappeared a long time ago. That man came and showed me who he was, who he could have been so when all that started. You (Mark) I don’t know you in that respect...

Karen expressed, “Lies and secrets have also played a part in my marriage. Right from the start of my marriage through present day.”

...In July, he bumpered a car. He didn’t even tell us. I said “what happened to the bumper on the car? Looks like the bumper’s pulled out.” “Nothing-no something hit the bumper. I don’t know what happened to the bumper on the car.” Well here he drove, pulled out from a stop sign and I don’t know how he did it. He said he turned and it seemed like the steering wheel just kept at the turn and hit the guard rail and it tore the bumper. Okay, I can see that happening I guess, but then in August he went over to [nearby town] to pick up a take out order and backed into someone’s car. He never said a word; never said anything and I came home from work and he said the State Police were here today. I said “They were-for what?” He knew I’d find out about that. He only ever tells me things that he knows I’m going to find out...He said, “Somebody got my license number. I
didn’t back into anybody.” I said, “you had to have, how would they get your license number?” He knew it. He knew he hit her. He then admitted...he always says things like, “well maybe I did it. Maybe I did, I don’t remember”...

...Everything’s a secret...You know he only told me; it’ll be 3 years, that he had a child that’s as old as his one son. Apparently, he did this to his first wife. He had her and another girl pregnant at the same time and I didn’t know it...actually our history goes back to like, 40 years ago...I’d see him coming and going but when my husband and I divorced I bumped into him in a store and he said, “well aren’t you gonna say hello to me” and I didn’t recognize him. We started talking and he said he was divorced, which was another lie...I said I am too and then he said “would you like to go to a movie sometime” and I really wasn’t interested...He called and bugged and bugged and bugged, then we got together. He wasn’t divorced...that was the first lie. I said everything was always a lie and a secret. I didn’t even know he had this kid until like, 3 years ago. We’ve been together 25 years. I know of all these secrets...I feel sometimes, he never loved me...

Karen shared that “negativity and verbal abuse have been present throughout her marriage.” She said, “Now that ALS has hit Mark and made him so physically weak, I no longer have to worry about my safety around him, but that wasn’t always the case.”

...He just told me 2 weeks ago that he could get women to come over here (to their home) and do things for him. I said, “well you better get your purse out because it’s gonna cost you some money.” I mean I can give as good as I get. He told me the one day, I used to be a size 8- a size 10; I’ve put on a lot of weight. I lost 13 pounds...but he told me “find yourself somebody up at work that likes a
broad ass cause your ass got broad. Those guys up there like a wide ass. You used to be skinny.” I said, “you used to be a lot of things” and I said, “you know, my broad ass is taking care of you right now”… I told him when he starts looking like Ken; I’ll start looking like Barbie… He told me that if my life, if I think my life is hard, he can make it a lot harder…He’ll be nice some days. He’ll be really, really nice and that’s been my whole life. He’ll be so sorry; he’ll be really nice for a while but then he’ll go…he can be doubly mean…There’s always something wrong every day. It’s like he sits all day and waits for me to come home and I get something. And I try telling him that. I said, “you know it would be nice to just come in the door-Just one day, just for 15 minutes. Just let me get in the door for 15 minutes.” Nope…

When I asked her about whether she fears for her safety around Mark, especially after talking with me, Karen replied:

I don’t now. I did before; a couple months ago when he was still going down to the garage. He has guns all over the place so I have the keys to the gun cabinet now. He told me that financially, he could wreck us. He’ll just go to the bank one day and get whatever. We don’t have that much. I took the bankcard, that’s upstairs. He was gonna go down to the garage and shoot himself and I thought yeah, I’ll go down there and he’ll shoot me instead so I took the keys to the garage…There was one rifle down there and I know there’s a handgun down there somewhere but I haven’t found it yet. I have a dumpster out here; I’ve been cleaning out the garage…The day I took the garage keys he told me he was gonna call the State Police and have me arrested for taking his garage keys. Can you
believe that? I’m bathing you, feeding you, and taking you everywhere you need to go. I said, go ahead…Aren’t I afraid? That doesn’t bother me so much because I see how he is (physically now)…He pretty much can’t do a whole lot of stuff…One night he was really mad at me when I was telling him these things, and he grabbed ahold of his walker and stomped it on the floor and tried to take off real fast and he couldn’t. I’m thinking he can’t even do that. He can’t hurt me. He can’t physically hurt me. I have no fear of that. The only way he can hurt me anymore is with his mouth and what he says…

“My husband is controlling” (Obstacles to the caregiving role). Karen shared, “Mark has always had a controlling manner” in relation to their marriage and “his resistance to many of her caregiving efforts has really impacted my life.” As a caregiver, Karen said she has “met resistance” concerning his activities of daily living (ADL’s) and in situations where Mark’s safety was a concern.

I think that a lot of the things that he says to me…Maybe I just like to believe this, he still wants to be in control…I know what he’s been like and I think this is a last ditch effort. If I can’t be in control bodily, I can still use my mouth. I’ll control her that way. I’ll control the situation… I still want something to say about myself…I’m taking care of him now…He pretty much had control of things all of our married life. Pretty much had control of everything and now I’m in control and it’s not sitting well…He really doesn’t want me doing anything for him because he wants to do it himself…I don’t think he’s ever been appreciative of a whole lot but since the whole diagnosis, I think he doesn’t want to (be appreciative)…If he has to give me credit for doing something, then he doesn’t
like it…The one day I said to him, “Why do you get fully dressed every single day?” …I can see it if we’re gonna go somewhere or he has to go somewhere, but it takes a lot of energy out of him…I said, “Why do you put yourself through that?”… He’s had accidents because till he gets his pants unbuckled, gets the pants down…You know save your energy. Nope, he won’t do it. If I say something, then for 3 days later he’s fully dressed then maybe on the 4th day …but it’s his decision…. It still has to be his decision…He was going up the stairs until about 3 months ago…I was waiting any day for him to go backwards. I told him you know you’re gonna kill yourself. “As long as I can go these stairs I’m going these stairs”…So I said, “Do you want me to put the baby gates across for you because I will” and I did a couple days because I don’t trust him. He can’t even try to go to the stairs now…Let’s face it, my husband is controlling…

Even when Karen is trying to ensure his safety while she is at work, she reported, “Mark resists it.” She stated, “most of this resistance comes from any new idea not being his own along with his desire to have total control over me. Unfortunately these control issues can delay safety measures that I would like to have for him while I’m not at home.”

He’s stubborn about everything…I tried to talk to him about a cell phone (and Medic Alert button). I said “I’m gonna get you a cell phone and you can call me at work if there’s something wrong.” He said, “I don’t want a cell phone. I don’t want no people coming up. That alarm (Medic Alert button) goes off and all kind of people are gonna come here. I don’t want all kind of people coming here”…

Then it got really hard for him to get in and out of the bathtub with just the
(stationary) bath chair… So one Sunday my youngest daughter—she has 3 boys…Big strapping boys and her husband. I got them to get the tub chair (stationary bath chair) out of there. He was so mad at me…He said to my grandson, “Oh, she had to go get that out today. What’s she got you guys doing that for?” Blah, Blah, Blah— but you know what? Now that he’s using it (new larger bath chair that rolls in and out of the shower), he loves it. He loves it; to get himself in and out. But it’s just the resistance that he puts up with things…I can introduce things, I can introduce them slowly but I can’t tell him. He still is a person that you will not tell how it’s going to be…

Karen was emotional during both of the interviews as she spoke about her husband’s “sense of entitlement;” She said “He feels he’s entitled to everything and that makes caregiving so emotional for me.”

I think now…he’s become more dependent and more like he’s entitled now…He knows he’s sick and he really expects it now…Like he says “All you do is take me to the doctor.” “Don’t you see what else I’m doing for you?” I told him the other day, “You know, no one takes me out to eat. No one takes me for a drive. No one hugs me”. I don’t want him to. Actually, right now, I’m to the point where he’s said and done so much to me that I really don’t want to…I got through that (all the womanizing) and then he got sick and I’m taking care of him and I think I’m more sad about it than he is…He’s more angry. I said to him, “Is this how you want to live out the rest of your life?” He’s not getting it. I don’t think he’s getting it…He still has time but, I think some days, oh today’s a good day. Maybe he got it but then he’ll say something like, “your ass is really broad—maybe
there’s some guys up there who like broad asses.” It’s like, Oh my God. I can’t believe you just said that to me. The first time he said it to me, it’s very painful…I think first you’re hurt and then you get angry… I think I feel more bad than he does…I don’t know…But now I know he’s sick. I can’t not take care of him…There must be something wrong with me… Sometimes I feel like… I never was a special as I thought I was to start with…

**His actions have consequences (Obstacles to the caregiving role).** According to Karen, “over the years, her children, grandchildren, and friends have all tried to establish relationships with Mark. Every time, Mark inevitably pushed them away, which he has grown to regret.” She shared, “This has greatly impacted the amount of support from his friends and family now when he needs it the most.”

He was always saying, oh, come, come; but when people come, once someone’s moved in, then it’s not good…A lot of times I get mad. I tell him, “Is this how you wanna live out the rest of your life? Is this how you want the kids to remember you? Is this how you want the grandkids to remember you?”…They’ve given him chance after chance after chance and she (her daughter) said, “You know mom, he (Mark) thought when you had breast cancer you were going before him and then he could really play around with women. You’d be gone.” But they get so mad and angry about the way he treats me…They come over here and they see how he talks to me…When [grandson] lived here…he (grandson) was always in the way (according to husband); there was always somebody in the house, blah, blah, blah. And he (Mark) just told [grandson] last week, “I miss you now that you’re not here. I really miss ya.” I
said, “yeah and when he was here, how were you when he was here?”…I used to
tell him that they’ll be gone one day. You’re always gonna be here. I’m at work
all day and no one is here. They say be careful what you wish for; you just might
get it and now he says nobody’s here…

Now that her grandchildren are young and visiting Karen, she said “Mark likes seeing
them run around the yard and play and enjoys this because he is all by himself during the
day while I’m working but the grandkids come to see me, not him because of how he has
pushed them all away in the past.”

…The kids (their grandchildren) are young. I get to see them run around and
whatever and he even likes that. You know, I think now that he doesn’t have it
and he can’t get out, he’s starting to appreciate the activity because there isn’t any
here (at their home) all day. There’s no activity so when somebody does come,
he’s starting now to realize that how important it is and he can’t go himself so it
does have to come to him. I think he’s starting to realize that sooner or later, he’s
going to get it now. He has really pushed a lot of people away and you know
what you get; now you get. You have to be grateful for (what you have)…

Karen also shared, “His treatment of me over the years has carried over to our sex life as
well.” Karen was the only caregiver who spoke so openly about how Mark’s treatment of
her and his disease have impacted their sex life together.

The other night the boys said, “Grandma, I think he’s trying to pull you down on
the floor on top of him cuz he fell he wanted you to fall!” As far as the sex goes,
the other night I washed his back for him. It’s got the spray thing on it and I love
it myself… and I said “You’re going to really like it when you get your shower
tonight” so I scrubbed his back with it and he said, “Oh that is really nice” and he said to me “if you get in here with me, I’ll wash your back for you.” Then he started talking more about it…About a week or so ago he goes, and maybe this sounds vulgar but I’m going to say it to you because I like you, “So what am I doing, just getting a hard-on around here for nothing?” I said, “Those days are over buddy. Don’t even think about it.” I said, “There were times when I wanted you; you were always looking somewhere else. I’m not going there. Those days are gone.” For him to say it to me now and all this other stuff; he’s a pig!...It ain’t gonna happen!!! But I find more now he’s talking more about that and he didn’t ever…year and years and years…Well when he stands up with his legs like this and his diapy that’s sagging…He looks like a new year baby and old man winter at the same time! You know what I’m saying? I laugh. I get mad at the fact that when we had the chance to do these things, where the hell were ya?...I said “What do you want to get one good one in before you kick off?”…He said, “I guess you have no interest.” I said, “No, I don’t.” I’m not going to lie…I still have a little dignity…

“Watching my husband deteriorate” (Adaptations from ALS). Karen has watched her “once strong, highly independent husband” have his physical abilities deteriorate to the point where she stated, “I have to take care of him as well as all the household stuff.” This is in addition to working full-time in the restaurant retail business. This man, at one time, he could pick up this house and carry it across the street. Very, very strong- He’s small. He was small but very strong…When he’d have a fit of temper it was nothing for him to go out and kick a fender or do whatever.
He was really, really tough... He never wanted to act sick. He was never a pill taker. We tried to stay normal (after his diagnosis of ALS) but he did a total 360-degree turn; so dependent (currently). “Did you get my pills? I have to have this pill. Did I take my pills?” All the time, the pills, but before... I was the one that would get the migraines and be sick and “you’ll never get me to take a pill. I’m not taking a pill!” If he had a cold and he had Benadryl or something, he would never take it. Never! Always tough, always “nothing’s gonna happen to me!”... I think he’s more frightened and scared than he wants to let on... I think about it sometimes and I think maybe that’s why... I think anger really is a form of fear... He really can’t do anything. I’m carrying in all the groceries by myself. I’m carrying all the heavy stuff by myself... I have everything. I’m cutting the grass now; assuming all household duties... I’ve been cleaning out the garage. I have the dumpster down there now... He sleeps on the sofa and every night I make that bed... I make sure all his bottles; he drinks that Ensure now for his muscles... His vitamins are ready for him every day; any kinds of juices that he wants. I get all kinds of things and open up the individual bottles for him. I never get more than a half a gallon of milk at a time because he can’t lift a gallon of milk... I get his bowl and his spoon and cereal out of the cupboard so he doesn’t have to reach for that. Any snack that he wants during the day... He comes out with his walker, with his basket, puts it in the mic, mics himself his lunch or if it’s a sandwich, it’s up in there, whatever, and then I come home and take care of dinner. That’s how I work it now... In the beginning, I didn’t have to get his cereal out for him,
because he could do that, but now he says, “I can’t reach the cereal. I’m having a hard time with the bowls because the bowls are in the cupboard”, so I get that…

“I like to be told that someone else sees what I do” (Support that helps the caregiver). Karen reported, “I get support from a few close friends, my family doctor, my girls and the ALS team.” Having others praise her caregiving efforts is “greatly appreciated and important” to Karen because she said, “I don’t feel appreciated for any of my caregiving efforts by Mark.”

I have some close friends. The one girl that I lived nearby in [town] we don’t have to see each other for a year of 6 months, and we can pick up right where we left off, you know…but I found that with all that I have to do, I don’t really need those in depth visits as much as I just need to know that I have the connection. If I want to, I can pick up the phone anytime and vent and talk. I don’t need to sit every week with somebody just as long as I know that it’s out there…

…My family doctor really helps me a lot…He doesn’t just spend 10 minutes with me or whatever. When I’m up there, I’m up there a good 45 minutes to an hour with him and he’s the one that said he (Mark) had control over everything, basically in our married life. You couldn’t do much about the women or anything else. That was always in his ballpark and he controlled everything but his impulsiveness and now he’s gotta look back and that and some of the things he’s done. He’s lucky you give him a bit of food everyday…

…My kids tell me, and even at the med center (ALS clinic), they told me you’re doing a good job. He’s holding up, he’s healthy, he eats, he gets his vitamins, he gets his visits. So to me that makes me feel good because if they tell me I’m
doing a good job, I like that. I like to be told that someone sees what I do, even if he doesn’t…

Support can be “missing” (Support can make caregiving more difficult). Karen stated, “I have strong support systems in place, but having support from the girls I work with everyday is something that is missing”. She said, “Mark is never mentioned in my workplace because of his past history there.”

…The girls I work with, sometimes they’re a pain in the royal whatever, but, I help them a lot, they like me, my bosses tell me I do a good job, so that’s a support system there. The only thing is that I’m an older woman with a pain in the ass husband and many of the girls there don’t know what to say to me about him. They know about him. He had a reputation here and it wasn’t good so they don’t talk to me ever about him. That’s okay, but it’s like the elephant in the room and I wish I could talk to someone there about it, just sometimes. I have my kids but it’s hard. I keep things close into me but it would be nice to have a little support there too. Not much. Just a hug or how are you doing, but we never talk about him. We never mention him. I don’t know, I’m getting older, getting out of bed in the morning is hard when I have all this to think about…

Her “joy” is her home and family activities (Caregiver respite). For Karen, down time, or respite, involves “simple activities” around her home. “Pride in her home and working outside”, as well as “spending quiet time reading” provides her with “down time” to help her “recharge” for her caregiving role.

I like my work around here (her home). I like the house…I like what I have to do…It’s my joy. My employment is from Wednesday thru Sunday. Monday and
Tuesdays are my days off…Monday morning; my major requirement is I get to be in my pajamas until 9:00. I mean it!...I feel like that’s a treat for me…That’s my time…I’m a reader. I love to read. I just read “Lady Chatterley’s Lover”, after all these years. I’ve wanted to read that book forever…I like the yard work. It’s been really, really hot but I think our yard looks good for one person…I keep the flowerbeds, I think looking good. Mulched and whatever so that makes me feel good. I have pride. I have pride in my home…It’s like the chickens. I got those chickens to take care of. That’s not work for me. Cleaning up isn’t work for me…I like the kids coming over. To me that’s even an escape because it’s different. You know the kids are young. I get to see them run around…I like my job…I really feel needed up there because they like me…I help them a lot. They like me. My bosses tell me I do a good job…

“Believe in my own abilities” (Strategies aiding the caregiving role).

Although Karen rejects the idea of going to support groups saying, “if I think about going to a support group and everybody talks about it and talks about it, because we talked about it when this was going on with me (cancer) and I found the less we talk about it, the better I can push forward because the more I’m reminded of it, the more that I talk about it, that brings on the sadness…” she has “other ideas about what helps me deal with Mark’s ALS and the consequences of his disease.”

I know what I have control over and what I don’t too…I try to put myself in other people’s shoes…I’m a 2 time cancer survivor. When you life’s just running along, you’re just skating along and doing what you gotta do and you hear other people have cancer and other people have things happening to them. You don’t
really pay attention to it because it’s not happening to you…When I was going through it (cancer), I was fixed on getting my treatments…I’m going to the doctor, I’m going to get my meds, then I’m going to be okay. I had it in my head that I’m going to be okay both times and both times so far I was. So what I do is I fix in my head that I can do this, this and this and that’s how I get through the day; the stuff that happened. Once in a while I’ll think of it and I’ll get very sad about it. And him (husband) and all of this…The more I keep fixed on what I hafta do, the less I have time to think about all of that sadness and all of that junk and I’m okay…I just believe in my own abilities; that gets me through all this…

Karen shared, “Spirituality plays a big part of my life. There is a purpose for everything that has happened to me so far in my life, including meeting you (nurse researcher) and being interviewed for your study.”

I believe in God and I think I’ve come to believe in all that’s happened already to me that there’s a reason you are where you are and why you’re there. There’s a reason you’re (nurse researcher) coming here today to talk to me and there’s a reason I’m talking to you. There’s a reason I had a daughter single at 16 years old. There’s a reason that my dad was mean and ugly and I had to see that. My mother always said I was an old lady in a kid’s body. There’s a reason I have a husband who has ALS and now maybe I’ll see somebody someday else who’s gonna deal with that. When I’m at work and I hear people talk about, oh my husband has a back operation. He’s driving me crazy, I’m there. I know what that’s like…
Karen said she has also “drawn strength” from the realization that she is “not the only one who is caring for an ALS patient who will eventually die.” She stated, I believe in my own abilities to survive and face whatever comes.”

In the beginning it was really hard. I thought, Oh my God, he’s really gonna die. He’s dying. I could go driving down the highway and get killed too but that’s no because anybody knows that I’m going to be dying. I know he’s gonna die…But I think if he dies, you’re here by yourself. But then, I read a lot and I think there’s people that there’s other people like me…I’m not the only person that’s ever lost a husband. I’m not the only person that’s ever lived alone. I’ve thought about how will I deal with it and then I go to that place…Why do I have to go there yet because I’m not there and don’t you have enough on your plate now? So I go back to God saying, you have enough to deal with today; lets get through the day. Tomorrow takes care of itself. So, it’s sufficient for today. Just to get through the day. You know, if I go off to those places, of course I go there. I go there and I think what am I gonna do? Am I gonna live here in this big house by myself? How can I support myself? What am I gonna do? And then I think, well, you can figure that out just like I’m figuring this out…I’m pretty resilient, I think…

“Nobody knows what goes on in the mind of a caregiver” (Focus of others). Karen stated that when Mark was initially diagnosed with ALS, “people would ask about me and how I was doing, but that has changed over time to where now their attention is entirely on Mark.” She shared, “even the literature that is given out in the ALS clinic focuses more on the patients than the caregivers and the information that is for the
caregivers really does not paint an accurate picture of what a caregiver’s life is really like.”

They (friends/family) know what’s going on but I notice that it’s…if it doesn’t affect you, you really don’t know…nobody really realizes what you go home to…I don’t know if they’re thinking it’s gonna make me sad or that I don’t want to talk about it, because initially everybody when they first found out came to me and asked if there’s anything they can do…and there isn’t really anything anybody can do. When I’m there, they’ll say, well what are you doing, what are you doing on vacation and I’ll say “I’m spending it at the VA this week” and then they’ll laugh…Now that I’m into this almost a year, no one ever says, “how are you doing?” They’ll say how’s [Mark] doing? Tell him I asked about him. How is he?... No one ever says “and how are you doing? How are you holding up?” Sometimes it makes me feel like you have no idea what I’m doing. You have no idea...You just don’t know what this is all about. You just don’t. I wish I could write a book. You just wish you could let people know...Does anybody ever look at the person that’s giving the care and how much they’re abused?... I think there should be separate literature for caregivers that states, you may feel this way, you may feel that way...Just paint a real picture...Like in one of those newsletters and stuff- Oh she came home from work today and the bowl was on the table and the pills were on the table and she was afraid to go in the living room because she didn’t know what she’d find. No that stuff’s not in there...I’m tired of seeing some of this stuff and it’s all about the person that has the disease but there’s not so much about the people that are around that are watching it...You know on top
of taking care of a person, you have other areas you have to deal with so nobody really knows what’s in the mind of a caregiver. You can’t just take care of that person. You got other people to take care of too…Nobody knows what goes on in the mind of a caregiver…

“I’m just worried about today” (Looking toward the future). When I asked Karen if she looks ahead to see what could be coming down the road for Mark or if she likes to deal with the here and now, this was her response:

I do both. I like to know what’s here and what can happen and then I also know that if he passes away next year, I’m going to be alone. I gotta figure out what I’m going to do. I can’t just only think about him because I hafta think about me because I know if I’m going to stay here or am I going to find another place to live? Some of these things that you think about, you know, am I gonna be able to do my job, how much money am I going to have coming in? Am I going to be alright? All of those things I think about and I try to do some kind of solutions in my head, thinking, well maybe I’ll do this, maybe I’ll do that but this disease has taught me, you really don’t know. You can plan and think you’re going to do this or that and you’re really not so I don’t put so much into, but I throw it around. I’m not afraid to do that. It’s scarier not doing it…I’ve read every piece of whatever they’ve (ALS team) given me. I’ve read it over and over and over. It helps me understand like the things he can and can’t do…All the material they’ve given me; I read well what can happen ahead? I try not to think about it until I have to deal with it. I mean, I’ve read it, I know it, but I don’t every day wake up and go, what am I gonna do when he can’t get out of bed? What am I gonna down
when…because if I do that, I can’t deal with today. I’m just worried about today…

Figure 4.11. Chronological Pattern Diagram: ALS caregiver 7 (Karen)

**Chronological pattern diagram narrative: Karen**

When I was reviewing the pattern diagram with Karen, she decided that there were three events that were equally the number one stressor for her: (a) when she was diagnosed with breast cancer in 2007 and Mark “didn’t care”, (b) Mark’s “verbal meanness” to her, and (c) Mark’s attitude of “entitlement.” She stated:

I think having the breast cancer and no one caring about it is…that’s a lonely…that’s a scary time and a lonely time when I felt that he didn’t care…It
seems like he’s always been real, ya know entitled, but you can deal…but since
he’s been sick it seems like he has more…like an angry entitlement. Like he
things you gotta do this, do that. I want this and I want it this way and I want it
now…It’s hard for me to deal with the meanness…Hard to deal with the
meanness sometimes when I’m trying to do for him and help him and I remember
a time when he didn’t care at all about me or helping me and so I don’t know how
to do that…that’s pretty painful…I think anger really is a form of fear and I think
sometimes he’s more afraid than he ever wanted to admit…When someone talks
mean to you or they order you around and act like they’re entitled because they’re
sick, you feel like you’re not worth anything…

Closely related to her number one choices, Karen found two events to rank number two
on her pattern diagram. These were (a) having to assume all household duties, and (b)
Mark being diagnosed with ALS. She said:

I have to do everything…the fact that he can’t do anything. I’m carrying in all the
groceries by myself. I’m carrying all the heavy stuff by myself. Just that I have
everything. I’m cutting the grass now…He never really did much in the house
but outside he did cut the grass. If I went grocery shopping he carried all of that
stuff in. When the plumber comes, I have to be out with the plumber. I had to
show him everything the way I wanted it done…I have to remember to do things
now that weren’t really on my job list…You’re taking time away from yourself;
from everything that you did normally. You’re trying to do everything to keep
things like they were…You gotta fit it in with the stuff you did before. You gotta
fit it in with the stuff you always did before…moving it into those spaces…
Karen made a point about Mark’s ALS diagnosis and how the ranking of that changed from when he was diagnosed and when it would rank now due to her “learning curve about the disease.”

I think the diagnosis…I think that has levels of stress because in the beginning, if you don’t know anything about it…because I knew nothing really about ALS…I knew there was something wrong. I thought it was a stroke…in the beginning I thought it [ALS diagnosis] was better than a stroke because I thought he had a stroke…As we got to the doctor’s more and more and then I started to read about this and I knew where we were headed. That’s when it became stressful because it was the hows. How am I gonna this? How am I gonna do that? What’s the next step? Where are we going? Who do I go to? What do I do? That’s where all the questions came when I started to know more about the disease….I needed to know, but that’s when all of the how tos, the where fors…I didn’t even have time to go to the why because I’m so worried about what I’m gonna do…Once you know about it, that’s when your stress level starts because that’s when you have to figure out what you’re gonna do…

Next, Karen ranked Mark not being appreciate of her efforts and stated, “You feel like what you’re doing, no one sees that you’re really trying your very best to keep things and they don’t care…” This was followed by seeing Mark slow down and falling more.

Next, she ranked Mark’s affairs starting stating:

Honesty, that’s near the bottom because that’s basically been my (life)…I’ve dealt with this…I told him one time that the man that came to see me (when they first started to date), he disappeared a long time ago… I thought he’d be sorry.
“I’m sorry, I’m not going to do anything like that again. I know how much I hurt you, blah, blah, blah”…I made a life within a life…

The bottom two events were her husband having carpal tunnel symptoms and lastly Mark not being mentally as clear. Karen stated, Mark not being mentally as clear “doesn’t bother me so much because I can say the same things over and over…mental changes, I’ve dealt with them since I knew him…” and the carpal tunnel thing, “that is not so much [stress]” for her.

**Transformations/Insights**

When I asked Karen whether talking with me had given her any added insights or things to think about that she hadn’t before, she immediately said “I’m so glad that you’re doing this.” Having someone stop and listen to her story was “very validating” of her efforts and “something that no one has ever taken the time to do to this point” in her caregiving experience. Karen was very eager to share her experiences because she said, she “was not alone in all this” yet no one had written about the “everyday experiences of caregiving” that she had seen.

I’ll tell you what you want to know…there’s gonna be a whole lot of people with this (ALS caregiving)…Material is really important. That does help…Just the fact that you’re doing this means somebody gives a rip about the people on the other end of it that don’t have it easy…somebody’s gonna do something that would paint the real picture…I’ve learned a lot about the disease. I’ve read a lot about the disease…but the real picture hasn’t been painted. I’m learning that every day. I’m doing the real picture every day. I haven’t seen anything on paper about some of this stuff…how people really live. How people are inside their
houses...So nobody knows what the ride home is like sometimes...from the hospital, from the car...When we got home and got in the door and he peed his pants or he fell on the floor...Putting the bath chair together. I mean these sound like little things but they’re big things... So the fact that somebody’s gonna paint a real picture would be just wonderful...we all have different real pictures. No one’s picture’s the same as mine...So stuff like that gives me comfort...I feel sometimes caregivers aren’t recognized for a lot of the stuff that they do...The most painful part is that when you feel like you’re doing it and it really doesn’t matter to someone...

Karen is at the Unbinding Stage of Young’s Stage of Evolution (Newman, 1984). She has made a “life within a life” and has been freed from the boundaries of her abusive marriage (Unbinding Stage). She still provides care to her husband, but lives her own life in the moment at the same time she lives her other life of caregiving for Mark. She has extended beyond the boundaries of her marriage (De-Centering Stage) and sees herself living a life free of abuse while still being present to provide care to her husband. She is free from fear of physical abuse and throws off his verbal abuse to live her own life where she enjoys taking care of her home. Being able to live a life released from the bounds of just being her husband’s caregiver has provided her with an expansion to higher levels of consciousness.
**Narrative Summary: ALS Caregiver 8 (Barbara)**

ALS caregiver 8 (Barbara) is a woman in her early seventies who has been providing care to her similarly aged husband (Bob) not since his ALS diagnosis in 2008, but since Bob received a heart transplant in December, 2007. According to Barbara, at the time of these interviews, Bob was only the second patient at the ALS clinic who was a heart transplant recipient in addition to having ALS. Bob is part of the < 2% of all heart transplant recipients who after the transplant needed a pacemaker as well (American Heart Association, 2012). Bob is a veteran having served two tours in Vietnam and a career in military intelligence. Barbara is retired from a career in retail management.

Barbara and her husband have been together for 52 years and married for 49 of these years. They have four grown children, three girls and one boy. Two of their daughters are RN’s and live close by to their parents. One of these two daughters was recently diagnosed with multiple sclerosis, which the ALS neurologist has stated is not related to her father’s diagnosis of ALS.

Bob has limb presentation of ALS and no bulbar involvement at the time of these interviews. He has no cognitive impairment and can still bear a small amount of weight. He is on over 20 heart medications, including anti-rejection medications, and takes Rilutek for ALS. He has an implanted pacemaker/defibrillator and Barbara reported his most current FVC value was 55%. Bob’s current symptoms/adaptations include: (a) no use of his arms and hands except for one finger on right hand, (b) decreasing strength in legs, (c) C-Pap at night, (d) voice activated phone and computer, and (e) use of transport wheelchair. He is eligible for three 100% disability ratings from the VA.
Barbara’s current caregiving duties include: (a) bathing, (b) feeding, (c) dressing, (d) washing hair, (e) range of motion exercises, (f) preparing and administrating medications, (g) toileting, and (h) lifting Bob out of their bed and his reclining chair.

Thematic representation of emerging pattern of the whole for Barbara

“The heart is a priority” (Suspicions emerge but ALS diagnosis is delayed).

Due to Bob’s heart attack and subsequent heart transplant, Barbara said, “We had to wait for over a year after he first started showing symptoms before his ALS diagnosis was made.” Even though they “sensed that something was wrong with his arm,” that condition was secondary to Bob’s heart issues and his care was prioritized to deal with the heart surgeries and subsequent cardiac rehabilitation. She shared, “Only when the heart condition stabilized were Bob’s arm issues addressed and he found out he had ALS.”

We knew something was wrong…We knew there was something going on…He started having a lot of trouble with his left arm. He could not raise it so when we got up to [medical center], we told them about it and they said if the heart doesn’t work, it doesn’t matter. The arm does not matter. Let’s get the heart straight…They said, “the heart is a priority.” When he had his heart problems, his ejection fraction would go down to 10…So then in 2007 he started going up for regular visits. Going to the hospital for so many days and then wait 2 weeks and then go back in because then he would be #1 on most of the heart list in the hospital. In December he received his new heart and it was amazing…The arm continued. He couldn’t lift it. I’d have to help him get his shirt on and off; his non-writing hand. He could write but he could not lift it. I would have to lift it
for him and he went through cardiac rehab and all that and we did the whole thing about cardiac…and something happened around 2007. He started having more and more trouble with his arm so we ended up going to a neurologist and the neurologist said that he saw little ripples on his back, like I guess ALS. He said, “I think you have ALS”. This was 2008…

“A strong, loving partnership” (Support that helps the caregiver). When I asked Barbara what helps her most as a caregiver, she said, “Bob does. We have always had a strong, loving partnership together. Our partnership started when we were first married and it is as strong a partnership now as it was then.”

We’ve had a good life and we were blessed. We’ve been broke…He has always said, we weren’t broke. He said, “I will dig ditches…I will dig ditches if I have to because there’s nothing wrong with digging ditches…I will provide for my family.” We didn’t have a lot at that time because he went in a lower rank than he should have but…he worked his way right up. He’s been a good provider, a fantastic father…

When Bob had a massive heart attack in 1998, Barbara said, “I stayed by his side and refused to leave him.” She shared, “Our partnership extends to medical care and advocating for each other when we need to.”

He had a massive heart attack in 1998. He had the widow-maker. They did not think he was going to live and it went on and on. I don’t know how long he was in the hospital but I stayed with him. He said when he was having his heart attack “Don’t ever leave me.” Well I had to fight with them to let me stay…They said you can stay in the waiting room and I said “No, he wants me here.”…They said,
“We can’t let you stay.” I said, “Listen, I’m not trying to critique what you’re doing. I just thank you for what you’re doing. He asked me never to leave him. I’ll sit outside the doors but don’t ask me to leave because I’m not going.”…I spent every night with him because he asked me, “do not leave me” and I took that literally and he meant it…The only place I left him was at [medical center] when he was in CCU but then I just felt like if he can’t ask for it, I’d have to… I will stand up for him as much as I possibly can which is the way we work, you know…He does the same for me… Barbara said, “His physical limitations have not made a big impact on our social lives. We have similar interest and spending time together at home has always been one of our favorite things to do despite his physical condition.”

[Bob] and I don’t go out socially…He was never one to go out as much…He is more of a homebody and we both have always been. We’ve never had huge parties, like on New Years Eve we never went out; we stayed home together. We’ve been very close…I’m always thinking about him…I’ll stretch out on the sofa and he’ll be listening to his books and I’ll be watching Judge Judy or something…We’ve always been that way, even when we were younger, I would think of him and he would think of me… Throughout all the interviews, Barbara spoke of the “deep admiration and love” she has towards Bob, which has made their “partnership strong” throughout their marriage.

…He has an amazing, amazing sense of humor...He’s pretty sharp. He keeps me going. He’s kept me going all these years…I haven’t heard him really negative…He’s a very strong person. Nothing fazed him. He tells the most
wonderful stories about things that he’s done and I want to tape him because it would make a wonderful book…He gives me so much hope and he gives me a lot of confidence and he always has…I just feel like he’s got a lot of strength that’s keeping me going…His attitude keeps me going through all the stress…He’s my baby and I’m his baby. He’s teaching me and I’m teaching him…

Since his ALS diagnosis, the partnership between Barbara and Bob has extended to efforts “educating medical students about ALS and end-of-life care planning.” This activity is something both of them “enjoy and plan to continue in the future.”

We go up to the “Neurology Island.” Twice we’ve done this. We go up to [Medical center] and we meet with the second year students. We meet with them about every 20-25 minutes and the students come to us. It is so much fun. They feed us…They have so many stations that the students go to and we might have about 10-15 students…We talk to the students. They ask him about different things…They know he has ALS…[Bob] talks to them about the end of life, you know, preparing, getting your papers ready, getting just everything done. End-of-life things that you need to do and we talk to the students for about 30 minutes and the last time he said they could throw money because they were getting educated! ...The students were wonderful and we’re going to do it again this November…

“**I’m a winner either way**” (Strategies aiding the caregiving role). Barbara said “spirituality and faith are a constant” in their world. She shared, “Our faith sustained us throughout his heart problems and we still rely heavily on it to see us through his experiences with ALS.” Relying on faith has made them “thankful for every day” that
they have been given together. Even when Bob did not receive the first heart they thought he was getting, Barbara said they “immediately started praying for the person who got the heart” and when Bob did receive his new heart Barbara said:

   We pray for the young man whose heart he received. We don’t know who he was and I pray for the young man’s family every night that somebody was kind enough to leave us a heart because had he not had the heart, he couldn’t have fought the 2 of them (ALS and heart disease)…We’ve been so blessed because he’s still with us…We were so thankful that he was alive that when we went to stress management, which [local] hospital offers, we went there not knowing we had any stress! …We were just thankful he was here…A lot of things we didn’t realize because we were so thankful for what the Lord has given him. This opportunity to continue with the world…The Lord has him here for a reason…He has a song that’s called, “I’m a Winner Either Way.” It says, “If I go, or if I stay, I’ll be healed either way. I’ll be healed in Heaven. I’ll live forever in Heaven or I’ll be healed here on earth, whichever way.” It’s an amazing song. It gets me through this. In fact, we’ve given it to a lot of people over in [medical center]…The words are beautiful. I’m a winner either way…He loves the Lord…He says “when the Lord calls, I’m going to come,” but I said “he also gives you a mind to say okay”…He’ll tell you there’s a reason the Lord didn’t need him then (at the time of the heart transplant)…

When speaking about the future, Barbara stated she and Bob “do not fear death”…”The good Lord’s taking care of everything”…Both she and her husband refer to his ALS
diagnosis as “a journey that we are both going on, but throughout this journey, our faith sustains us.”

We have a good life and we know that he’s on a journey and the journey will lead where it needs to go…It’s a new journey and that’s how he put it when he found out he had ALS…He’s on a new and exciting journey…

Barbara shared “Our faith has also led us to perform a ministry at a local nursing home.” Both “believe strongly in this ministry as a way of spreading the word” about their faith. Barbara also stated “Having the people there see Bob progress through his physical decline has been a positive experience for everyone involved in this ministry.”

We go to the nursing home once a month…he talks to the people about the Lord and we sing songs and he’s on their level, which is nice for them. It’s eye to eye. They saw him from standing up to going into the different chairs (wheelchairs), now to the big chair, not being able to do it (operate it) himself, but they’ve got a wonderful attitude and so does he…And I get to know all the people because I go. We go pick them up (in their rooms). We bring them back in their wheelchairs then we take them back to their rooms… We both love that. It’s a joyful thing for him and for me…They get to pick the songs that they want and we go around if they can’t open the books, we go and help them open their books…

**ALS has made them “adapt” (Adaptations from ALS).** As Bob has progressed through his ALS disease, Barbara said they have had to “adapt and find new ways to do things they enjoy.” Whether it is when they have their church group over where singing and clapping takes place, and Bob says, “I can’t clap with my hands but I can clap with my feet” or rearranging activities to do them in the morning because “he’s better in the
mornings…If he’s going to do things, he’s better off to do them in the morning,” Barbara and Bob have discovered new adaptations that meet his physical abilities at the time. As his physical condition has deteriorated to the point that he can no longer use his hands, Bob frequently uses the term “football minute” referring to when he asks Barbara to do something and she says, “I’ll be there in a minute.” Bob says her minutes are like “football minutes” which take a lot longer than a minute, like football minutes on TV are not “true minutes.” One upcoming event, their oldest daughters wedding, was of particular concern to Bob because “he knew he didn’t have the physical ability to walk his daughter down the aisle.”

We’ve had to adapt and we will continue to adapt to life as it is now…He’s concerned about the wedding because he’s not too sure how he’s going to be able to go down the aisle…I don’t drive that wheelchair too well so we’ve decided that my son will walk her down the aisle and [Bob] will be sitting at the end…He’s worried where he’s going to sit when he gets down the aisle and then if we’ll be able to go to the reception and he just doesn’t want things to go bad… Then he doesn’t think he’s going to be able to go to the reception and we’ve got a lot of people coming up. [Daughter] has gotten us a room. Somebody said you could let people go up and sit with him (in the room) if you want to be there, which I guess I could but I have to see he’s comfortable with that. What he’s comfortable with, I’m comfortable with…When he starts getting concerned, I do too…

With his military background, Bob has “always loved to skeet shoot and giving that up when his arms grew weak was very hard until he discovered a way to enjoy it despite his
physical limitations.” Barbara said he has “transferred his love of shooting to watching
me shoot a gun,” which she stated is a “new experience” for her.

He loves to shoot…Target shoot. He’s never killed anything but he does love to
transfer his love of shooting to watching
me shoot a gun,” which she stated is a “new experience” for her.

Target shoot…A gentleman’s wife used to love to go out in the woods and he’s the
one that developed this-being able to go out with the tractor or truck and they do
have this shooting device that he could do it. He could pivot and everything with
his mouth…He keeps buying the guns. He made me go down and get a carry
permit. Here I am fat and 70 and I’m walking into the place and looked at this
man, not too much younger than me and I said, “I’m here for a carry permit” and
he said, “What?”…He started laughing…I said, “Yes, that’s the way I feel.”…He
(Bob) said, “If you’re in the car and you’re by yourself, and even though the
gun’s in the back, you need to have a carry permit.” I don’t like guns…He’s
buying these guns for me now. He bought me a shotgun…He just loves guns. He
really does and I hate them…He took me out to learn how to shoot…So I got
there and it was 98 degrees. They’re all standing behind me looking at me and
I’m out here with [friend] and he’s showing me how to shoot…I shot it and I’m
starting to get dizzy…My husband was so proud that I was going to learn to shoot
from the hip and learn how to load without looking. I got so faint that I said,
“I’ve got to sit down and I went out (fainted). That’s how much I hate guns…”

Barbara said, “Traveling as Bob’s physical limitations have deteriorated has caused us to
adapt so that we can still go to places Bob wants to go to.” Finding out that Barbara’s
great granddaughter worked with General Custer and wrote a diary, which is still in
existence, is something “Bob would love to see.” She said “Because he physically
cannot make the long trip involved, our daughter and her family have decided to go for him”- an adaptation Barbara shared that has “really made Bob happy.”

There are places he would love to go and we just can’t. He would love to go out to the Black Hills because my great grandfather was a reporter with Custer, out in the Black Hills…We had always been told my great grandfather’s diary had been burned. My grandmother even thought his diary had been burned…[Bob] was online and found out that it’s (diary) not and that somebody bought it. There’s a museum out there (Black Hills) and [Bob] has grown very close to the man in the museum and he has sent [Bob] all of this information and [Bob] always thought he would get out there to visit him but he won’t so my daughter and her husband and 2 children are going to take a 3 week trip and they’ll go out there and he will take them to the Black Hills, which will be nice…

“Drawbacks” of support (Support can make caregiving more difficult). Even though Barbara said they have “great support” from their children and grandchildren, Barbara does “miss the alone time” she and Bob used to share together. She shared, “Having our children constantly around is wonderful, but it has it’s drawbacks too.”

We just have not be able to go (to ALS support group) because the children come up so much and you know it’s sort of hard to say don’t come. I have 7 grandchildren and one great grandchild…On the weekends the kids all come up. I mean, we have children all the time. It’s nice sometimes not to. I mean, as much as I love them, it’s nice sometimes to have a quiet weekend. I miss those times with just the two of us…
Barbara’s daughter and her husband and child are planning to move in with Barbara and Bob. Her daughter and family plan on selling their home and moving into the second level of Barbara’s colonial two-story home, while Barbara and Bob move into a new wheelchair accessible bedroom and bathroom on the first floor of their home. Even though the rationale for moving into the house is to help Barbara care for her husband, she said, “having all of our lives disrupted and losing even more of our privacy as a couple is a worry.”

She (daughter) and her husband; they’re fantastic. The only thing I’m really worried about is the change for them because I don’t think she realizes that there will be a change as far as people coming in and out of the house. He (Bob) can’t take so much of that. He can have company and everything but I’m not too sure…They’ll have the whole upstairs except for one room…

Although Barbara and Bob are “very grateful for all that the VA has done for them” with medications, home modifications, and insurance issues, they have experienced “significant delays” in their home renovation of adding the wheelchair accessible bedroom and bathroom that needs to be completed before their daughter and her family can move in with them.

They’re going to put this bedroom and the bathroom which will be handicapped and then we’re going to have a door; a handicapped door big enough for the wheelchair to get out of and we’ll have a ramp that goes that way and comes back this way and we’ve been waiting for that since last May…We didn’t know it would take till February to get through the plans…We don’t know (when the renovations will be done). Now with the government; we have not heard one
word. The last word we heard is that the VA had approved everything. It would have to go to there-the higher ups with them (VA). They (VA) told us, we would not like them by the time we were done. It was 7 months for the architect because he’s a perfectionist. And that was 7 months ago so it’s been 14 months as of August that we’ve been trying to get this room and bless the contractor’s heart. He’s sticking with us and I don’t know why, but he is…

**What helps her be a “better caregiver” (Support that helps the caregiver).**

To Barbara, caregiving is simply “making sure he gets what he needs.” Since she has been caregiving for Bob since his heart problems started, Barbara states “I have had it easier than many caregivers just because I have been doing it for such a long period of time.” She said this long history of caring for Bob has really helped her be a “better caregiver” than if she were just starting out as his caregiver (i.e. after he was diagnosed with ALS).

He’s been so sick for so long…Because I’ve been doing it now since 1998; not all of this; I’ve gradually gotten into the different things, which is not too bad…So many people haven’t had it going on since 1998…I’m sure it’s harder on a lot of people but he went over the edge and he has been there before he found out he has ALS. He went through an awful lot with that (heart transplant).

Barbara is one of up to 90% of ALS caregivers who at one point in the disease trajectory will be on anti-depressive or anti-anxiety medication (ALS Association, 2010). Barbara calls them her “happy pills” and states “they help me be a better caregiver.” She also expressed she’s “met so many good people” both health care providers and other patients and caregivers that she otherwise would not have met had her husband not been
diagnosed with ALS. These people are “a blessing” in her life and help her be “the caregiver she is today”.

The VA (Veterans Administration) has been a wonderful resource for Barbara and Bob providing them with his pain, antirejection heart and ALS medications, various adaptive equipment, and now home modifications. Their home addition “will allow Bob to live entirely on one level of the home,” which she said “is becoming increasingly important as his arm and leg weakness gets worse.”

The VA have paid quite a bit on the van we have…We have a slide going up the steps so I can get him up the steps. They’ve given us a transport wheelchair…They’ve given us a 300 and some pound wheelchair that we take when we go places…We get almost all our medicines from VA…I didn’t have enough Rilutek…They said to me that they will overnight it and they did…The VA has also given us a lift and the lift can go by battery or electric…They are helping with the house addition…He probably won’t even go upstairs (when it’s completed)…

Barbara and Bob are “very involved” with their church and church members have been “very supportive” of them, through providing company to Barbara as well as preparing meals. Barbara shared, “Our church Deacon has been especially supportive of Bob and has tried to help him enjoy activities that he used to even as Bob’s physical condition has continued to decline.”

Just before you came there was 7 men, they come over from church and we have a small church and they had their men’s meeting over here Tuesday mornings and he is very blessed to have such wonderful people…A couple of weeks ago we
were called and they (members of the church) said, “is it okay if we bring lunch over for you all.” I said, “yeah that’ll be fine” and I said “what can I do” and they said “nothing.” There were about 8 women and 3 men. All the food, everything was cooked. They even brought their own ice in a big baggie…His Deacon used to take him out fishing up until last year…When it got to the point [Bob] couldn’t balance, he went down into the basement and found a round leather chair that had the gold buttons and everything on it and he mounted that to his boat. It looked like it was King Brian and his minion going down the Susquehanna. [Bob] would hold it as well as he could, the line and then when he caught it, [Deacon] would pull it in…He loves going with him…

Barbara “really likes their paid caregiver who comes in three days a week” and “trusts Bob’s care to him with complete confidence.” This paid caregiver will often allow Barbara to have extra respite hours on Friday; often staying overtime if she asks him to. She said, “He (paid caregiver) makes my caregiving by doing things for Bob that are hard for her. He also gives me extra hours when I need it.”

We have a wonderful caregiver from the VA. He comes 10 hours a week and he’s amazing and we’ve had several that were good but never anything like [paid caregiver]. He and [Bob] watch the same movies, cowboy movies. He knows how to do [Bob]’s nails…I can’t use clippers so [paid caregiver] files his nails. [Paid caregiver] can feed him…He does range of motion 3 days a week. He comes from 9-12 two days a week; Monday and Wednesday and 9-1 on Friday… [Paid caregiver] has not gone with us but I think sometime- he wants to go and I think sometime I’m going to start letting him go…On Fridays I sometimes go out
shopping with my granddaughter and my daughter and we can go as long as I’m back by 1 and there are times I can’t get back by 1 and I can ask [paid caregiver] if he’s going somewhere else. If not, he is willing to stay here and watch the cowboy movies with [Bob]…I never leave him with anybody I cannot trust. I’m always thinking about him…[Paid caregiver] is wonderful…

Lastly, Barbara states that healthcare providers since his heart transplant have been “very supportive” in her caregiving role. Not only do “they guide” her husband’s care, but also “have established a trusting relationship with them” that has made her caregiving for Bob “easier” because she knows “he will be taken care of.”

When he was diagnosed with ALS, the fine doctor (ALS neurologist) and group, I just cannot say enough. I think people answer us, if we ask a question, they answered us with truth…I know that they would do the right thing for him…They would help me no matter what. You know, if I needed something they made sure I have it…Even at [Medical Center] he has, we’ve met the most wonderful people in the world. You hate to think you have to get this sick to get to know all these amazing people but if you have to get this sick to meet these amazing people it’s wonderful…

“Quiet time” (Caregiver respite). Now that there is a paid caregiver for Bob, Barbara says she “can leave home every Friday to have some quiet time” away from being a caregiver. She “loves being with family and friends” and “especially loves to go to the grocery store” where she can “chat with many people” she encounters there.

Well, I go to the grocery store or I return things. I read like for about 3 months then I’ll stop reading. Then I’ll return things for 3 months. Just kidding, but I can
go to the grocery store, I can go out with my friends, especially on Fridays. I can
meet [daughter] at the hospital and we’ll have lunch together. I can go with my
granddaughter. We’re going out to Toys R Us and places like that this
Friday…But I do get out and I do enjoy it and people come over here…I am a
talker…

**Others focus on her husband (Focus of others).** The focus of others remains on
Bob, not his wife, but Barbara said she is “happy with that” because she is “healthy and
happy” being her husband’s caregiver. Barbara said, “I have my faith to sustain me and
I’m doing well. I feel supported by many people.”

[Bob] has been so sick for so long, with his heart problems and all and all our
friends and family have been there for the ride. They focus on him, as they
should. I am doing fine. The Lord is taking good care of me and always will. I
don’t need their concern, [Bob] does. He’s the one with the problems, not me.
It’s not that this isn’t physically hard, it is, but [Bob] is the one who needs the
support. I have plenty of that anyway…

**What makes it harder to be a caregiver (Obstacles to the caregiving role).**
Because Bob cannot use his arms or hands, Barbara stated, “I worry about falling myself
and Bob not being able to get help. It’s my biggest worry and I really don’t know how to
solve that yet.”

The thing that frightens me is if suppose I fall and I can’t get him one of those
little things to put around his neck saying I’ve fallen and I can’t get up. He can’t
use his hands…Suppose I’m upstairs and I fall…What is going to happen…If I’m
upstairs and he’s upstairs and I should pass out for some reason, which I’m not
planning on it but I could fall down it worries me that he has no way to call and that’s my biggest worry…He can’t get out of bed, he can’t turn from side to side and he can’t pick up the telephone…

Barbara admits that she has “difficulty letting others help” her with Bob’s care. Even though his care demands much on her physically, she said she is “reluctant to release his care to anyone but myself.” This has made caregiving for Bob, especially outside the house, “very physically demanding” for her.

…You know, if I need help, I have a hard time asking for it because I just think I can do it and I don’t know what’s caused that. I don’t know. Maybe since his heart and he said never to leave him…When we go to church, we cause so much commotion. They just don’t know. It’s getting the big wheelchair in to begin with and then everybody wants to help and I’d like to get there before everybody’s there so I can do it by myself. I’m very protective of him. I want to do it. He keeps saying “[Barbara] other people can help you” and I don’t want nobody to help me. I want to do it…

Barbara was the only caregiver who discussed a problem encountered at the ALS clinic that makes her caregiving harder when it came to toileting Bob while at the clinic. She said “I’m hoping that by bringing it to the ALS team’s attention, it will make caregiving easier for all the caregivers who need to toilet their loved ones while at clinic.”

…I think he’s going to say something. The commodes up there, the toilets. He went and got down on it and he couldn’t get back up. They’re too low…We could even donate one of the seats because he didn’t realize it until he sat down. I think he thought about it but he had no other choice because he couldn’t stand up
and he had to go… We had to call a nurse in to help him because once he’s down, it’s hard for him to get up…

As Bob’s ALS progresses, Barbara reported “his change in food has changed. He no longer likes the food he used to.” This is not due to bulbar symptoms but according to Barbara “changes in his taste buds,” which is not a common symptom of the ALS disease (ALS Association, 2010). Preparing meals has now taken on “added challenges” for Barbara and although she has tried to adapt, she said these changes make “caregiving harder.”

I’m finding that now his taste is changing in food and so I’m having a very difficult time so I don’t even plan a meal until that night. If we have something frozen, I’ll pull it out if it’s something he wants. Some nights he likes waffles and bacon so it’s whatever he wants, I’ll let him have. He used to like real spicy foods. Now he doesn’t so I think that’s hard. It can be difficult to figure out what he wants so now I just say, “let me know what you want.” He’ll say “what do we have” and I’ll tell him and we go from there.

Barbara disclosed her caregiving efforts are made “more difficult by Bob’s refusal to let anyone but me bathe or toilet him.” This includes his paid caregiver, who he really likes, but Barbara said “he is not ready yet to have anyone else” but her complete these caregiving duties. This “greatly limits” her time away from him to do other activities, which she said she “has accepted, but wishes could be changed.” She stated, “…He doesn’t like anybody else to take him to the bathroom so when I go, I don’t stay too long and I take him just before I leave.” When asked if Bob had any problems with his paid caregiver giving him a shower, Barbara replied, “[Paid caregiver] would do it but he
(Bob) doesn’t want it. He’s not ready yet. He did it all the times in the hospital and he said he’s just right now, if I can do it he wants me to, he’s not ready.”

The last factor that Barbara identified as making caregiving harder is “having people coming in and out of the house so often.” This is something that Barbara has had to adjust to and said, “it’s been difficult for me.” Whether it is church members, family, or the paid caregiver coming to their home, Barbara “feels the need to clean prior to any visitors,” which said she knows “adds to her caregiving load.”

I have to adjust to somebody coming in the home, like [paid caregiver] because I’m very private. And I don’t mind it but I have to clean the whole house before anybody comes in and we never find what I put away. I’m serious. One time we had lost 2 calendars…I forgot where I put them…I was upset about them (visitors) coming. I get very upset about somebody coming in. I’m thinking, oh, I’ll have to keep the house clean, you know. I’ve got a fetish, I guess. I just rush everything. 15 minutes and I can get the house ready…

“Journey to the endpoint” (Looking toward the future). Barbara said she and Bob “like to know what is coming” and “trust their health care providers to provide them with that information.” She realizes that they “will eventually have somebody (paid caregiver) coming in more time.” They have qualified for more time (paid caregiving time), but “want those 2 days right now because if he wants to sleep in on Thursday mornings, he can and I can.” While Bob wants the health care providers to be truthful and blunt with him, Barbara said she likes a “softer” approach when bad news is given. She still wants to be told the truth, but breaking the news “more gently” to her is an
approach that she prefers. When asked if she is able to look 6 months in advance or if
that is painful, Barbara replied:

No, it’s not painful. We just don’t do it. We live for today. I don’t. I don’t know
if he does. I’m just thankful for every minute I have…I know what’s coming
possibly. Just seeing different things and what can affect him…He has an
amazing family doctor and [ALS neurologist] lets us know if it’s coming fast or
slow…I’ve never heard him (Bob) complain but he said the only thing he likes to
know is what’s happening like at the time it’s happening. He wants to know what
we can do and let’s get on with it and he’s always been that way…I know things
are happening but I like to live now…I want the truth but kind of layer it before
you get there. Give me a warning…It’s not that I don’t want the truth. But just
sugar it a little bit…

Due to his heart transplant experience, Barbara said she and Bob have been “very pro-
active” in their advanced planning efforts and “encourage others, especially the nursing
home residents or medical students he interacts with to do the same.”

He’s already done it (advanced planning)...We have all of the directives. My
power of attorney is [Bob] and he can’t sign anymore so I got mine done again.
But we’ve had a power of attorney for a long time...If something should happen,
we know what he does not want and what he wants and one of the students asked
him, ‘Well since you don’t want anything extraordinary done to you like a tube
down your throat or anything, do you think you could change?’ He said
‘Anybody could change but I don’t believe I will. Because I’m going to a better
place.’ We had that prepared and we have wills. He really believes that people
need to get that done early in life. He tells them that at the nursing home that they need to get that done and done early. He doesn’t want a ventilator. He has it all written down. He doesn’t want a PEG or feeding tube either. He said, ‘You never know, anyone can change, but I don’t think I will.’

Barbara stated, “I don’t worry about Bob being cared for in the future if something should happen to me because my kids live close to us.” She said her children have “remained very close” to both Barbara and Bob throughout their adult years and “having a close family connection with one another is very comforting” when thinking about her husband’s future.

No, I’m not worried because I know he’d be cared for. I know there’s enough people that would care for him and I know enough people love him…If there’s something happened to me, I know he would be taken care of and I know that they would not just throw him somewhere just to get rid of him; that I’m not worried about…

When talking about looking ahead into the future, Barbara said she felt she had “a different perspective” due to her experiences with Bob’s heart transplant and facing at that time that he would not survive. She said this “influences” her future views of what Bob’s journey with ALS will be like and the reaction to that journey.

…With the heart we were constantly in and out of the hospital…He had his heart attack then he was in and out of the hospital. Then we had a few years that he wasn’t. It was always, is the defibrillator going to go off? I was waiting for something, the other shoe to drop. Like one time the defibrillator went off and he said it was like a mule kicking you but he didn’t know if it was a dream or not.
At times he would have severe nose bleeds…I would have to rush him to the hospital with a severe nose bleed…I mean it was constantly going back and forth to the hospital and not that ALS is easier, but it’s not the constant fear right now that he’s not going to be with us and after the heart, I felt like, Lord, there was a reason. There’s a reason that the Lord didn’t need him then…Had he not had the heart, which they probably wouldn’t have given him had they known he had ALS, he would be here now…but during the years of the heart was always something constant…When he came home and I went to the grocery store and left him here with my daughter, an ambulance was on its way out this way and I thought, Oh Lord, this has got to be [Bob], but it wasn’t and I prayed for the person who it might have been…I would be driving home and he would sort of go like this and I would think, Oh my gosh, he’s dying and so I’d rush home and he’d be okay…Whereas this is a little bit different. I just feel it’s just a different way. I feel a little bit more comfortable but yet, I know that he’s getting worse and we just have to do what we can do… It is very different…I never knew when his defibrillator was going to go off and now, I just don’t know how long he’s going to be able to walk…There’s so much uncertainty with ALS…Right now, he’s doing it still, thank the Lord…You know what the end point is going to be but the journey to get to that end point it’s so varied and you don’t know when that’s going to be…
Chronological pattern diagram narrative: Barbara

The first four highest ranked stressful events on Barbara’s chronological pattern diagram all concerned Bob’s heart problems and side effects after his heart transplant. She ranked his “widow maker” MI in 1998 as “the worst event in her life” and with Bob’s heart problems, they were “constantly in and out of the hospital…I was waiting for the other shoe to drop.” His subsequent heart transplant (#2), where “they didn’t expect him to survive” was followed by two other heart related events, Bob’s pacemaker (#3), which was a very uncommon event to have happen after a heart transplant, and finally Bob’s two mini stroke events (#4), which was he was at higher risk because of his heart transplant history.

Barbara’s own fear of falling was ranked #5 and she stated:
I think after he fell I realized if I fell, suppose I tumbled down the steps and he could get to anybody... he would be totally alone with nobody to talk to... Nobody to call for help... He can’t pick up the telephone...

Barbara ranked her husband’s diagnosis with ALS as #6 stating, “I knew nothing about it (ALS). I didn’t know what (was to come).” When Bob was diagnosed with ALS, she did not know anything about the disease. She stated if she had known more about it and what it was all about at the time of his diagnosis, she would have ranked it much higher on the pattern analysis, but she simply knew nothing about the disease or what it was about. It still would not have ranked as high as his MI or the heart transplantation. She said, “It’s not that ALS is easier, but it’s not the constant fear right now that he’s not going to be with us.” This lack of having a constant state of fear of her husband’s death makes it lower in ranking as well.

Taking over the driving after Bob lost control of his arms was ranked #7 because Barbara knew that after losing function in his left arm, eventually he would lose control of his right arm as well.

He had been working his arms, but then his left arm had gone. We knew the right one was going to go so that was not as stressful... I used to have to drive by myself and it scared me to death. Now at least I have a GPS. It doesn’t scare me, I just don’t like it. I do not like to drive at all...

Barbara chose her daughter and family moving into their home as #8 on the pattern diagram stating the following:
I’m concerned because you hear so many families combining and then everything goes wrong and I think that bothers me a little because the thing I’m concerned about is we are so close…It’s going to be wonderful though. We’ll work it out.

**Transformations/Insights**

When I asked Barbara if talking with me had given her any new insights or new ideas, she had the following response:

Just talking to you, opening up, saying things that I haven’t said to anybody has been good. I just think you’re amazing. I think for you to have done all the work you have done and in the back of my mind there is so much I have learned from you. To say it, I don’t know, but to look at the chart (pattern diagram), to know you’re going from person to person to person, finding out what caregivers need to do…It’s helpful to see a timeline. I am a visual person too. I’m very visual. I think that’s fantastic, that little chart (pattern diagram). Just looking at it and then trying to decide what was important…

Barbara was the most difficult to establish on Young’s Stages of Evolution of Consciousness (Newman, 1984) because she seemed to vacillate between three stages. First, due to her strong spiritual beliefs and her statement that “she does not fear death” but rather “is ready whenever the Lord sees fit to call her” Barbara is experiencing the stage of Real Freedom. This is the stage where love and a state of unity exist and where opposites (i.e. life and death) are reconciled. She was the only caregiver in this study to reach the Real Freedom stage. However, at other times, such as when she “lives for each day” she is experiencing the Unbinding Stage where she is freed from the bounds of time and more present in each moment. Lastly, Barbara was in the Choice Stage when talked
about how it bothered her to have others help her with her husband’s care and now she welcomes it and welcomes others in (like Bob’s paid caregiver). In the Choice stage, old rules no longer apply and there is de-stabilization of established order, which shows movement towards expansion of consciousness.

**Summary**

This chapter has presented the nurse researcher/ALS family caregiver process that was present in this research study. The process that emerged was: (a) establishing a time and place for the nurse researcher and the ALS family caregiver to form a relationship, (b) developing a bond with each ALS family caregiver, (c) creating an atmosphere that allows the family caregiver and nurse researcher complete freedom to express themselves openly, (d) offering a sense of timelessness for insights about the ALS family caregiving experience, and (e) transformation as the nurse researcher and ALS family caregiver come together to find meaning in the chaotic experience of family caregiving for an ALS patient. The theory of health as expanding consciousness was applied to each ALS family caregiver. The patterns of the whole of all ALS family caregivers were enfolded in the pattern of the whole across all eight family caregivers who care for a patient with ALS (Aim 2). The process of interviewing families, analyzing the interviews, and synthesizing patterns of the whole led the researcher to the answer of the research question: What are the life patterns of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient through a unitary transformative paradigmatic lens? Lastly, the narrative summaries, chronological life pattern diagrams, associated narratives and analysis, and Young’s Stages of Evolution of Conscious for each individual ALS family caregiver (Aim 1) were presented.
Chapter 5
Discussion, Implications, and Limitations

Discussion of Significant Findings

The purpose of this research study was to advance understanding of the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient through a unitary transformative lens for the advancement of nursing science. First life patterns of the whole for the individual eight ALS family caregivers (Aim 1) were examined and then life patterns across all eight ALS family caregivers were determined (Aim 2). Nine themes emerged from the data representing life patterns of the whole across eight ALS family caregivers. These nine themes emerged through the process of analyzing data from audiotaped and transcribed interviews and field notes. Although data saturation occurred after the sixth ALS family caregiver, two additional ALS family caregivers were completed (n=8) as per the recommendations of health as expanding consciousness (HEC) theory methodology (Newman, 1984) of six to eight research participants. The dissertation committee HEC scholar oversaw the analysis process of this research study. These nine themes will now be presented first in a table (Table 5.1) and then in narrative form and compared/contrasted to relevant literature.
Nine emergent themes of life patterns of the whole across all ALS family caregivers

Table 5.1: Nine emergent themes of life patterns of the whole across all ALS family caregivers and relationship to relevant literature

<table>
<thead>
<tr>
<th>Life patterns of the whole across all ALS family caregivers</th>
<th>Relevant literature</th>
<th>Relationship to relevant literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suspicions emerge but ALS diagnosis is delayed</td>
<td>Mitsumoto and Rabkin (2007)</td>
<td>Substantiates findings: ALS diagnosis may take 9-11 months after symptoms emerge to diagnose (All ALS patients experienced delays in diagnosis)</td>
</tr>
<tr>
<td></td>
<td>ALS Association (2008)</td>
<td>Confirms findings: ALS diagnosis involves elimination of other diseases that mimic ALS (All ALS caregivers had other diseases eliminated prior to diagnosis)</td>
</tr>
<tr>
<td>Support that helps the caregiver</td>
<td>Ekwall, Sivberg, and Hallberg (2004); Bolmsjo and Hermeren (2001)</td>
<td>Supports findings: The importance of a support system to a family caregiver (Regardless of how it was provided, every family caregiver in this study expressed the value of having social as well as personal resources to help them in their caregiving roles)</td>
</tr>
<tr>
<td></td>
<td>Greenberger and Litwin (2003)</td>
<td>Reaffirmed findings: Social/personal resources need to be readily accessible for family caregivers (Caregivers in this study utilized resources available to them from ALS team, support groups, paid caregivers, volunteers, to church organizational resources)</td>
</tr>
<tr>
<td>Support can make caregiving more difficult</td>
<td>Livestrong (2012); Fisher, Nadler, and DePaulo (1983)</td>
<td>Endorses findings: Asking for help is stressful for many caregivers; Experiencing negative reactions when having to ask for help is not uncommon (All caregivers shared that at least initially it was very difficult to ask for help and some still had issues with this well into their caregiving journey)</td>
</tr>
<tr>
<td></td>
<td>Greenberg (1980)</td>
<td>Endorses findings: Negative feelings are due to caregiver being unable to reciprocate/indebted to the supporter (Expressions of “I can never pay them back, I can never make it up to them” revealed across ALS family caregivers)</td>
</tr>
<tr>
<td></td>
<td>Brehm and Coke (1966)</td>
<td>Confirm findings: Support can create negative emotions due to having freedom restricted (Loss of privacy and alone time a common life pattern across the ALS family caregivers)</td>
</tr>
<tr>
<td>Study</td>
<td>Findings</td>
<td></td>
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<tr>
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<tr>
<td>Fisher et al., (1982)</td>
<td>Validates findings: Negative feelings can come from threats to the family caregiver’s self-esteem (ALS caregivers shared “I should be able to do this by myself,” “I want to do this for him/her; not somebody else” or “I’m not ready to let go of that yet” saying that they wanted to do as much care themselves for as long as they could and “other peoples opinions of them matter”)</td>
<td></td>
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</table>

**Looking toward the future**

<table>
<thead>
<tr>
<th>Study</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Penrod, Hupcey, Baney, and Loeb (2010)</td>
<td>Reinforced findings: Anticipation of death is key characteristic of the caregiving trajectory; stage of Building a New Normal is prolonged with each new progression of the ALS disease (All ALS family caregivers were in the stage of Building a New Normal and were aware from the initial diagnosis that ALS was a terminal diagnosis)</td>
</tr>
<tr>
<td>Trail, Nelson, Van, Appel, and Lai (2004)</td>
<td>Corroborates findings: Concerns about ALS disease progression are among the highest stressors of family caregivers (Life patterns revealed “what would be coming next” was a high concern to all ALS family caregivers)</td>
</tr>
<tr>
<td>Benditt, Smith, and Tonelli (2001)</td>
<td>Substantiates findings: Purposeful attention to end-of-life care planning can decrease uncertainty/pain that accompanies a terminal disease like ALS (Efforts by the ALS team to educate about key markers in the disease (i.e. FVC values, physical symptoms) were acknowledged as being important to the ALS family caregivers. All had advance directives completed. Two ALS patients participating in advanced care research study at time of interviews)</td>
</tr>
</tbody>
</table>

**Adaptations from ALS**

<table>
<thead>
<tr>
<th>Study</th>
<th>Findings</th>
</tr>
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<tbody>
<tr>
<td>Grbich, Parker, and Maddocks (2001)</td>
<td>Endorsed findings: Delineated four common adaptations caused by ALS on family members (All ALS family caregivers identified adaptations they have had to make ranging from loss of privacy, financial concerns, developing new role/relationship with loved one, or changes in sex life)</td>
</tr>
<tr>
<td>Emanuel, Fairclough, Slutsmian, and Emanuel (2000)</td>
<td>Validated findings: Dealing with financial concerns a common adaptation with ALS disease (All ALS family caregivers expressed financial concerns associated with disease, either presently or in future. Two caregivers were in severe financial distress and had remortgaged homes to address concerns)</td>
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</table>

**Obstacles to the caregiving role**

<table>
<thead>
<tr>
<th>Study</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wiener and Dodd (1993)</td>
<td>Endorse findings: Phase of trajectory, family support, financial resources, assistance from health care professionals, initial diagnosis/new symptoms all influence uncertainty (ALS family caregivers all spread across ALS caregiving trajectory; All utilized varying forms of family or social support depending on the where their loved one was in relation to the...</td>
</tr>
<tr>
<td>Source</td>
<td>Findings</td>
</tr>
<tr>
<td>--------</td>
<td>----------</td>
</tr>
<tr>
<td>Benner and Wrubel (1989)</td>
<td>expected death trajectory and the current symptoms present</td>
</tr>
<tr>
<td>ALS Association (2010b)</td>
<td>Supports findings: Caregiver respite time is essential because it provides the ALS caregiver with the opportunity to devise a plan of care for themselves (All ALS caregivers acknowledge the need and benefits for respite/relaxation time; All utilize it in varying amounts)</td>
</tr>
<tr>
<td>Armon, 2006; Murphy, Felgoise, Walsh and Simmons (2009)</td>
<td>Confirms findings: Physical and emotional strain to the family caregiver of providing care to an ALS loved one (All ALS caregivers expressed physical and/or emotional toll of caring for their loved one, especially at the start of the diagnosis or in the final stages of the disease)</td>
</tr>
<tr>
<td>Penrod, Baney, Loeb, McGhan and Shipley (2011)</td>
<td>Supports findings: Nine strategies caregivers use to help themselves care for a loved one (Life patterns across ALS family caregivers reveal varying strategies ranging from “keeping husband as independent as possible” to “a new us” to adapting home, car, and travel environments)</td>
</tr>
</tbody>
</table>

The first life pattern theme of the whole that emerged was *suspicions emerge but the ALS diagnosis is delayed*. All of the family caregivers experienced delays in the diagnosis of ALS even though all were showing symptoms that something was physically wrong on average two years prior to their diagnosis. Two of the ALS family caregivers’
loved ones experienced unnecessary surgeries (#4-Hannah and #7-Karen) based on a misdiagnosis of their loved one’s symptoms. This delay in diagnosis was accomplished through the involvement of family physicians as well as neurologists who do not specialize in treating and diagnosing ALS. This ALS diagnosis delay substantiates findings from Mitsumoto and Rabkin (2007) who found that an ALS diagnosis may take 9-11 months after symptoms appear before a diagnosis can take place. It confirms findings by the ALS Association (2008) that the ALS diagnosis involves the elimination of other diseases that mimic ALS before a definitive diagnosis can be accomplished. According to the ALS Association a delay in the diagnosis of ALS can be common especially if a neurologist (who does not specialize in ALS) does not recognize the symptoms presented as indicative of ALS. This delay in diagnosis can also occur if the neurologist does not make a prompt referral to a neurologist who specializes in ALS diagnosis and treatment. The delay in referral to a neurologist specializing in ALS was present in ALS family caregivers 1-7 in this research study. ALS family caregiver 8 (Barbara)’s husband (Bob) experienced a delay in diagnosis, but Bob’s heart transplant and subsequent heart issues made diagnosis of his hand issues secondary to his ALS diagnosis. ALS caregiver 8 (Barbara) stated “the physicians and surgeons involved in [Bob’s] care did not think he would survive the heart transplant pacemaker surgery so they really weren’t worried about his hand. I don’t know how long it would have taken him to be diagnosed with ALS otherwise.”

The second life pattern theme of the whole that emerged was support that helps the caregiver. All of the ALS family caregivers experienced support in their caregiving roles by family, friends, community, church, and healthcare professionals. The amount
varied depending on the progression of their loved one’s ALS and the caregiver’s willingness to seek and accept support, but support from others helped the ALS family caregivers in learning about the disease, plan for the future, and perform their daily caregiving roles. The importance of a support system to a family caregiver has been documented by Ekwall, Sivberg, and Hallberg (2004). Their research showed that resources and support systems are essential to decrease caregiver burden. Reduced availability to support systems is associated with family caregiver decreased quality of life. Ekwall, Sivberg, and Hallberg also described an important association between weak social support, loneliness and decreased mental quality of life. Bolmsjo and Hermeren (2001) confirmed the need for caregivers to have someone to confide in and give them support was very important. Greenberger and Litwin (2003) stated it is essential, especially with the growing dependent older population and the rise in chronic illnesses, that social and personal resources be more readily accessible for family caregivers. All of the family caregivers in this study had varied forms of resources available to them. These resources ranged from support groups, paid caregivers, volunteers, to church organizational resources. Some of the family caregivers also benefitted from having adaptive equipment donated to them by friends, the ALS Association, or the Veterans Administration. Regardless of how it was provided, every family caregiver in this study expressed the value of having social as well as personal resources to help them in their caregiving roles. Given et al (2008) reported that providing family caregivers with information about patient symptom management, especially literature on patient symptoms and adaptations for the ALS patient, can support the caregiver and help alleviate some of the uncertainty regarding decision-
making in the home setting. All family caregivers in this study have received literature about the disease of amyotrophic lateral sclerosis as well as how to be a caregiver to an ALS patient from the ALS Association and the Muscular Dystrophy Association through their ALS clinic visits. In addition, many of the ALS family caregivers also used the Internet as a valuable source of information about ALS and ALS caregiving.

*Support can make caregiving more difficult* was the third life pattern theme of the whole identified. Although support is necessary for the caregiving role, support can have negative implications on the family caregiver and produce increased stress as well. This finding has been supported by Livestrong.org (2012), which is a non-profit organization supporting cancer research has reported that the experience by family caregivers of asking for help can prove to be especially stressful, especially for family caregivers who are used to relying on themselves to provide care for their loved ones. Negative reactions experienced when having to ask for help are not uncommon (Fisher, Nadler, & DePaulo, 1983). This is due primarily to negative feelings of being unable to reciprocate and therefore become indebted to the supporter (Greenberg, 1980), feelings of having freedom restricted (Brehm & Cole, 1966) and threats to the family caregiver’s self-esteem (Fisher et al., 1982). All of the ALS family caregivers in this study struggled at least initially with asking for help with their loved one. Many continued to try to do as much on their own before asking for help from others. ALS caregiver 1 (John) was resentful of a paid caregiver assist his wife (Jane) when his daughter and granddaughter already were doing the services this paid caregiver performed. ALS caregiver 6 (Aaron) was still struggling with having help come in the home after his daughter and her family returned home after spending the summer with he and his wife (Ashley). Many of the
family caregivers in this research study also felt a “loss of privacy” by having others come into the home, and ALS caregiver 4 (Hannah) found having others come into the home stressful because “it was just one more thing she had to plan for” in her life. ALS caregiver 8 (Barbara) found it stressful to have support come into her home because she felt the need to “clean up the house” prior to any visitors helpers coming into her home.

The fourth life pattern theme of the whole that emerged was looking toward the future. All ALS family caregivers were aware from the beginning of their loved one’s ALS diagnosis that the ALS disease was terminal. The eight ALS family caregivers were also aware that plans would need to be made for their loved ones, if not currently, then in the future. Future planning was a key element to the ALS family caregiving trajectory and whether their loved ones disease progression as faced on a day by day basis, or planned months ahead, it emerged as an important caregiving role. The concept of trajectories has been further advanced through the study of informal family caregivers (Penrod, Hupcey, Baney, & Loeb, 2010; Penrod, Hupcey, Shipley, Loeb, & Baney, 2011) where a theoretical model delineating the phases and transitions of end-of-life caregiving were superimposed upon known death trajectories, such as the expected death trajectory of ALS. A unifying theme of seeking normal (i.e. dependable patterns in everyday life) emerged for the family caregivers while meeting the demands of caregiving for their loved ones. Through this research, it became apparent that the caregiving trajectories are not disease driven but rather the anticipation of death was the key characteristic of the caregiving trajectory. This is especially important in ALS because ALS represents a known or expected death trajectory where the stage of Building a New Normal is prolonged as the family caregivers have the primary responsibility for caring for their
loved ones through distinct periods of physical and in some cases mental decline. This was shown by all caregivers as they constantly were working to “build a new normal” with each new progression of the ALS disease. Some of the ALS family caregivers in this current research study liked to plan ahead to anticipate future presentations of the disease (i.e. ALS family caregiver 4-Hannah) but many preferred to “deal with things as they happen” (i.e. ALS family caregiver 1-John, ALS family caregiver 3-Andy, and ALS family caregiver 6-Aaron). Regardless, all of these ALS family caregivers were aware of the end point of their loved one’s ALS diagnosis, but tried to “seek normal” in the midst of whatever challenges they faced as caregivers for their loved ones.

Trail, Nelson, Van, Appel, and Lai (2004) studied ALS patients and their family caregivers and compared the needs of both ALS patient and family caregiver and their research showed that concerns about the ALS disease progression to be among the highest stressors among ALS patients and family caregivers alike. Benditt, Smith, and Tonelli (2001) studied ALS end-of-life care planning and found that although end-of-life advanced care planning remains one of the most difficult topics to discuss with ALS patients and their family members, purposeful attention to end-of-life care planning can decrease some of the uncertainty and pain that accompanies a terminal disease like ALS and can be a useful strategy in assuring that both ALS patient and family caregiver wishes are the same and congruent with each other. These findings were verified by the family caregivers in this study as they were all aware of the forced vital capacity values of their loved ones (i.e. all reported the FVC values to the nurse researcher) and the relevance of those values in terms of end-of-life advanced care planning. Even ALS family caregiver 6 (Aaron) whose wife was newly diagnosed with ALS understood the
importance of his wife’s “breathing results” because he had been told by the ALS team at their first clinic visit that planning for services such as Hospice would need to be done well in advance of his wife’s need for hospice. The ALS team served as the main resource to implement and guide all of these family caregivers through this end-of-life planning and offered advance directive guidance/clinical trial opportunities to all the families utilizing their ALS clinic.

*Adaptations from ALS* was the fifth life pattern theme of the whole that was revealed from the data. From the start of physical or mental decline to their current stage of caregiving, all eight ALS family caregivers experienced adaptations they were required to make because their loved one had ALS. These required adaptations from ALS been shown in the literature. Grbich, Parker, & Maddocks (2001) found ALS caused adaptations due to (a) changing family roles, (b) uncertainty about being alone after their ALS loved one died, (c) uncertainty about treatment plans, and lastly (d) financial concerns imposed on the family as either the ALS patient or ALS family caregiver had to reduce or quit working due to the ALS progression of the disease. Refinancing or re-mortgaging their homes to help alleviate the financial pressures of the disease has been shown to be an adaptation faced by many ALS caregivers by the research of Emanuel, Fairclough, Slutsman, and Emanuel (2000). All of the family caregivers expressed adaptations that they experienced as a result of their loved one’s ALS disease progression. These adaptations ranged from financial concerns (ALS caregiver 5-Brittany), developing a “new us” describing their marriage partnership (ALS caregiver 4-Hannah), loss of privacy as care demands required help from volunteers or
paid caregivers (ALS caregiver 5-Brittany; ALS caregiver 8-Barbara), or changes in their
sex lives (ALS caregiver 7-Karen; ALS caregiver 5-Brittany).

Obstacles to the caregiving role were situations that made it more difficult for the
ALS family caregiver to perform in their caregiving role. These could be “speed bumps”
(as identified by ALS caregiver 2-Alex) caused by the disease (i.e. each new symptom
experienced in the ALS disease trajectory) or could be caused by the ALS patient
him/herself. In their seminal work on illness trajectories of chronic diseases, Wiener and
Dodd (1993, p. 19) looked at uncertainty amidst the backdrop of chronic illness
trajectories and found the degree of uncertainty was affected by: (a)”the phase in the
illness trajectory, (b) the nature of family support, (c) the type of financial resources, (d)
the quality of assistance from health care professionals, and (e) the extent to which the
respondent was experiencing an initial diagnosis or a new symptom”. Benner and
Wrubel (1989, p. 62) stated "Stress is the experience of the disruption of meanings,
understanding and smooth function. Coping is what one does about that disruption. Since
the goal of coping is the restoration of meaning, coping is not a series of strategies that
people choose from a list of unlimited options. Coping is always bounded by the
meanings and issues inherent in what counts as stressful." For this current research
study, the ALS family caregivers were spread across the expected illness trajectory,
ranging from newly diagnosed (ALS family caregiver 6-Aaron) to an ALS family
caregiver who was actively dealing with having hospice services initiated (ALS caregiver
1-John) to another family caregiver (ALS caregiver 4-Hannah) who was working with
her husband (Tony) to decide whether or not to extend Tony’s life through mechanical
ventilation. Others in this research study were in the middle part of the trajectory (ALS
caregiver 3-Andy, ALS caregiver 2-Alex, and ALS caregiver 5-Brittany) and dealing with “speed bumps” or progressive loss of physical/mental decline. All had different strategies about how to deal with each of the “speed bumps” of the disease that impacted their caregiving efforts. They all utilized varying forms of family or social support depending on the where their loved one was in relation to the expected death trajectory and the current symptoms present.

*Caregiver respite* was the seventh life pattern theme of the whole that was uncovered from the data. Although all eight ALS family caregivers chose varied forms of caregiver respite, it was an important element of their caregiving journey and enabled them with the physical and mental release needed to meet their caregiving duties on a daily basis. According to the ALS Association (2010b) caregiver respite time is essential because it provides the ALS caregiver with the opportunity to devise a plan of care for themselves, which is commonly overlooked by the ALS family caregiver. This interval of rest or relief provides the ALS caregiver with a much-needed break from the physical, emotional, or mental caregiving role and could be a few hours or days at a time. By experiencing respite self care time, the ALS Association states the quality of life can be improved for family caregiver and ALS patient alike by presenting a respite, or break from the normal everyday responsibilities of ALS disease care. The family caregivers in this current research study had varied ways of experiencing “down time” (as identified by ALS caregiver 7-Karen) or respite time. Some chose to socialize with others through golfing (ALS family caregiver 6-Aaron) or through grocery shopping (ALS family caregiver 8-Barbara). ALS family caregiver 3 (Andy) used three different support groups not only for the information they provided, but also as a source of respite enabling him to
be with his daughter and others who could relate to his experiences of caregiving. ALS family caregiver 1 (John) loved to be outside experiencing nature and Alex (ALS family caregiver 2) loved to “escape from caregiving” through his “living and breathing model trains.” In contrast, ALS family caregiver 4 (Hannah) has her “own form of respite” where instead of taking time away from her caregiving duties, she instead “sets limits” around her caregiving role and having this control over her limited time away from work is what she describes as being her “down time.” Also having time with her daughter, such as in the mornings before school helping her get ready, was quality respite time for Hannah. Although this concept of respite differed from the other seven ALS family caregivers, it served Hannah well, giving her control over her caregiving world, which for her was respite or relaxing in nature.

*Focus of others* refers to the attention of others, family and non-family members and whether the ALS patient or the ALS caregiver is the focus of attention from others. All of the eight ALS family caregivers stated that at some point in the ALS caregiving experience they had others ask about the well-being of the ALS family caregiver, but reported that although there was varying amount of focus on the ALS family caregiver, the primary focus of support systems was directed to the ALS patient, not the ALS family caregiver. The physical and emotional strain to the family caregiver of providing care to an ALS loved one has been documented (Armon, 2006; Murphy, Felgoise, Walsh, & Simmons, 2009) and the importance for family caregivers to be seen not only as co-providers of care to their loved one, but also co-recipients of care, due to the equal importance of the family caregiver’s physical/mental needs, has been documented by Penrod, Baney, Loeb, McGhan, & Shipley (2011). Their research has shown that the
environment of care, including the focus of care on the family caregiver can have a
dramatic effect on the caregiving experiences of family caregivers of loved ones with
life-limiting illnesses.

For this current ALS family caregiver research study, five of the ALS family
caregivers (ALS family caregivers 1-John, 2-Alex, 3-Andy, 7-Karen, and 8-Barbara)
stated the attention of others (i.e. family, friends, and health care providers) was directed
more toward their loved one with ALS. ALS caregivers 4 (Hannah), 5 (Brittany), and 6
(Aaron) stated others asked equally about their welfare while providing care to their ALS
loved one. Brittany (caregiver 5) noted that the attention of others upon herself was
probably due to her many health needs and having an organized group of volunteers
assigned to help not only her daughter (Anna) and husband (Jacob) but Brittany as well.
Hannah (caregiver 4) stated her family and her husband’s family focused on her needs
because all of them had previous caregiving experience and applied those caregiving
experiences to Hannah’s current caregiving role. Aaron (caregiver 6) said others were
concerned about him as well as his wife (Ashley) but this may have been due to her new
diagnosis and the attention that brought from others. This concept about the focus of
others shifting after the initial diagnosis was made was confirmed by ALS caregiver 7
(Karen) who stated others originally would ask how she was doing, but as time went on,
their attention shifted to only her husband (Mark) with each new deterioration in his
physical/mental condition.

One surprising development of this theme (Focus of others) was in how the ALS
team was regarded. Although every ALS family caregiver lauded praises for the ALS
team and regarded the team as a great resource, identifying their focus was primarily on
their loved one with ALS was a surprise to this nurse researcher after spending over two years in that ALS clinic. Despite the ALS team’s efforts to include family caregivers into the clinical visit and focus on the caregivers’ needs as being just as important as the ALS patients’ needs, this concept has not been fully integrated for the ALS family caregivers in this research study.

The last life pattern theme of the whole that emerged from the data was strategies aiding the caregiving role. Even though the presentation of the ALS disease progression required different strategies from the eight ALS family caregivers, all had to devise the best way to provide care to their loved one. The acquisition of strategies to aid the caregiving role has been examined by Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) who uncovered nine core caregiving processes. These skill sets consisted of (a) monitoring, (b) interpreting, (c) decision making, (d) taking action, (e) making adjustments, (f) utilizing resources, (g) providing direct care, (h) working in tandem with the ill person, and (i) traversing successfully through the healthcare system. The ALS family caregivers in this research study employed various strategies to deliver care, based on their loved one’s disease presentations, but all had skill sets as described by Schumacher, Stewart, Archbold, Dodd, and Dibble. All provided direct care and monitored their ALS loved one’s progression to the disease. All interpreted their loved one’s symptoms and took action, usually in the form of contacting the ALS nurse manager when they had questions or concerns regarding the interpretation of how their loved one was doing. With the exception of ALS caregiving 1 (John) who utilized his daughter (who was an RN) as the contact person for the ALS nurse manager, all other family caregivers in this study were active in taking action themselves when contacting
the ALS nurse manager. With the exception of ALS family caregiver 3 (Andy), all worked in tandem with their loved one for providing care. Andy (ALS caregiver 3) did not do this due to the cognitive impairment of his wife (Emma).

Schumacher, Stewart & Archbold (1998) found that providing care well is a high priority to family caregivers and caregiving competency, knowledge, and skills are often a main concern for new caregivers. ALS caregiver 6 (Aaron) was the only new caregiver in this research study, but gaining knowledge, competency and caregiving skills was very important to him and he stated he “read as much as he could” about ALS and within a week of their first ALS clinic visit, Aaron stated he read “everything the ALS team gave him” and would continue to utilize the ALS team resources in the future. Schumacher, Stewart, and Archbold also asserted caregiving skills are gained over a period of time and can be varied based on caregiving expertise. The skills needed for caregiving extend beyond information acquisition or knowledge building. Instead family caregivers possessed personal characteristics and behaviors that influenced their caregiving abilities. The caregiver’s experience was shaped by a combination of previous skills, the ability to integrate knowledge about the care recipient including his or her identity, concerns and personal history into the experience and caregiving skills and strategies developed over time. Strategies developed over time was best explicated by ALS family caregiver 8 (Barbara) who had been providing care for her husband (Bob) since his heart transplant surgery, giving her the longest caregiving experience of all the family caregivers in this study. ALS caregiver 4 (Hannah) showed the ability to integrate knowledge about her husband and his identity through her efforts to “keep him as independent as possible, for as long as possible” which influenced how she regarded advice from the ALS team as
well as how she dealt with her family’s caregiving efforts. She stated “although he can’t use his body, he can still use his brain” and expected her husband to take responsibility for finances and other household responsibilities that he (Tony) could oversee. Caregiver 2 (Alex) also applied his past history of caring for his paralyzed friend in his current caregiving role with his mother (Rebecca). All of the ALS family caregivers were adapting and changing along each step of their ALS caregiving journey.

**Health as expanding consciousness (HEC).** This current research study demonstrated the use of Newman’s research method to explore expansion of consciousness and advance understanding of the everyday world of providing care to an ALS family member. This process provided the opportunity for increased awareness and new meaning of the ALS family caregiving experience in relation to self to be revealed. For example, ALS caregiver 1 (John) stated “It gives me an idea of what’s going to happen yet that I’ll probably have to make some big decisions about. Get hospice to help out here…” This statement showed movement towards realization that hospice was something he needed to consider and act upon, even though it would be done in conjunction with his daughter. Alex caregiver 2 (Alex) confronted his feelings of guilt over his decision to turn over the main caregiving duty to others and stated “…I’ve felt a lot of guilt over this decision, even though everyone else seems to be doing ok with it. I really need to stop feeling guilty and just be happy…” ALS caregiver 3 (Andy) stated he realized through our conversations together that thinking about the future and the future plans with his wife (Emma) is something that he needs to think about sooner than later after his scare with Emma’s relapse with her recent urinary tract infection. He said, “it’s the thinking of what to do with her in the future and that. It’s got me thinking more…”
ALS family caregiver 4 (Hannah) was so focused on the planning of details for her husband’s (Tony) care that often she did not see the bigger picture of his disease. She stated, “I think it’s (our interviews) helped build the picture (bigger picture) because I’ve never sat down and talked about being a caregiver with anybody.” Hannah also stated she “felt validated” by having someone sit down and talk to her and listen to her story about what it is like to be a caregiver. ALS caregiver 5 (Brittany) gained increased awareness about her respite time and the fact that someone had taken the time to talk with her. She said the following:

I’m finally getting a chance to talk…It’s very cathartic because for me, this is my personality and talking is cathartic…When you asked me what I’d do with an hour (of respite time), I now don’t think I’d want to be social. I did have that desire. The reason I don’t want to be social now is because everything centers around, ‘Well, how’s it going?’ … I’m really sick of me. I am sick of us. I am sick of talking about us. I’m sick of dealing with us. So that hour, I do need to do something just for me…

ALS family caregiver 6 (Aaron) expanded his consciousness about letting others help him with his wife’s care, even if it was in the future. He said, “I see that I may have to let some other people help me with her. If not now, then in the future…ALS caregiver 7 (Karen) found insights about being valued as a caregiver just through participating in this process, which was valuable to her because she did not feel valued by her husband (Mark). She stated she was “so glad” that this nurse researcher was doing this study. Having someone paint a real world picture of caregiving was important to her and brought her to increased consciousness about the caregiving she was doing. She asserted:
…the fact that somebody’s gonna paint a real picture would be just wonderful…we all have different real pictures. No one’s picture’s the same as mine… I feel sometimes caregivers aren’t recognized for a lot of the stuff that they do…The most painful part is that when you feel like you’re doing it and it really doesn’t matter to someone…

Lastly, ALS family caregiver 8 (Barbara) was the most vocal about the use of the chronological pattern diagram and how that helped her see important life patterns. She said,

To look at the chart (pattern diagram), to know you’re going from person to person to person, finding out what caregivers need to do…It’s helpful to see a timeline. I am a visual person too… I think that’s fantastic, that little chart (pattern diagram). Just looking at it and then trying to decide what was important…

By being able to reflect upon the ALS caregiving experience, family caregivers were able to experience understanding of self and new perspectives of their caregiving roles. The use of the chronological life pattern diagram, based on Newman’s HED theory enabled the ALS family caregivers to reflect on their caregiving experiences. In the process, the ALS family caregivers were able to focus on their caregiving role, themselves and the relationships that defined their caregiving journey within a new understanding of self and as such, experienced transformation.

To be fully present with the ALS family caregiver without being judgments, goals or intervention strategies was one of the aspirations for this nurse researcher. The presence of this nurse researcher assisted ALS family caregivers with the recognition of
their own life patterns of interacting with their environment and loved one with ALS. By releasing all notions of prediction and control, this nurse researcher was able to focus on what was most meaningful to that ALS family caregiver and the recognition of their own life pattern, which is consistent with the HEC theory (Newman, 1994).

Through pattern recognition, potential for action can be realized and through that potential for action the possibility of transformation can occur. Newman (2008) states that it is important to realize that the potential for action does not occur solely with the participant, in this study the ALS family caregiver, but with the nurse researcher as well and “should not be viewed as a means to an end, but rather a reward on it’s own” (M. Newman, personal communication, August 2009). With this present research study, the potential for action by both ALS family caregivers and nurse researcher was acknowledged and discussed through the chronological pattern diagram dialogues. However, because this study only involved two interviews with each ALS family caregiver, this nurse researcher was not able to see the actualization of this potential. Only through following ALS family caregivers over an extended period of time would the true understanding of the impact of transformation be possible.

This research study illustrated how a mutual, meaningful partnership between an ALS family caregiver and this nurse researcher can become transformational for both. In partnership, the dialogue is open, caring, mutually responsive and non-directive (Picard & Jones, 2005). Through the discussions that took place through this mutual partnership, life patterns of each caregiver were derived. Through this process of mutual partnership, the nurse researcher was able to understand the life pattern of the ALS family caregiver as a whole.
Exploring the life pattern of the whole for each ALS family caregiver and synthesizing their patterns was instrumental to explicating the nurse researcher/ALS family caregiver process (Newman, 1994) for this research study. The nurse researcher/ALS family caregiver process of facilitating health as expanding consciousness experienced by this nurse researcher for this study is: (a) establishing a time and place for the nurse researcher and ALS caregiver to form a relationship, (b) developing a bond with each ALS caregiver, (c) creating an atmosphere which allows the caregiver and nurse complete freedom to express themselves openly, (d) offering a sense of timelessness for insights about the ALS caregiving experience, and (e) transformation as the nurse researcher and ALS family caregiver came together to find meaning in the chaotic experience of family caregiving for an ALS patient. This nurse researcher/ALS family caregiver process confirms and builds upon previous research studies by health as expanding consciousness researchers (Endo, 1996, 1998, 2000; Falkenstern, Gueldner, & Newman, 2009; Litchfield, 1993, 1999; MacLeod, 2008; Pharris, 1999, 2002).

**Nurse Researcher/ALS Family Caregiver Process and Time/Timing.** Newman (1994) identified the concept of time when she was originally developing her nursing theory. She originally said that time was linear in nature, but later changed this to viewing time as a way to capture the rhythm between the nurse researcher and ALS family caregiver. The concept of time/timing was important in this research study because the nurse researcher interacted with the ALS family caregivers at a time when they were still in the midst of chaos and all were still actively engaged in their role of caregiving. This is not always the case with past research utilizing HEC. Pharris (1999, 2002) interviewed incarcerated adolescent males and found that the teens said they
wished they had met her before committing the murders they had been incarcerated for. Tommet (1997) and Litchfield (1999) studied families with seriously ill children and found families would have benefitted more had the HEC research been done at a time when the family was experiencing a tumultuous period with their children, especially immediately following the birth of their children. Falkenstern (2009) discovered in her HEC research with families caring for children with special needs that all families stated they wished the study had taken place earlier. In the Falkenstern study, all families identified experiencing states of disorganization where having a nurse researcher interact with them would have been most helpful “to clear a space, to stop time for a little while, just to think what to do.” This is especially important for this current research study and its implications/application to Young’s Spectrum of Evolution of Consciousness (Newman, 1994), which is discussed later in this chapter.

**Time and Space.** Falkenstern (2009) was the first HEC researcher to address time and space in relation to the HEC theory. As the first step in this current HEC study (establishing a time and place for the nurse researcher and ALS caregiver to form a relationship) this step may sound simplistic, but should not be discounted as unimportant because all of the ALS family caregivers in this study led very busy lives in addition to their caregiving roles. Finding sufficient time in the caregivers’ busy schedules was difficult even with all eight caregivers expressing the desire to participate in the research study. Making sure that the family caregivers allotted enough time to tell their story as well as having a quiet, peaceful environment to tell their story was an integral part of the nurse researcher/ALS family caregiver process.
**Timelessness.** Another important step of the nurse researcher/ALS family caregiver was offering a sense of timelessness for insights about the ALS caregiving experience. This was accomplished by allowing the ALS family caregiver to determine how much time they wanted to spend with the nurse researcher. This was not predetermined prior to the interview, but rather emerged as mutual presencing between nurse researcher and ALS family caregiver occurred. This enabled the family caregiver to communicate and relax into the process. As the nurse researcher and ALS family caregiver joined in rhythm, a sense of timelessness emerged. Throughout this process, the nurse-researcher and ALS family caregiver were unaware of the linear passing of time and all ALS family caregivers expressed surprise at the passage of measurable time (i.e. hours/minutes), effectively ending the sense of timelessness.

**Health as Expanding Consciousness and Young’s Stages of Human Evolution**

Through this research study, ALS family caregivers’ reflections and recognition of their potential ability to move forward through their own caregiving journeys and beyond enabled the nurse researcher with the opportunity to recognize the interconnection of Young’s Stages of Human Evolution (Young, 1976) with Newman’s HEC theory (Newman, 1994). This interconnection was realized through the recognition of life patterns, a desire to move forward and the potential for evolution and transformation.

Using Newman’s HEC research protocol (described in chapter 3), each of the eight ALS family caregivers was placed at their appropriate stage of Young’s Stages of Evolution (Young, 1976) based on the emerging data. This was completed after all eight caregivers had been analyzed for their individual life patterns. This nurse researcher
needed to see the “larger picture” and examine the life patterns across all eight ALS family caregivers so that the gestalt of the caregiving experience could be examined prior to placing each individual ALS family caregiver on the correct stage of Young’s Stages of Evolution. What this nurse researcher discovered was that there was often a sharing or shifting between stages based on Young’s Stages of Evolution (see Table 5.2). Only three of the eight ALS family caregivers were they identified as being placed at a single stage of Young’s Stages of Evolution (ALS family caregivers 3-Andy, 5-Brittany and 7-Karen). Four of the eight ALS family caregivers spiraled between two different stages (ALS family caregivers 1-John, 2-Alex, 4-Hannah, and 6-Aaron) and one family caregiver (ALS family caregiver 8-Barbara) spiraled up and down between three of Young’s Stages of Evolution. When thinking about what might cause this spiraling between more than one stage of Young’s Stages of Evolution, this nurse researcher examined past research studies utilizing HEC methodology, and the concept of time/timing appeared to be an important factor. In HEC studies where the nurse researcher joined with the participant after the period of chaos and disorganization had passed (Falkenstern, 2009; Litchfield, 1999; Pharris, 1992, 2002) the placement of participants on the Young’s Stages of Evolution appear to be placed on a single Young Stage, while HEC research involving caregivers who are actively engaged in a period of disruption and chaos (MacLeod, 2008) there is frequent shifting between Young’s Stages.

This is an important distinction because understanding an individual’s ability for transformation and expansion of consciousness is crucial in the formation of effective actions (MacLeod, 2008) and by gaining the understanding of the Young’s Stage that a caregiver is at in the process of expansion of consciousness can help nurse researchers
better understand that caregiver’s readiness for change as well as the receptivity to action. This has not been explicated in any prior research studies utilizing Newman’s health as expanding consciousness.

Table 5.2. Health as Expanding Consciousness and Young’s Stages of Human Evolution

<table>
<thead>
<tr>
<th>ALS Family Caregiver</th>
<th>Young’s Stages of Human Evolution</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: John</td>
<td>Binding-&gt;Centering</td>
</tr>
<tr>
<td>2: Alex</td>
<td>De-Centering-&gt;Unbinding</td>
</tr>
<tr>
<td>3: Andy</td>
<td>Choice</td>
</tr>
<tr>
<td>4: Hannah</td>
<td>Choice -&gt; De-Centering</td>
</tr>
<tr>
<td>5: Brittany</td>
<td>De-Centering</td>
</tr>
<tr>
<td>6: Aaron</td>
<td>Centering-&gt; Choice</td>
</tr>
<tr>
<td>7: Karen</td>
<td>Unbinding</td>
</tr>
<tr>
<td>8: Barbara</td>
<td>De-Centering-&gt;Unbinding-&gt; Real Freedom</td>
</tr>
</tbody>
</table>

**Extant literature examining family caregivers utilizing health as expanding consciousness.**

Family caregiving has previously been examined utilizing health as expanding consciousness. Endo (2000) focused on Japanese family caregivers of wives/mothers who were hospitalized with a diagnosis of ovarian cancer. Ten families and four nurse researchers participated in this study. The dyad of a primary family caregiver and the woman in the family with cancer were the participants and Endo stated that in the process of the research, families experienced increased openness and more trusting relationships
and the focus of the dyad shifted from separate identities to a more caring trusting relationship in the family unit.

Yamashita (1999) studied family caregivers of loved ones with schizophrenia. There were 12 family members in this study and Yamashita stated the family caregivers were experiencing “aloneness” within the daily struggles associated with mental illness. There was a disconnect between the family caregivers and healthcare professionals and the family caregivers stated they did not have enough information to enable them to understand their family member’s illness and behavior. Through expansion of consciousness, the family caregivers expressed they felt a closer connection with their loved one with schizophrenia and were able to separate the actions of their loved one with the person that was their loved one. When the family members were able to be more open and explain their situation to non-family members and ask for assistance when they needed it, it marked a turning point and through the dialogue with the nurse researcher appeared to experience added insight and the potential for action and change was achieved.

Picard (2002) examined family caregivers and their response to the death of a child and discovered that family members adjusted their rhythm and energy with each other and limited their demonstrations of being sad with each other, especially concerning issues that were painful to them. Picard found that once dialogue around the sharing of meaning amongst the family members took place, they were able to visualize the bigger concept of shared family pattern of meaning.

Both Litchfield (1999) and Tommet (2003) explored family caregivers of an ill child. In both of these studies the nurse-parent relationship and through shared dialogue
discovered meaning as the family caregivers struggled to obtain resources for their children while traversing the difficult aspects of an every changing health care system.

MacLeod (2008) studied spousal family caregivers of patients with coronary artery bypass surgeries. She discovered that family caregivers experienced vigilance as a result of the uncertainty that was present in the recovery process after coronary artery bypass surgery. Feelings of caregiver control were enhanced by knowledge, and this control reduced the uncertainty presented by the recovery period following surgery. The mutuality that was present between the nurse researcher and spousal caregiver helped the family caregivers draw meaning and gave them new perceptions on their remaining life that they still have to live.

Falkenstern (2009) examined family caregivers of children with special needs and found that there were critical times in each family’s life when a caring nurse practicing within Newman’s theory of health as expanding consciousness could have made a difference in the life of that family. The influence of community was present throughout each family’s trials as well as their successes with their child.

**Discussion/insights of utilization of HEC methodology**

As this research study unfolded, changes to the HEC methodology six-step implementation guide (Newman, 1994) were made. First, the opening question of “Can you please tell me about the most important people in your life” was utilized with the first two ALS family caregivers (ALS family caregiver 1-John and 2-Alex) in accordance with Newman’s research method protocol, but this proved to be ineffective in establishing the focus of the research study. Instead, a broad opening question of “Could you please tell me about your husband/wife/mother who you care for” was utilized with ALS family
caregivers 3-8. This nurse researcher found this opening question to be much more effective in starting the process of co-creating the meaning about the process of being an ALS family caregiver. Although this opening question of “Can you please tell me about the most important people in your life” has been used in past HEC research studies examining the phenomenon of family caregiving (Falkenstern, 2009; MacLeod, 2008) to establishing a chronological life pattern diagram that illustrates meaningful people and events in that caregiver’s life, this nurse researcher found that meaningful people and events in the ALS family caregiver’s lives emerged as the interviews unfolded just through the meaningful presencing and co-creation inherent in the research process. For any future research studies utilizing this HEC framework, this nurse researcher would follow this alteration (i.e. “Could you please tell me about your husband/wife/mother who you care for”) in the opening question.

Secondly, this nurse researcher asked each ALS family caregiver at the end of the second interview if through our interactions together had given them an added insights or new ideas. This enabled this nurse researcher to have data from the ALS family caregivers about their interpretation of their own expansion of consciousness and thus not rely on the nurse researcher’s interpretation of the impact of this mutual partnership of meaning. Being able to have this expressed openly by the ALS family caregiver was a new approach to utilization of the HEC theory and one that this nurse researcher would utilize again in future studies.

The insights provided by ALS family caregiver 4 provided a refinement of past Newman research in terms of the chronological life pattern diagrams. Separation of the life pattern diagram into two different aspects of ALS caregiving (physical and
emotional) and establishing different patterns on both has not been explored in past research studies utilizing Newman’s theory. Although ALS caregiver 4 was the only caregiver to explore this separation of types of caregiver stress experienced in the everyday world of ALS family caregiving, it provided a possible point of exploration for future research studies utilizing HEC.

Determining the placement of each ALS family caregiver on the appropriate stage of Young’s Stages of Evolution of Consciousness after completing the life patterns of the whole across all ALS family caregivers instead of immediately after the analysis of life patterns for each individual ALS family caregiver, as recommended in the Newman research protocol (1994), would be another refinement that this nurse researcher would continue in future HEC research studies. Young states, “the physical manifestations of disease may be considered evidence of how one is interacting with the environment. The task is to gain an understanding of that pattern and to work with it” (Newman, 1994). By understanding the life patterns of the whole of all caregivers enabled this nurse researcher to more clearly gain an understanding of each ALS family caregiver’s own life patterns and subsequent appropriate placement on Young’s Stages of Evolution of Consciousness. This refinement of the Newman method (Newman, 1994) would be another procedure that would be followed for future research studies.

The concept of research bias was something that solidified for this nurse researcher as this research study evolved. Throughout this nurse researcher’s doctoral studies the definition of bias was geared toward the classic definition of bias being “any influence that distorts the results of a study and undermines validity” (Polit & Beck, 2008,p.748) until I expanded my own consciousness about the unitary-transformative
paradigm that framed and guided this current ALS family caregiving research study. In the unitary-transformative paradigm, bias is embraced, but this definition of bias is clearly different from Polit and Beck’s definition of bias. For HEC, which is nestled in the unitary-transformative paradigm, the definition for bias that solidified for this nurse researcher was “the bringing forth of all personal experiences, both present and past” to the research study. This did not distort nor undermine the validity of the study, but rather provided the forum for authentic presence and co-creation of meaning to take place between the nurse researcher and each ALS family caregiver.

Implications

There exists a gap in theoretically driven nursing research about the ALS family caregiving experience. If nursing is to continue to develop and maintain its scientific body of knowledge, then theory driven research is essential (Newman, 2008). Roy and Jones (2007, p. 28) state, “Nursing theory expresses the values and beliefs of the discipline, helps to frame the human experience and guides the caring process.” Newman (1994, p.141) asserts, “Caring is a moral imperative for nursing…Theory that does not take into consideration the caring dimension is not nursing theory.” This concept of caring in the human perspective is central to the theory of health as expanding consciousness.

The research findings from this study provide a theoretical explanation of what it is like to care for an ALS patient by the family caregivers performing this care. These findings add a unique perspective to the current body of scientific literature examining ALS family caregiving that have not previously been reported in the literature. This is the first research study to utilize Newman’s theory of health as expanding consciousness
(HEC) and research method in studying the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient. Through this theory driven research study, this nurse researcher was able to gain a deeper understanding of meaning in the ALS family caregiving experience through the identification of life patterns first on an individual ALS family caregiver level (Aim 1) and then through identification of life patterns across all eight ALS family caregivers (Aim 2).

By understanding the meaning of the ALS family caregiving experience and through dissemination of this research, the potential to inform nursing research and practice about the real world meaning of being an ALS family caregiver is enhanced. This understanding of the everyday meaning of ALS family caregiving can increase insights and raise awareness in nursing research and practice that can impact possible future interventions/outcomes for ALS family caregivers as they traverse their complex caregiving journey.

Health as expanding consciousness provides a theoretical framework/method to study a phenomenon, such as ALS family caregiving, from a nursing perspective, which produces results that are foundational in the development of effective nursing interventions. These nursing interventions can be instrumental in improving patient care by embracing the concept of seeing the family caregiver “as a whole” in a holistic manner. According to MacLeod (2008, p. 199)

Nurses need to be able to assure the health of not only the individual patient but also of those individuals within that patient’s life who are essential to the caregiving process. In order to achieve this goal, nursing must have the power to expand beyond the current environment of care and be able to acknowledge and
meet their patients’ needs in a mutual, reciprocal partnership geared toward transformation and expansion of consciousness.

Through examining life patterns of the ALS family caregivers, nurses can gain a deeper understanding of the caregiving experience and meaningful events in that family caregiver’s world. If nurses do not understand what is meaningful to these family caregivers, then they will not know what questions to ask to discover the unmet needs of the ALS family caregivers. Through the recognition of life patterns, such as those provided through this research study, discharge education can be less-task driven and more focused on the “whole” of the ALS caregiving experience and what is meaningful to the ALS family caregiver. With this increased understanding of the meaning in a caregiver’s life pattern, nursing has the opportunity to understand what kinds of support are most important to that ALS family caregiver and provide interventions based on this increased insight into the ALS family caregiver’s journey with their loved one.

This research study of the understanding of the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient endorses Newman’s theory of health as expanding consciousness (HEC) as a transformative nursing research method and theoretical framework for nursing practice and research. The interpenetration of the nurse researcher and ALS family caregiver’s energy fields illuminated the pattern for the whole of the nurse researcher/ALS family caregiver process. This nurse researcher formed a caring relationship with each ALS family caregiver while making a conscious effort to fully engage and be present in the moment during all interview interactions with each ALS family caregiver. The co-creation of meaning between the nurse researcher
and ALS family caregiver created a partnership where both nurse researcher and ALS family caregiver experienced pattern recognition, insight, and transformation.

The research question was: What are the life patterns of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient through a unitary transformative paradigmatic lens? The nurse researcher/ALS family caregiver process of facilitating health as expanding consciousness in family caregivers caring for a loved one with ALS revealed in this research study was (a) establishing a time and place for the nurse researcher and ALS caregiver to form a relationship, (b) developing a bond with each ALS family caregiver, (c) creating an atmosphere that allows the family caregiver and nurse researcher complete freedom to express themselves openly, (d) offering a sense of timelessness for insights about the ALS family caregiving experience, and (e) transformation as the nurse researcher and ALS family caregiver come together to find meaning in the chaotic experience of family caregiving for an ALS patient. It was revealed that this is neither a stagnant nor a linear process. Instead the process is spiral in nature with one stage evolving forward and backward from one another. The identification of the nurse researcher/ALS family caregiver process of facilitating health as expanding consciousness in ALS family caregivers adds to the body of literature about the “nurse-client” process (Newman, 1984) utilizing HEC.

Eight ALS family caregivers participated in this research study and over 900 pages of transcribed pages of interview data were analyzed to arrive first at a pattern of the whole for each ALS family caregiver (Aim 1) and then across all ALS family caregivers to reveal a pattern of the whole enfolding all eight ALS family caregivers (Aim 2). The nine patterns of the whole across all ALS family caregivers were (a)
suspicions emerge but ALS diagnosis is delayed, (b) support that helps the caregiver, (c) support can make caregiving more difficult, (d) looking toward the future, (e) adaptations from ALS, (f) obstacles to the caregiving role, (g) caregiver respite, (h) focus of others, and (i) strategies aiding the caregiving role. All eight ALS family caregivers moved through at least one stage of Young’s Stages of Evolution of Consciousness, yet from the data emerged the insight that because these ALS family caregivers were actively engaged in a disruptive, chaotic time in their ALS caregiving role, the majority of the ALS family caregivers were associated with at least two stages of Young’s Stages of Evolution of Consciousness, which was a unique finding in research studies utilizing Newman’s health as expanding consciousness.

Allowing the ALS family caregivers to have the time and space to be themselves, freely express their emotions, relate what is meaningful to them, and act upon what is important to them empowers them to action that otherwise might not have been offered other than through this research study. As ALS caregiver 7 (Karen) shared,

No one has ever taken the time to talk with me about being a caregiver but we are the ones who have the real story of what it’s like. No one else is painting the real picture. We are the real picture.

All of the ALS family caregivers were in the midst of a very complex caregiving experience, and this research study showed how nurse researchers have the opportunity to really make a difference in an ALS family caregiver’s life as well as the nurse researcher’s own life. “Nurses who utilize and embody health as expanding consciousness are energized by their own transforming power of presence” (Newman, 2008, p. 35) because they relate and see “the whole person.” According to Falkenstern,
Gueldner, and Newman (2009, p. 278), “the key is the relationship.” The nurse researcher/ALS family caregiver relationship is above all a “human to human relationship” (p. 278) and it is through this research as praxis, which is embraced through the HEC theory, that nurse researchers and ALS family caregivers have the opportunity to resonate with each other and in turn transform each other in the process.

**Transformation of the nurse researcher.** As a result of this research study, this nurse researcher experienced transformation and expansion of consciousness through the process of co-creation of meaning with the ALS family caregivers. This impacted this nurse researcher not only on a personal but a professional level. Through this research experience, this nurse researcher experienced transformation, as many of the ALS family caregivers would express their emotions with me, and I with them. There were tears shed together and many periods when time was needed for the caregiver to recover and gather his/her thoughts before the ALS family caregiver could continue with his/her story. Through this research study process, this nurse researcher saw every caregiver achieve insight into his/her own life, gain openness about sharing their life experiences, and discover new awareness/understanding into their caregiving role with their loved one both now and for the future. Following each interview, the nurse researcher required private quiet time to not only record field notes, but to also emotionally recover from the interactions with the family caregivers. Often a period of meditation would be required to emotionally center myself after each interview due to the emotions revealed through the dialogue with each family caregiver.

The transformation for this nurse researcher went far beyond knowledge about caregiving brought forth prior to this research study by examining statistics/research/facts
about ALS family caregiving or even the experience gained by prolonged observation of family caregivers in an ALS clinic. This research study was a journey that touched my soul and my heart and gave me such a deep admiration of what these ALS caregivers are willing to sacrifice to bring forth the best care to their loved ones in the midst of deep personal, professional, or family sacrifice. Yet, none of the caregivers complained about this role, rather their focus remained on their loved one and how to bring forth the best closure to this last chapter in their loved ones life. Some were able to even look forward into the future when their loved one would no longer be with them and the changes that would exist in their life then. Their strength in the midst of the challenges they faced on a daily basis amazed and humbled me. They also confirmed for me that they are so worthy of future research efforts that can support them as they travel this complex caregiving journey with their loved one with ALS. As we are the sum of our experiences in life, my life patterns have been changed forever through the honor of coming together as one with each of these ALS family caregivers.

When this nurse researcher met Margaret Newman in 2009, I asked her if she had any advice for me as a novice researcher starting my dissertation journey and she said (M. Newman, personal communication, August, 2009) to “Stand in the center of your truth” and to me this meant that if I was willing to open myself up to the truth of the universe and all it could offer, it could guide and direct me throughout any communication/interaction with anyone I would ever meet. I tried to apply this concept to my interactions with every ALS family caregiver and this advice helped me to be fully present and open and as a result, found the co-creation of meaning to be effortless, unforced and a natural occurrence as the caregivers and I dialogued together to uncover
life patterns of meaning in their caregiving worlds. This advice is something that I will carry forth with me in any future research study as well as in my professional role as a nurse educator or practicing clinical nurse.

**Strengths and limitations**

This research study had many strengths. First the ALS family caregivers were evenly distributed between males and females and all of the ALS family caregivers were caring for ALS patients whose forced vital capacities (FVC) values were distributed across the entire ALS disease trajectory (on the basis of FVC values and clinical presentation) capturing FVC values that were above 80% (representing ALS patients with the fewest clinical presentations), above 50%, (representing the middle of the ALS trajectory where respiratory support is needed but end of life discussions are not imminent), below 50% (representing where end-of-life decisions are first discussed), and below 30% (representing where hospice plans are initiated). One ALS patient (#4-Tony) had and diaphragm pacemaker, and one ALS patient (#3-Emma) had also been diagnosed with frontal temporal dementia (FTD), two ALS patients had a familial history of ALS (#3-Emma and #7-Mark), two were participating in ALS clinical trials (#4-Tony and #6-Ashley), two had PEG tubes (#1-Jane and #4-Tony), all patients used assistive devices ranging from StairGlides, eye gaze devices, mobility assists, and devices to aid activities of daily living (ADL’s), one ALS patient (#8-Bob) had a heart transplant, and one (#4-Tony) had a history of cancer. This representation of FVC (forced vital capacity) values and clinical presentations are important because these ALS patients provide a diverse representation of the ALS patient trajectory and this representation is reflected in the care provided by the ALS family caregivers in this study. Research by Murphy, Felgoise,
Walsh, & Simmons (2009) showed that the time, amount and intensity of the ALS caregiving experience is directly related to the progression of the ALS disease. Despite all the diversity of the ALS patients in this study and the correlating diversity of care provided by the ALS family caregivers, all of the ALS family caregivers share commonalities as evidenced by the nine life patterns of the whole across all eight ALS family caregivers in this study.

There were limitations to this study. The research participants volunteered for participation and although they were initially purposively sampled and then theoretically sampled, they may have been more open to sharing their life experiences as being an ALS family caregiver than those who chose to not participate. All ALS family caregivers expressed the desire to share their caregiving experience with the hopes of helping healthcare providers and other individuals who care for a loved one with ALS. There was also a lack of ethnic diversity with all caregivers being White. Future qualitative research studies involving ALS family caregivers of various ethnic and racial backgrounds would add additional meaningful data that could help provide culturally sensitive care. Only one son ALS family caregiver was among the 8 other ALS family caregivers and it would be important for future family caregiver research studies to include more participants representing adult children taking care of their parent with ALS. Also having more family caregivers in the age range of 20-30 years of age could provide meaningful insights into differences created by having different generational ages of the family caregivers.

All of the spousal ALS family caregivers except one (ALS family caregiver #7-Karen) in this research study reported having a happy marriage and all spousal ALS family caregivers had been married for a lengthy time (range 14-58 years). As the literature suggests
that prior marital satisfaction may play a role in caregiver attitude and burden, it is recommended that future studies include ALS family caregivers with more varied marital backgrounds (Edwards & Scheetz, 2002; Goldstein, Atkins, Landau, Brown, & Leigh, 2006; Seltzer & Li, 2000).

**Future research**

Following the same ALS family caregiver over the trajectory of the ALS disease, including family caregivers who care for a loved one who has chosen mechanical ventilation for life extension, utilizing the HEC theoretical framework and methodology could provide a rich descriptive account of the ALS caregiving experience over time while providing the opportunity to see the action potential of the ALS family caregiver over time so that transformations over the caregiving trajectory could be explored.

Exploring the generational effects of ALS family caregiving through engaging with younger spousal family caregivers (i.e. ages 20-40) or sons/daughters caring for a parent with ALS could provide meaningful insights into another aspect of ALS family caregiving that has not to date been addressed.

Exploring how nurse researchers experience their own transformation and evolution of consciousness following the utilizing of HEC could provide added insights into the transformation process as co-creation occurs. Because of the intentional presencing brought forth by the HEC theory, the potential for increased awareness of self and other could bring more clarity to research findings, and provide added insight into the nurse researcher/ALS family caregiver process.

**Summary**

This research study examined the experience of family caregivers who care for an amyotrophic lateral sclerosis (ALS) patient within the theoretical framework of
Newman’s health as expanding consciousness (HEC). The researcher formed a caring relationship with each family caregiver and made a concerted effort to be fully present in the moment during all interactions with each ALS family caregiver. The caring relationship initiated by the nurse researcher blossomed into a partnership in which both nurse and ALS family caregivers experienced pattern recognition, insight, and transformation.

The nurse researcher/ALS family caregiver process began with a caring relationship initiated by the nurse researcher. Trust was established as the nurse fully and nonjudgmentally engaged in each ALS family caregiver’ dialogue. Pattern recognition flowed when the family was enfolded with an authentic, caring presence. The nurse researcher/ALS family caregiver pattern of the whole revealed for this study was: (a) establishing a time and place for the nurse researcher and ALS caregiver to form a relationship, (b) developing a bond with each ALS caregiver, (c) creating an atmosphere which allows the caregiver and nurse complete freedom to express themselves openly, (d) offering a sense of timelessness for insights about the ALS caregiving experience, and (e) transformation as the nurse researcher and ALS family caregiver came together to find meaning in the chaotic experience of informal family caregiving for an ALS patient.

Nine patterns of the whole across all ALS family caregivers were identified (Aim 2). These nine patterns of the whole were: (a) suspicions emerge but ALS diagnosis is delayed, (b) support that helps the caregiver, (c) support can make caregiving more difficult, (d) looking toward the future, (e) adaptations from ALS, (f) Obstacles to the caregiving role, (g) caregiver respite, (h) focus of others, and (i) strategies aiding the caregiving role. Even though all of the ALS family caregivers in this research study were
actively caring for a loved one with ALS representing a wide range of symptoms/adaptations across the trajectory of the disease, these nine patterns of the whole were present across all the ALS family caregivers.

All eight ALS family caregivers were placed on at least one stage of Young’s spectrum of the evolution of consciousness (Newman, 1994), four were placed on two stages and one was placed on three stages of Young’s spectrum. This was proposed to be due to the chaotic nature of actively caring for their ALS loved one during the time of the interviews.

This research provided new insight into the life patterns of ALS family caregivers as well as showing the importance of understanding the meaning of this unique caregiving experience. The insights revealed through this research study disclosed important implications for nursing research and practice while adding to the empirical support of health as expanding consciousness (HEC) and the potential for expansion of this nursing theory and method.
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Appendix A

Invitation Letter from ALS Neurologist

Dear ALS caregivers:

Over the recent months, many of you have met Peggy Shipley, researcher from Penn State School of Nursing, who has been observing ALS clinic visits. For her dissertation, she is interested in studying ALS caregiving and is interested in uncovering the “everyday experience” of caregiving. The goal of her research is to help healthcare professionals, such as those on our ALS team, better understand the experience of being a caregiver, thus enabling us to enhance our supportive efforts for caregivers.

Your participation in this research project is voluntary. At your next clinic visit, the nurse manager will ask you if you are interested in participating in this study. If you are interested, then Peggy Shipley will contact you. If you choose to participate in the research, you will be interviewed two times within one month of time. In most cases these interviews will be conducted in your home.

Attached is an invitational letter, which provides a summary explanation of this research study. Thank you for your consideration of this research endeavor.

Sincerely,

Signature of ALS clinic neurologist
Director, Neuromuscular Program & ALS Center
Appendix B

Invitation Letter from Nurse Researcher

Dear ALS caregiver,

I am a doctoral student at Penn State University in nursing and have been working in the [Name] ALS clinic for over a year as a research assistant. For my dissertation I am interested in exploring what it is like to be a caregiver for an ALS patient. I would like to interview caregivers about their experiences as it relates to caregiving. If you would be interested in sharing your story of your experiences caring for an ALS or PLS patient, please let [ALS nurse manager] know at your next clinic visit and I will contact you.

Thank you so much for your consideration.

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1989 Bachelor of Science in Nursing The Pennsylvania State University, University Park PA
1981 Bachelor of Science in Music Education The Pennsylvania State University, University Park PA

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August, 2011-present: Tenure track Assistant Professor, Slippery Rock Department of Nursing, Slippery Rock, PA
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September 2007-September 2010-Substitute school nurse, State College Area School District- grades K-12
July 1988-September 1993: Staff Registered Nurse-Intensive Care Unit/Coronary Care Unit, Centre Community Hospital, State College, PA
September 1984-June 1986: Band and Choral Director, grades 10-12 Philipsburg-Osceola Area High School, Philipsburg, PA

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