Resiliency Factors: Predictors of Quality of Life in Family Caregivers of Patients with Amyotrophic Lateral Sclerosis

Beatrice Hamblin Chakraborty

Philadelphia College of Osteopathic Medicine, beatricech@pcom.edu

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RESILIENCY FACTORS: PREDICTORS OF QUALITY OF LIFE IN FAMILY CAREGIVERS OF PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

by Beatrice Hamblin Chakraborty

Submitted in Partial Fulfillment of the Requirements for the Degree of
Doctor of Psychology

February 2007
PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY

Dissertation Approval

This is to certify that the thesis presented to us by Beatrice Hamblin Chakraborty

on the 20th day of June 2006, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Stephanie Felgoise, Ph.D., ABPP, Chairperson

Barbara Golden, Psy.D., ABPP

Zachary Simmons, M.D.

Robert A. DiTomasso, Ph.D., ABPP, Chair, Department of Psychology
Acknowledgments

I am personally grateful to all of the clinical psychology graduate students of the Philadelphia College of Osteopathic Medicine who volunteered to collect data for this study. I am also thankful for the amazing support given to this project by the ALS clinic directors and their staff members. I will remain forever indebted to you for your generous and personal involvement.

Finally, I want to thank the caregivers who graciously volunteered to participate in this research. I am personally and professionally indebted to all of you and wish you a positive quality of life, going forward.
Dedication

This thesis is dedicated to the memory of my mother, Emma Elizabeth Tilghman, who inspired me early on with her spirit of resiliency against enormous odds.
Abstract

Amyotrophic lateral sclerosis (ALS) is a progressive, neurodegenerative disease resulting from generalized degeneration of motor cells in the brain and spinal cord (The Amyotrophic Lateral Sclerosis Association [ALSA], 2004). Also known as Lou Gehrig’s disease, ALS has no conclusive etiology, no known cure, and death generally occurs within three to five years following the diagnosis (Rabkin, Wagner, & Del Bene, 2000). Given the devastating and predictable course of ALS, it is understandable that this disease can have a profound, adverse impact on the quality of life (QOL) of the patient and the caregiver. However, not all caregivers, particularly spouses who assume the primary care for patients with ALS, perceive the experience of caregiving as a profound burden (Miller & Lawton, 1997). In fact, some ALS caregivers appear to be psychologically resilient to the stress associated with caregiving, and even endorse satisfaction with their QOL. Yet the protective factors, or resiliency variables, that contribute to ALS caregivers’ positive QOL are largely unexplored in empirical research. This is a cross-sectional study, and data generated by ALS caregivers using the following measures were collected: Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS), State Hope Scale (SHS), Life Orientation Test – Revised (LOT-R), Social Problem Solving Inventory – Revised: Short (SPSI-R: S), and the World Health Organization Quality of Life – Brief Form (WHOQOL-BREF). The following hypotheses were tested: (1) Hope, optimism, social problem solving abilities, relationship satisfaction, and religiosity/spirituality will be significant predictors of the quality of life
for caregivers of patients with ALS. (2) Positive problem orientation and rational problem solving skills will be positively correlated with the relationship satisfaction of spousal caregivers of patients with ALS. (3) ALS caregivers’ religiosity/spirituality will be positively correlated with caregivers’ state hope and dispositional optimism (i.e., positive life orientation). Analyses of the data collected from the sample participants (n = 58) are at least preliminarily consistent with prior research suggesting that there are some significant inter-construct relationships between the independent variables. This study supports the notion that clinicians can identify at-risk caregivers early in the caregiving experience, in order to engage these caregivers in appropriate interventions designed to enhance their quality of life and the quality of life of patients living with ALS. Limitations of the study and clinical implications of the development of the ALS Caregiver Resiliency Training, an intervention model, are discussed.
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Chapter 1

Statement of Problem

Amyotrophic lateral sclerosis (ALS) is a progressive, neurodegenerative disease resulting from loss of both upper and lower motor neurons that are responsible for innervating voluntary skeletal muscles. Clinical evidence of ALS is characterized by a generalized degeneration of motor cells in the brain and spinal cord, leading to multisegmental muscle weakness and, as the disease progresses, severe impairment of mobility, speech, and swallowing (The Amyotrophic Lateral Sclerosis Association [ALSA], 2004; McCluskey, 2000). Also known as Lou Gehrig’s disease, ALS has no conclusive etiology and no known cure. Death is primarily due to respiratory insufficiency or aspiration, often after reaching a decision not to start or to discontinue ventilatory support, and generally occurs within three to five years of the diagnosis (Rabkin, Wagner, & Del Bene, 2000).

The incidence of ALS is approximately one to two in every 100,000 adults annually worldwide, and the prevalence of the disease is estimated to be from one to seven per 100,000 population (Cwik, 2001). In the ALS Patient Care Database, the ratio of men to women was 1.6:1, while age at ALS symptom onset in men was 52.8 years ± SD 16.0 years, and in women was 57.3 ± 13.5. Peak ALS onset age was between 60 and 70 for both sexes (Cashman, White, & Anderson, 1999). The incidence and prevalence of ALS among minority populations in the United States is estimated to be the same as their representation in the general population (ALSA, 2004).
The combined findings of two studies published recently suggest that United States veterans of the 1991 Persian Gulf War are twice as likely as the general public to develop ALS (Haley, 2003; Horner, Kamins, Feussner, Grambow, Hoff-Lindquist, Harati, et al., 2003). With the exception of an unusually high frequency of cases occurring in specific regions of the western Pacific, particularly Guam, there is no pattern of geographic clustering of ALS (ALSA, 2004).

Early research proposed that the clinical presentations of ALS did not typically include signs of dementia or cognitive deficits (McCluskey, 2000). This would suggest that as the patient’s body is deteriorating, the mind remains intact and aware of all that is happening within and without. This state is sometimes referred to as the totally locked-in syndrome (TLS) in an advanced stage of the disease (Hayashi & Kato, 1989). In contrast, newer research suggests a closer association between ALS and cognitive impairment. For example, Flaherty-Craig and Simmons (2004) found that ALS is associated with cognitive decline, particularly a frontotemporal lobar degeneration (FTLD), which eventually progresses into dementia marked by predominant executive functioning deficits. However, investigators admit that the prevalence rates of ALS comorbid with FTLD are variable, ranging from 3% to 48%, likely due to the lack of standardized criteria for determining cognitive disturbance within that population (Murphy, Odell, Kramer, Miller, & Lomen-Hoerth, 2004). Given these recent findings, albeit inconclusive, it appears that a growing number of patients with ALS present with significant risk factors for progressive executive dysfunction, and this has serious implications for patient-physician-caregiver collaborative disease management, treatment interventions, and the patient’s competency to make end-of-life decisions.
Impact of ALS on Family Caregivers

Given the devastating and predictable course of ALS, it is understandable that this disease affects the patient’s entire family and can have a profound impact on the psychosocial and spiritual quality of life (QOL) of the patient and the primary caregiver (McDonald, 2001). Primary caregivers, in this study, are operationally defined as spouses or domestic household partners who assume primary responsibility for: (1) the patient’s emotional support, (2) helping with activities of daily living, (3) administration of medications, (4) provision of any special nutrition plan, and (5) help with other aspects of physical care during the course of the disease (Le, Leis, Pahwa, Wright, Ali, & Reeder, 2003). Also in this study, reference to spousal caregivers is inclusive of primary caregivers married to patients with ALS, primary caregivers in common-law unions, and primary caregivers in same sex partnerships. Finally, quality of life is a multidimensional concept and is operationally defined as the subjective appraisal of and perceived satisfaction with one’s physical functioning, psychosocial well-being, socioeconomic status, emotional well-being, family functioning, symptom distress, and spiritual well-being (Le et al, 2003; Del Bene, 2001; Shewchuk & Elliott, 2002).

Over the past two decades, psychologists and other social scientists have demonstrated a growing interest in the various issues that concern family caregivers (Shewchuk & Elliott, 2002). Pearlin, Mullan, Semple, and Skaff (1990) report that family caregiving research has produced an enormous literature base and insight into the experiences encountered by those who provide ongoing homebound care to chronically ill relatives. Many studies address the burden of caregiving and the pernicious effects of prolonged family caregiving on one’s physical health, such as disruptions in
cardiovascular and immune functioning (Rabkin et al., 2000; Vitaliano, Zhang, & Scanlan, 2003). Also, the literature tends to emphasize the effects of psychosocial stress and depressive symptoms on the mental health of caregivers (Albert, 2004; Chiò, Gauthier, Montuschi, Calvo, DiVito, Ghiglione, et al., 2004).

In contrast, there is evidence that family caregivers may derive a sense of psychological well-being and personal meaning in caregiving (Miller & Lawton, 1997). Indeed, some findings have clearly shown that many individuals do not necessarily experience depressive symptoms, even under severely stressful caregiving circumstances (Sarason, Johnson, & Siegel, 1978), and they maintain a high quality of life. Much of the quality of life research in ALS is focused on patients and their sense of well-being (Allen, 2004; O’Doherty, Hickey, & Hardiman, 2004; Rabkin et al., 2000; Simmons, 2004). Yet a review of the literature to date reveals that the positive aspects of caregiving and quality of life in the context of ALS rarely receive empirical attention. This study will focus on the quality of life of ALS caregivers who effectively manage the role demands and challenges as de facto health care providers in the home (Shewchuk & Elliott, 2002).

Quality of Life Issues Facing Family Caregivers

Dementia Caregivers. Rabkin et al. (2000) report that the extensive literature on psychiatric and physical morbidity associated with caregiving has focused largely on providing care to patients with dementia. Of the many studies exploring the health outcomes of dementia caregivers, where measures of distress and depression were included, elevated rates of depressive symptoms were prevalent (Rabkin et al., 2000). It appears that the prevailing assumption in dementia research is that a majority of all
caregivers might experience elevated levels of depressive symptoms or subjective distress. Supporting evidence based on a report from the Cleveland Clinic Foundation suggests that primary caregivers spend a median of eleven hours a day caring for patients, and 50% of them reported feeling unwell, both physically and mentally (Krivickas, Shockley, Saito, & Mitsumoto, 1995). In addition, they found that financial distress was a common theme among caregivers because they often had to reduce or discontinue employment and health insurance almost never covers all expenses.

**Cancer Caregivers.** Cancer literature has recognized the burden that the diagnosis and treatment of cancer place on close family members since the early 1980s (Le et al., 2003). According to recent research, family caregivers of patients with cancer experience increased symptoms of depression, anxiety, psychosomatic symptoms, restrictions of roles and activities, strains in marital relationships, and diminished physical health (Northhouse, 1998). Baider and Kaplan-DeNour (1998) found that spouses of cancer patients actually suffer as much if not more distress than the patient. Common concerns and worries from the caregiver’s point of view included the perception of the cancer patient’s pain, body disfigurement, and sexual problems related to the disease (Le et al., 1998). In addition, the authors found that at least two thirds of the caregivers worried about having adequate financial resources.

**Amyotrophic Lateral Sclerosis Caregivers.** In contrast to dementia and cancer research, Rabkin et al. (2000) found that neither patients with ALS nor their caregivers displayed significant depressive symptomatology, and they concluded that clinical depression is not inevitable and not as common among this population as it might be among patients with dementia or cancer. Del Bene’s (2001) more recent study on QOL
issues found that most patients with ALS may express reactive sadness in response to losing physical function, but she explains that this is not clinical depression, referring to the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV). Also, her research suggests that ALS caregivers may reasonably expect to have a normal emotional reaction to a very distressing situation, which may or may not be a QOL issue for them.

Del Bene (2001) did conclude, however, in concert with available research on dementia and cancer, that the financial issues of ALS can be devastating. Insurance companies define ALS home care as custodial care because improvement is not expected. Further, the increasing need for assistance with activities of daily living and the need for supervision and safety are not covered under custodial care (Del Bene, 2001). Krivickas et al. (1995) reported that expenses can reach $150,000 annually for patients who require ventilatory assistance and who are also cared for at home.

Quality of Life Issues Facing ALS Spousal Caregivers

Although all family caregivers of patients with ALS are deeply affected by the illness, the impact of ALS on spouses and intimate partners is particularly overwhelming. Plus, there is the pressure of trying to maintain a positive affect. If the caregiver appears to be overwhelmed and distressed, that may only add to the patient’s perception of being a burden, which in turn exacerbates the patient’s distress (Rabkin et al., 2000). In the late 1990s, investigators began to examine specifically the QOL of spousal caregivers of patients with ALS.

Physical and Emotional Health. Woolley and Ringel (1997) found that spouse-caregivers reported both physical and mental health well-being scores close to those of
the general population. They evaluated over 800 primary caregivers using the 36-item self-report Quality of Life Scale (QoLS) and additional questions and reported high life satisfaction among study subjects, which did not change with the progression of ALS, even though their roles would change as the disease progresses. Bromberg and Forshew (1998) interviewed 15 patients with nearly normal pulmonary function and 14 spouses in a pilot study, using the Schedule of the Evaluation of Individual Quality of Life (SEIQoL). In contrast to the former study, Bromberg and Forshew (1998) found that ALS had a more pronounced impact on the mental health and the QOL of caregivers than on patients, which may be higher than the general population.

Rabkin et al. (2000) explored another aspect of distress, that is, spousal caregiver adjustment to the care recipient’s illness progression and functional impairment. They report two significant findings. First, caregivers who cannot afford outside help are likely to be more distressed because they feel guilty about leaving their spouses alone and they tend to neglect their own health care needs. Second, those who found positive meaning in caregiving perceived less caregiving burden, regardless of time since diagnosis or illness progression.

A more concrete example of a biopsychosocial stressor that may compromise the QOL of spouses and partners living with ALS is the progressive loss of conjugal intimacy. Depending upon the perceived quality and frequency of intimacy before ALS, decreased physical contact (i.e., kissing, touching, intercourse) or loss of same could be a significant QOL issue (Ciechoski & Heimen-Patterson, 2004). Moreover, the authors found that ventilator-dependent patients and spouses certainly experience a greater loss of intimacy than non-ventilator-dependent couples.
Another potential threat to ALS caregivers’ QOL is increased social isolation. The level of distress may also depend upon the type and frequency of past social activities in the years preceding ALS. Ciechoski and Heimen-Patterson (2004) found that (1) as increased care demands infringed upon the caregiver’s personal time, and (2) as the course of illness progressed towards totally locked-in syndrome (TLS) and ventilator dependence, (3) social contacts outside the home seemed to decrease.

**Role Changes and Relationship Strain.** The changes in roles necessitated by the decreased functional abilities of the ALS patient can lead to an unrecognized and unacknowledged shift in the relationship between spouse and patient, from a husband-wife dyad to that of caregiver-patient. In her ALS Patient Profile Project, McDonald (2001) found that couples that reported having high-quality lives despite ALS said that living, not ALS, was the center of their lives. Couples who were successful in living fully and maintaining their relationships, through the course of ALS, saw the disease as a shared experience and were able to communicate well enough so that resentment, guilt or other negative emotions did not build up over time (McDonald, 2001). For the psychosocial-spiritual well-being of both patient and spouse, McDonald suggests that the ALS caregiver-patient couple can nourish and maintain a warm and intimate husband-wife relationship by having other people help with physical care and by continuing previously shared activities, such as seeing movies, playing cards, watching sunsets, being intimate, or going to the park.

**Finances.** The financial issues of ALS can be devastating, and spouses often exchange or undertake unfamiliar money management roles after onset of the disease. McDonald (2001) found that before the onset of ALS, only 3% of the spouses described
themselves as very worried about money. After onset, that percentage rose to 18%, and some spouses were forced to take on a job to meet the growing financial obligations. Health insurance rarely if ever covers home care, but a caregiver who is skillful in finding positive meaning is more likely to adapt and problem solve to get from a perceived state of financial burden to a state of positive opportunity.

Resiliency

Some caregivers appear to exhibit resiliency when the integrity of their quality of life is threatened by unexpected, adverse circumstances. In the wake of negative life events, these individuals use their resources well, maintain a positive affect, derive personal satisfaction in the act of caregiving, and even find positive meaning in the experience (Miller & Lawton, 1997). In one isolated study assessing resilience and distress in patients with ALS and caregiver spouses, the investigators imply that finding positive meaning in caregiving is a behavioral manifestation of resilience (Rabkin et al., 2000). Yet the concept of resilience is largely unexplored within the caregiving population.

Perhaps the lack of research attention to resiliency in caregivers is because this construct is difficult to operationalize within a psychological context (Miller, 2003). For example, in the medical model, the concept of resilience is likely to be associated with bouncing back from a difficult surgery or surviving a physical disease like cancer. In a psychiatric context, also conceptualized within a medical model, adult resilience literature understands resilience as the absence of pathology in the aftermath of a traumatic event such as sexual assault (Miller, 2003). The assumption in the latter model
appears to be that the traumatic experience triggered a spontaneous resilient response, which somehow made it possible for the victim to survive the event. Therefore, if it were not for the experience, the individual would not be perceived as resilient, because resiliency is in the eye of the observer.

In contrast, caregiving is an ongoing, subjective experience. In the case of ALS spousal caregiving, there is greater potential for a particularly intensive experience, with unique inherent challenges, due in part to the predictive negative course of the disease (Shewchuk & Elliott, 2002). Caregiving in this setting requires not only adaptive survival instincts, but an entire set of resiliency skills. Resilient behavior becomes more than the absence of pathological symptoms after a major negative life event (Miller, 2003), such as the initial ALS diagnosis. Resilient behavior, in this strength-based model, becomes the presence of an existing cognitive-behavioral skill set which predisposes the caregiver to: (1) recognize the negative event (ALS diagnosis) and accept it, (2) embrace it and avoid denial, (3) anticipate new role expectations, and (4) plan for the patient-caregiver dyad to live life in the moment (Miller, 2003).

The aim of this current study was to explore the concept of resiliency in caregivers of patients with ALS within the theoretical framework of positive psychology. The primary assumption is that resiliency is a lifespan process of amassing and assimilating unique human strengths and virtues (Seligman & Csikszentmihalyi, 2000) into a virtual repertoire of cognitions and behaviors that become part of one’s identity. A second assumption is that it is the interaction of certain core strengths and virtues that balance and sustain individuals through crises, even over an extended period of time. Also, this study aimed to identify and examine selected core resiliency factors as they
may contribute to or predict the quality of life and psychological hardiness of spousal and partnered caregivers of patients with ALS. It was hypothesized that caregivers who exhibit resilient behavior: (1) possess future-oriented worldviews (i.e., hope and optimism), (2) have premorbid satisfying and empowering relationships with the care recipients, (3) are grounded in spiritual beliefs and practices, and (4) have the ability to skillfully solve problems are more likely to endorse a positive quality of life during their caregiver experience.

Resiliency Constructs

Hope. One of the core factors of the caregiver resiliency model, in this study, is hypothesized to be hope. As conceptualized by Lopez, Snyder and Pedrotti (2003), hope is cognitive based and has two components, pathways thinking and agency thinking. The authors go on to define pathways thinking, the planning component, as the perception that one is capable of generating alternative paths to reach one’s goals. Agency thinking, the motivational component, is when the value of a given goal is perceived to be sufficient enough to motivate a person to pursue it. If a chosen path is blocked, agency thinking keeps the goal in sight and provides the motivation and confidence to use an alternate path (Lopez et al., 2003). Relating this concept to ALS caregivers and their desired goals, the presence of hope is likely a significant factor in determining how resilient they are.

In general, it is accepted that a caregiver’s goal is to keep the patient’s quality of life stable as long as possible and to avoid becoming subjectively distressed over the prognosis of the illness (Rabkin et al., 2000). Often, the ALS patient begins to have
serious medical complications sooner than expected. According to the hope theory, spousal and other caregivers who exhibit resilient behavior will appraise such a negative circumstance as emotionally stressful, much like anyone else (Lopez et al., 2003). However, they are most often accustomed to dealing with stress and reaching their goals successfully in spite of impediments, and they perceive that they are capable of continued success. The hope theorists (Lopez et al., 2003) would refer to these caregivers as high-hopers, whose positive emotions have sustained the caregivers’ motivation to continue looking for ways to reach their desired goal, as long as the value of the goal (i.e., quality of life and psychological hardiness) is perceived to be worth pursuing.

Optimism. There is growing evidence that the positive emotions that sustain motivation and inspire confidence in high-hopers are a function of optimism (Carver & Scheier, 2003), another core resilience factor. Optimism is also a construct of personal strength that involves future-mindedness, perseverance, and the capacity for flow and insight (Snyder, Ilardi, Michael, & Cheavens, 2000). Peterson (2000) found that optimism has cognitive, emotional, and motivational components, linking optimism to hope. Peterson (2000) further observes that individuals high in optimism exhibit better moods and are more persevering and successful.

In a recent analysis comparing hope and optimism, Bryant and Cvengros (2004) found that optimism correlated equally with the hope theory’s agency thinking and pathways thinking. Also, these investigators suggest that optimism focuses on expected quality of successful outcomes in general, whereas hope is more concerned with successful attainment of specific personal goals.
Given that the caregiver’s goal is to keep the patient’s quality of life stable as long as possible (i.e., primary care), and avoid becoming personally distressed (i.e., prevention), the presence of optimism should be a significant factor in the caregiver’s quality of life and psychological well-being. Seligman and Csikszentmihalyi (2000) propose that dispositional optimism mediates between external events and how a person perceives those events. Research shows that people high in both optimism and hope are able to accept unfavorable information about an illness and are better prepared for the realities, even though they have put a more positive spin on the outcome (Peterson, 2000).

**Social Problem Solving.** Lazarus and Folkman (1984) narrowly defined problem solving as a form of problem-focused coping, which contends that problem solving is adaptive only when stressful conditions are changeable or when the person can control the environment. However, within a cognitive-behavioral framework, D’Zurilla and Nezu (1999) theoretically conceptualized problem solving more broadly to include the equally important notion of emotion-focused coping. Thus, these authors proposed that problem solving is not only adaptive for problem-focused coping, but also for emotion-focused coping, that is effectively managing the range of emotions that are generated by the stressful event(s), in order to bring about a solution (D’Zurilla & Nezu, 1999). Effective problem solving is definitely an adaptive coping strategy, but not all ways of coping are adaptive or effective problem solving (D’Zurilla & Maydeu-Olivares, 1995).

Moreover, D’Zurilla, Nezu, and Maydeu-Olivares (2002) understood that individual differences in problem-solving ability do exist in the real world, and that one’s ability to cope with, manage emotional reactions to, and resolve real-life stressful
problems is related to a person’s quality of life (e.g., social competence, psychological well-being). Also, a positive correlation was found between positive psychological well-being, effective problem-solving, and optimism (Chang & D’Zurilla, 1996). In fact, Nezu (1987) found a significant relationship between deficits in problem-solving and depressive symptomatology (i.e., psychological distress). Thus, it is anticipated that effective problem-solving will mediate or moderate the deleterious effects of stressful caregiving (Nezu, Nezu, & Felgoise, 2000), and significantly predict a positive quality of life among ALS caregivers.

As an adaptive coping strategy, social problem solving consists of two domains: problem orientation and problem solving skills (D’Zurilla & Nezu, 1990). The former refers to a mind set that reflects one’s personal cognitive-affective style of responding to problems in living and one’s ability to solve those problems. The latter refers to the specific cognitive-behavioral ability of the problem-solver to apply the right strategies and implement the right solution to effectively alter the problematic nature of the situation or task (D’Zurilla & Nezu, 1990).

Problem orientation, primarily a cognitive response to problems, can be positive or negative. Nezu, Nezu, Friedman, Faddis, and Houts (1998) found that given a positive problem orientation, the problem is conceptualized as a challenge to be overcome, which in turn is more likely to facilitate effective problem solving. Conversely, a negative problem orientation can lead to a negative affect, avoidance of problems, and impulsive behavior, which in turn is more likely to inhibit effective problem solving. Nezu et al. (1998) found that two important aspects of problem orientation are appraisal (i.e., the evaluation of the importance of the problem) and personal control beliefs (i.e., beliefs
regarding the likelihood that a problem can be effectively controlled. Therefore, those who are positively oriented to realistically appraise the problem and their ability to control or alter the problem are more likely to engage in effective problem-solving strategies (Nezu et al., 1998).

Problem-solving skills are the specific cognitive and behavioral abilities that enable a person to solve a problem in the most effective way. D’Zurilla and Nezu (1999) formulated a problem-solving skills model which suggests that there are three problem-solving styles: rational problem-solving style, impulsive and carelessness style, and avoidance style. According to this model, caregivers who exhibit a rational problem-solving style would set specific goals and then deliberately and systematically use effective techniques. Caregivers who go about problem solving in a haphazard, careless manner generally use an impulsive style, often resulting in incomplete and ineffective solutions. The third type of problem solver avoids the problem by putting it off and waiting for the problem to resolve itself, which is often highly ineffective.

Religiosity and Spirituality. Although religiosity and spirituality still do not figure prominently in a review of ALS caregiving literature, both constructs are receiving more recognition as important factors in how the patient copes with the illness (Del Bene, 2001; Murphy, 2003). When religiosity and spirituality are included in stress and coping literature, they are frequently used interchangeably or so vaguely defined as to make it difficult to distinguish one from the other (Koenig, McCullough, & Larson, 2001).

Adult social behavior literature and literature from the psychology of religion make the distinction that characterizes religiosity as formal, overt, observable behavioral expressions of institutional beliefs (Hill, Pargament, Hood, McCullough, Swyers, Larson,
and Zinnbauer, 2000). Individual and group participation in a religious organization implies, by association, that one’s personal beliefs are actively validated and supported by the rituals and practices prescribed by that organization (i.e., church, temple, synagogue, etc.; Hill et al., 2000; Shreve-Neiger, 2004). In contrast, spirituality is viewed as a more subjective, private, and covert experience, described by some as a state of having a special relationship with a sacred or higher power such as God (Hill et al., 2000). Thus, spirituality may even be independent of religions and institutions, given the evidence of those adults who consider themselves spiritual but not religious (Koenig et al., 2001; Koenig, George, & Titus, 2004). Kaye and Robinson (1994) found that caregivers of patients with Alzheimer’s disease believed that spirituality is an important perspective to have to the degree that it helps to lessen caregiver burden. In another study involving caregivers of patients with Alzheimer’s, Mullins-Riveria (1998) looked at the impact of spirituality, financial status, and social support on the perceived burden of 180 caregivers. Using regression analysis, the investigator found that caregivers’ transcendent spirituality predicted low levels of caregivers’ distress. Murphy’s (2003) findings suggest that, for the ALS caregivers in her study, a private spirituality and a personal connection to a higher power were more likely to predict a caregiver’s quality of life than regularly attending public religious services.

Many theorists have taken a negative stance toward public religion but not spirituality. For example, Freud (1953) referred to religion as an obsessional neurosis, a societal barrier to science and reason that restricts people’s basic impulses and prevents them from facing reality. Tsang and McCullough (2004) reviewed a number of empirical studies in the mid-20th century that linked religion with prejudice and negative social
attitudes. In essence, religion is ritualistic and bad. Spirituality, in contrast, is perceived by many people as positive, experiential, and genuine (Hill et al., 2000), or essentially good.

Of course, other studies have supported the positive relationship between religion and physical and mental health, absent any differential reference to spirituality (Tsang & McCullough, 2004; Murphy, 2003). From a positive psychology perspective, theorists propose that religion is operationally defined as the search for the sacred within a religious community, while spirituality is the emotional and cognitive experience of the search for the sacred (Hill et al., 2000; Tsang & McCullough, 2004). According to Tsang and McCullough (2004), this definition allows individuals the flexibility to claim to be (a) religious and spiritual (i.e., a common search for the sacred), (b) religious but not spiritual (i.e., searching for other than sacred within a religious community), or (c) spiritual but not religious (i.e., pursuing the sacred without the religious community).

In the coping literature, Chang, Noonan, and Tennstedt (1998) examined religious/spiritual coping (i.e., the degree to which religion or spiritual beliefs helped them “handle this whole [caregiving] experience”) as it relates to psychological distress among 127 caregivers of frail, disabled elderly. Additionally, they questioned whether or not the quality of the caregiver-care recipient relationship was influenced by the caregivers’ spirituality. The authors found that the degree of the caregivers’ utilization of religion or spiritual beliefs as a coping strategy impacted their appraisal of the quality of their relationship with the elderly patients. Further, when controlling for relationship quality, religion/spiritual coping had no effect on psychological distress (Chang et al., 1998). Yet the presence of religious/spiritual coping and a high quality relationship
appears to enhance the psychological functioning of those giving care (Chang et al., 1998). Thus, it is likely that those ALS caregivers who are spiritual and also belong to a religious network increase the likelihood that they have a support base to call upon for help as needed, such as when relationships are strained by giving and receiving care. Church, temple, or synagogue members often assume the role of an extended family, fulfilling many of the support functions of the biological family, and proxy family caregivers (Belgrave & Jarama, 2002). Such a rich social support base should not be overlooked and might significantly enhance the quality of life and psychological well-being of caregivers who cannot afford paid assistance.

Relationship Satisfaction. The perceived satisfaction with the relationship in a spousal dyad may be determined by the couple’s degree of emotional closeness, including communication and affectional expression, and the degree of tension and conflict (Spanier, 1976). The literature suggests that relationship satisfaction is not only a critical construct in couples’ therapy, but is gaining importance as a mediating variable in caregiving research. For example, Chang et al. (1998) explored the possibility that the caregiver’s use of religious and/or spiritual coping influenced the quality of relationship satisfaction in the patient-caregiver dyad and in turn was indirectly associated with psychological distress in caregivers. They found that subjects in their sample of caregivers of disabled elderly who used religious/spiritual beliefs to cope with their caregiving experience indeed reported a better relationship with their elderly patients, and they experienced lower levels of depression (Chang et al., 1998).

In a related study, Yates, Tennstedt, and Chang (1999) hypothesized that the caregiver-care recipient relationship satisfaction variable, plus the caregivers’ perception
of stress and burden with respect to caring for disabled elderly relatives and the degree of emotional support and external resources would mediate the relationship between caregiver coping and psychological health. The authors tested their hypothesis on 204 caregiver-patient dyads, assessing such issues as caregivers’ beliefs about control over their situation, quality of the dyad relationship, depressive symptoms, and role overload (Yates et al., 1999). Study data suggested that caregiver stressors could indirectly lead to caregiver depression, through the latter’s perception of role overload. However, the quality of the patient-caregiver relationship mediated the relationship of the stressors (i.e., objective demands of caregiving), caregiver burden, and depression.

Within the conceptual framework of positive social psychology, relationship satisfaction is hypothesized to be the perceived achievement of an emotional balance between the contributions made to a relationship and the benefits received from it (Matthews & Clark, 1982). These authors further qualified relationship satisfaction as a state of experiencing a validating relationship, characterized by empathy, unconditional acceptance, and appreciation by a significant other. In the context of ALS caregiving, as couples negotiate the phases of ALS, the negative course of the disease is likely to adversely affect the balance of the most stable and intimate relationships. It is reasonable to expect that spousal caregivers who exhibit resilience will perceive that the quality of their pre-ALS relationship satisfaction is valuable enough that they are motivated to maintain that balance, against all odds. In contrast, if the relationship is already in jeopardy or becomes unbalanced enough, the perceived value of the imbalance may not be sufficient to motivate the caregiver to model resilient behavior (Lopez et al., 2003).
Literature covering ALS patients’ and caregivers’ relationship satisfaction and caregivers’ quality of life is somewhat sparse. In one ALS caregivers study, the investigator initially found that relationship satisfaction was not a significant variable in the caregivers’ quality of life or psychological morbidity (Murphy, 2003). Murphy attributes this finding in part to the heterogeneity of her sample, which included spouses, but 14.6% were children, siblings, parents and friends. Thus, the various types of relationships diluted the anticipated results. In a post hoc regression analysis, Murphy used only the spousal caregivers and a more comprehensive measure of relationship satisfaction. Her second finding suggests that relationship satisfaction does contribute to the prediction of psychological morbidity among spouses of patients with ALS. However, the results were not conclusive regarding the prediction of quality of life.

This current study aimed to contribute to the evidence that relationship satisfaction is a core factor of strength and resilience and is a reliable predictor of quality of life in spousal and partnered caregivers of patients with ALS.
Summary

The literature on family caregiving and ALS spousal caregiving suggests that caregivers have a number of different career trajectories and caregiving outcomes that are as different as the unique experiences regularly observed between and within caregivers (Le et al., 2003; Shewchuk & Elliott, 2002). Le et al. (2003) emphasized that the caregiving experience includes both positive and negative elements, and it is difficult to determine which elements will have the greater impact on the quality of life of a given caregiver. Perhaps if researchers can conceptualize caregiving within a positive psychology framework, then theoretically how a person perceives and internalizes the caregiving experience is ultimately a critical determinant of that person’s quality of life in response to disease-specific caregiving stress.

Research questions. First, are the constructs of hope, optimism, social problem solving, relationship satisfaction, and spirituality significantly related in a sample of ALS caregivers? Secondly, how well do these factors predict ALS caregivers’ quality of life?

Research Hypotheses

Unless otherwise indicated, the following qualifiers will apply to the predictive variables in the current study’s hypotheses: (a) hope, as measured by the State Hope Scale (SHS), will be the sum of the pathways and agency subscales, (b) optimism, as measured by the Life Orientation Test-Revised (LOT-R), will be the result of one overall score that represents the degree to which a participant is optimistic, (c) social problem-solving skills, as measured by the Social Problem Solving Inventory-Revised: Short Form (SPSI-R:S), will refer to the total score generated by the problem orientation subscale
(i.e., positive problem orientation and negative problem orientation) and the problem-solving styles subscale (i.e., rational style, impulsive style, and avoidance style), (d) relationship satisfaction (i.e., the degree to which caregivers perceive satisfaction with the quality of their dyadic relationships), as measured by the Dyadic Adjustment Scale (DAS), will be the total scale score of the 32-item DAS resulting from responses to the four adjustment subscales (i.e., dyadic consensus, dyadic cohesion, dyadic satisfaction, and affectional expression), and (e) religiosity/spirituality, as measured by the Brief Multidimensional Measure of Religiousness/Spirituality: 1999 (BMMRS), will reflect the sum of the 12 numeric subscale scores (i.e., daily spiritual experiences, meaning, values/beliefs, forgiveness, private religious practices, religious and spiritual coping, religious support, religious/spiritual history, commitment, organizational religiousness, religious preference, and overall self-rating), yielding a possible range of 0-175, and scaled in a negative direction with lower scores denoting higher religiousness/spirituality.

As for the criterion variable, quality of life, as measured by the World Health Organization Quality Of Life-Brief Form (WHOQOL-BREF), will refer to the caregiver’s quality of life profile expressed as four individual domain scores (i.e., physical health domain, psychological domain, social relationships domain, and environment domain) converted to transformed scores using a 0-100 scale (WHOQOL, 1997, p. 10). Thus, the following hypotheses will be tested:

1. Hope, optimism, social problem-solving skills, relationship satisfaction, and religiosity/spirituality will be significant predictors of the four domains (i.e., physical health, psychological well-being, social
relationships, and environment) of the quality of life for caregivers of patients with ALS.

2. Positive problem orientation and rational problem-solving skills will be positively correlated with the relationship satisfaction of spousal caregivers of patients with ALS.

3. ALS caregivers’ religiosity/spirituality will be positively correlated with caregivers’ state hope and dispositional optimism (i.e., positive life orientation).
Chapter 2

Method

Participants

Sixty-four individuals (48 women and 16 men), who self-identified as the primary caregivers for patients being treated for ALS at the Milton S. Hershey Medical Center ALS clinic and the Pennsylvania Hospital ALS clinic, consented to participate in the study. The Hershey Medical Center serves a mixture of rural and suburban populations living in central Pennsylvania, including the surrounding cities of Harrisburg and Lancaster. The Pennsylvania Hospital serves a similar demographic population living in southeastern Pennsylvania and cities within a commutable distance in Delaware and New Jersey. One additional ALS clinic director in southeastern Pennsylvania has agreed to participate in the data collection for this study. Thus, it is important that the results and analysis that follow in this paper be considered exploratory and preliminary.

Recruitment

Caregivers were recruited when they accompanied patients with ALS to the clinic. The clinic director approached these caregivers, explained the rationale and purpose of the study, and requested their voluntary participation. In the absence of the director, designated ALS clinic staffers who knew the caregivers and who were involved in the care of the patients of that clinic also approached caregivers to explain the rationale and purpose of the study. Those caregivers who were interested were asked to read and sign informed consent forms (see Appendix A) before they completed any of the study
instruments. Whenever the clinic director had at least three weeks’ notice of a patient’s next clinic appointment, a letter was sent to the caregiver over the signature of the attending neurologist, explaining the rationale and purpose of the study (see Appendix A). An informed consent form was included with the letter, along with instructions for the caregivers to read the form and bring it to the clinic at the next visit. If they were interested in participating in the study, they were instructed to read and sign the informed consent form at their next clinic visit, before completing the questionnaires. Efforts were made to recruit both genders, all age groups, and all minority groups as they are represented in the ALS caregivers’ population and the population at large. The population within the Hershey Medical Center’s service area is predominately white, as was the sample.

Inclusion criteria for participation were:

1. Age 18 years and over.

2. Spouse, domestic partner, or other family member and functioning as the primary caregiver for an individual with clinically definite, clinically probable, or clinically probable – laboratory supported ALS, as diagnosed by the attending neurologist using revised El Escorial Criteria (Brooks et al., 1998; Brooks et al., 2000). Primary caregivers are spouses, domestic household partners, or other family members who assume primary responsibility for (1) the patient’s emotional support, (2) helping with activities of daily living, (3) administration of medications, (4) provision of any special nutrition plan, and (5) help with other aspects of physical care during the course of the disease (Le et al., 2003).
3. Providing primary care for a spouse or family member with ALS for at least 3 months.

4. Fluency in English at the 6th grade level or higher, as determined by self-identification and ability to comprehend the informed consent.

5. Willing and able to provide informed consent.

Exclusion criteria were:

1. Lack of willingness or ability to give informed consent.

2. Dementia of the patient with ALS, as determined by the attending neurologist. Note that ALS with dementia is a rare occurrence in the course of ALS disease progression (McCluskey, 2000), and generates a host of unique caregiving issues that are not within the design of this study.

3. ALS comorbid with severe medical problems (e.g., cancer) or a psychiatric disorder (e.g., schizophrenia), as determined by the attending neurologist. These conditions have unique caregiving issues that cannot be addressed within the scope of this study.

4. Caregivers with a history of severe psychiatric disorders.

Instruments

All participants were asked to complete self-report measures of criterion and predictive variables. On average, completion of the selected instruments took about 45 minutes.
1. **Demographics Questionnaire.** In addition to the standardized self-report measures, each participant completed an eight-item questionnaire designed by the investigator to collect demographic data, such as age, race, household income, relationship to ALS patient, religious affiliation, and number of years as an ALS caregiver (see Appendix B).

2. **The World Health Organization Quality of Life-Abbreviated Form (WHOQOL-BREF).** The World Health Organization has developed two instruments for measuring QOL: the WHOQOL-100 and the WHOQOL-BREF (World Health Organization, 1997; 1998). The former instrument is a 100-item questionnaire that was developed in 15 culturally diverse field centers around the world. The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100. Four domains are assessed: physical health (e.g., pain, energy, level of independence), psychological (e.g., negative feelings, positive feelings, spirituality, religion, and personal beliefs), social relationships (e.g., personal relationships, social support, sexual activity), and environment (e.g., financial resources, self-improvement, recreation, access to health care). The World Health Organization (1997) claims that the nine domain scores of the WHOQOL-100 and the four domain scores of its abbreviated form display good discriminate validity, content validity, and test-retest reliability. This measure takes approximately 5-10 minutes to complete (see Appendix B).

3. **Adult State Hope Scale (SHS).** The six-item State Hope Scale (Snyder et al., 1996) is a brief, modified version of the original 12-item Hope Scale (Snyder et al., 1991), which was developed and validated previously as a dispositional self-report measure
of hope. The SHS is internally consistent and a valid self-report measure of an individual’s ongoing goal-directed thinking, that is, the state hope. “The scale is responsive to events in the lives of people as evidenced by data gathered through both correlational and causal designs” (Snyder et al., 1996). The SHS reflects the authors’ theorized agency and pathways components of hope: the agency subscale score is derived by summing the three even-numbered items; the pathways subscale score is derived by adding the three odd-numbered items. Summing the three agency and the three pathways items derives the total State Hope Scale score. Scores can range from a low of 6 to a high of 48. It takes less than 5 minutes to complete this measure (see Appendix B).

4. The Life Orientation Test-Revised (LOT-R). The LOT-R (Scheier, Carver & Bridges, 1994) is a brief, modified version of the original LOT (Scheier & Carver, 1985). It is a ten-item measure of individual differences in optimism. Respondents were asked to rate the extent of their agreement to the items on a five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Scheier and Carver (1987) found in a factor analytic study that the LOT-R is unidimensional, with one overall score representing the degree to which an individual is optimistic. Additionally, the LOT-R has adequate internal consistency (α = .78) and acceptable test-retest reliability (rs range between .56 and .79). They also found that LOT-R is moderately correlated with the related constructs of depression, hopelessness, self-esteem, perceived stress, and locus of control (Huprich & Frisch, 2004). It takes approximately 5 minutes to complete this measure (see Appendix B).
5. **Social Problem Solving Inventory-Revised (SPSI-R:S).** The SPSI-R (D'Zurilla, Nezu, & Maydeu-Olivares, 2002) aims to measure important factors related to a person’s ability to problem-solve in social situations, including the ability to make a decision after reviewing consequences of each option. This self-report inventory has two forms: a short form (SPSI-R: S, 25 items) and a long form (SPSI-R, 52 items). The instructions ask participants to respond using a five-point Likert-type scale ranging from 0 (not at all true of me) to 4 (extremely true of me). Both forms provide scores for five scales of problem solving. Two scales measure the individual’s problem orientation, the motivational component of the problem-solving process (Maydeu-Olivares, & D’Zurilla, 1996): Positive problem orientation (PPO) and Negative problem orientation (NPO). It is assumed that the problem orientation dimensions overlap with the constructs of optimism and pessimism (Maydeu-Olivares, & D’Zurilla, 1996). A sample item measuring positive problem orientation: “When my first efforts to solve a problem fail, I usually think that if I persist and do not give up easily, I will be able to find a good solution eventually.” An example of a negative problem orientation item: “When my first efforts to solve a problem fail, I get very angry and frustrated.” The three remaining scales measure an individual’s style or approach to problem solving, the “rational search for a solution through the application of specific problem-solving skills [assumed] to increase the probability of finding the ‘best’ solution or coping response…” (Maydeu-Olivares & D’Zurilla, 1996, p. 116). The three style dimensions are: Rational Problem-solving style, Impulsivity/Carelessness style, and Avoidance style. The long form provides a more detailed assessment of the rational problem-solving scale by expanding it to provide
four subscale scores: problem definition and formulation; generation of alternative solutions; decision making; and solution implementation and verification. An example of an item that loads on the rational problem-solving style factor is: “When I have a problem to solve, one of the first things I do is get as many facts about the problem as possible.” The impulsivity and avoidance styles are characterized as dysfunctional dimensions (Maydeu-Olivares & D’Zurilla, 1996): the impulsive style is hurried and incomplete and the avoidance stance is to procrastinate or wait for the problem to solve itself. Examples of items assessing these styles include: impulsive approach, “When I am attempting to solve a problem, I usually act on the first idea that comes to mind,” and the avoidance approach, “When a problem occurs in my life, I usually put off trying to solve it for as long as possible.” The short form was used in this study and takes approximately 5 to 10 minutes to complete.

6. **Dyadic Adjustment Scale (DAS).** The DAS (Spanier, 1976) is a general measure of satisfaction in an intimate relationship. This 32-item measure, designed for married or cohabiting couples, yields a total score and four subscores: Dyadic Satisfaction, Dyadic Cohesion, Dyadic Consensus, and Affectional Expression. The DAS has demonstrated discriminant validity by distinguishing between married and divorced couples and concurrent validity by correlating with the Marital Adjustment Scale (Locke & Wallace, 1959). The response format within the measure varies. For example, responses pulling for ratings of agreement and frequency are given using a six-point Likert-type scale ranging from 0 (always disagree, all the time) to 5 (always agree, never). Responses calling for dichotomous ratings are given, using 0 (yes) and 1 (no). Scores range from 0 to 151, with higher values indicating more favorable
adjustment. Spanier (1976) reports that most respondents can complete the DAS in 10 minutes or less (see Appendix B).

7. **Brief Multidimensional Measure of Religiousness/Spirituality: 1999 (BMMRS).** The BMMRS (Fetzer Institute & National Institute on Aging [NIA] Working Group, 1999) is a 39-item scale developed to examine select dimensions of religion and spirituality as they relate to physical and mental health, when there are known biobehavioral or psychosocial mechanisms at work. Such is the case in this study, exploring the mental health and quality of life of spousal caregivers of patients with ALS. Fetzer and NIA (1999) focused on a broad range of religious and spiritual domains that are only moderately correlated with one another, suggesting that they are separate and distinct constructs. Responses to these domains generate 12 subscales: Daily Spiritual Experiences, Meaning, Values/Beliefs, Forgiveness, Private Religious Practices, Religious/Spiritual Coping, Religious Support, Religious/Spiritual History, Commitment, Organizational Religiousness, Religious Preference, and Overall Self-Ranking. Previous research has found adequate reliability for all of the subscales (Pearce, Little, & Perez, 2003). The BMMRS was embedded in the 1997-1998 General Social Survey (GSS), a random national survey of the National Data Program for the Social Sciences, and greatly benefited from a unique opportunity to examine how its measures relate to other measures of religion in the GSS database (Fetzer & NIA, 1999). “In terms of sampling procedure, response rate, validation procedures, data cleaning, and quality control, the GSS meets the most demanding standards of contemporary survey research” (Fetzer & NIA, 1999, p. 89). For instance, the reliability of specific domains ranges from
adequate, \( r = .54 \) (Negative Religious Coping Scale), to exceptional, \( r = .91 \) (Daily Spiritual Experience Scale). This BMMRS can be completed in 10 minutes or less (see Appendix B).

8. **Level of Care Index (LCI).** The LCI is a three-item caregiver-specific checklist developed to assess the total number of hours of care and the types of care routinely provided by the primary caregiver per week. The types of caregiving tasks are divided into (1) providing assistance with direct tasks or functional activities of daily living (ADLs), such as helping the patient to get out of bed, and (2) helping with independent tasks of daily living (e.g., arranging and supervising outside services). Respondents check all of the tasks that apply to their situations, with a total sum of 13 representing the maximum number of tasks and the highest level of care.

Additionally, the total number of hours of care per week have been categorized to range from 1 (0-8 hours) to 4 (40+ hours). Murphy (2003) found a moderate to high inverse correlation between caregivers’ perceived level of care and the patients’ functional capabilities \( (r = -.690, p = .001) \) in 59 ALS caregiver-patient dyads. This finding suggests that the caregivers did not over-report the amount of care they provided relative to the patients’ level of functioning. The LCI is being used in this study to provide a descriptive measure of the amount of time spent providing care and the kind of care required by the patient. Also, the LCI will provide additional evidence that an individual meets the operational definition of primary caregiver. It takes less than 5 minutes to complete this index (see Appendix B).

9. **Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R).** The ALSFRS-R (Cedarbaum et al., 1999) is a quickly administered, 12-item, disease-
specific functional rating scale, completed by the ALS patient’s neurologist at each clinic visit. The ALSFRS-R uses an ordinal rating, from 4 (normal) to 0 (poor or loss of function), to determine patients’ global assessment of their capacity and independence in 12 functional activities. This scale has demonstrated high internal consistency, test-retest reliability (ALSFRS ALS CNTF Treatment Study (ACTS) Phase I–II Study Group, 1996; Cedarbaum et al., 1999) and construct validity when compared with subjective rating scales such as forced vital capacity (FVC%), an independent measure of pulmonary function, and the Sickness Impact Profile (SIP), a quality of life measure (Cedarbaum et al., 1999). The ALSFRS-R has been used in this study as an objective assessment of the amount of assistance with activities of daily living (ADL) that the patient may require from the primary caregiver.

Study Design

This was a prospective, cross-sectional study designed to test the proposed hypotheses by obtaining data from a representative sample of ALS caregivers in rural and urban communities in central and southeastern Pennsylvania. This research design utilized correlations and a series of hierarchical multiple regressions. Also, frequencies and descriptive statistics were used to describe caregiver personal characteristics.

Procedure

Data were collected and recorded by research assistants (RA) who were advanced doctoral students in clinical psychology. These data collectors were trained and supervised by a licensed psychologist, who is also a core faculty member of Philadelphia
College of Osteopathic Medicine (PCOM). Research assistants received a set of standard instructions to follow that were approved by PCOM’s Institutional Review Board (IRB) (see Appendix C). The ALS clinics involved in this study included: Penn State Hershey Medical Center, Pennsylvania Neurologic Institute of Pennsylvania Hospital, and Drexel University’s Hahnemann Medical Center.

At the beginning of each clinic day, the neurologist identified all potential caregiver participants who were scheduled that day, using the eligibility checklist. Once eligibility was determined, the study was introduced to the caregiver, and if the person chose to enter the study, a signed informed consent form was obtained and the questionnaires were administered. Completion of the questionnaires took approximately 35 to 40 minutes. Another recruitment method for introducing the study involved sending a letter of introduction from the clinic director about the study and an informed consent form to caregivers prior to a pending clinic visit. This approach was advantageous in obtaining advanced participant cooperation and minimizing the caregivers’ time and energy once they arrived at the clinic. See Appendix C for details of the IRB-approved protocol.

Data Analyses

Statistical analyses were performed on the data that emerged from the quality of life and resiliency measures, using statistical software from SPSS Graduate Pack 11.0 for Windows (SPSS, Inc., 2001).

Demographic characteristics were summarized by calculating means and standard deviations for continuous variables, such as age. Frequencies were calculated for nominal or categorical data such as race or gender, and cross-tabs for description of
demographic variables by groups, where relevant.

If a respondent elected not to complete a particular questionnaire, the participant was eliminated from the analysis of that one measure. Such was the case with the Social Problem Solving Inventory-Revised: Short Form (SPSI-R:S), which was inadvertently omitted from the survey packages of 24 participants. Although those respondents were contacted (i.e., according to IRB-approved protocol) and asked to complete the omitted measure by telephone or by mail, 16 persons chose not to complete the questionnaire.
Chapter 3

Results

Sample Representativeness

Table 1 describes the primary characteristics and demographics of the study sample (n = 58). Sixty-three caregivers generously volunteered and consented to participate in the study. However, five persons were determined ineligible because they had far less than the required 90 days of experience as a primary caregiver. In summary, the majority of the caregivers were Caucasian (88%), female (72%), in spousal relationships with the ALS patient (72%), and employed outside of the home (65%), either full-time or part-time. The average age is 51.4 years, ranging from 18 years to 79 years, and 42% of the ALS caregivers reportedly completed high school. All respondents denied a history of psychiatric problems, and only 17.5% reported a current problematic physical health status.

Descriptive Statistics

A summary of the means, standard deviations, ranges, and minimum and maximum scores for the instruments in this study are presented in Table 2. ALS spousal caregivers had a mean score of 89.31 (SD = 37.35, range 0-131) on the total Dyadic Adjustment Scale (DAS; Spanier, 1976), measuring relationship satisfaction of married and cohabitating couples across four subscales: Dyadic Satisfaction, Affectional Expression, Dyadic Cohesion, and Dyadic Consensus. Higher scores reflect greater
satisfaction with the dyad relationship and more favorable adjustment to the relationship within the context of the ALS-caregiving experience.

The Social Problem Solving Inventory-Revised: Short Form (SPSI-R:S) provided an average total standard score for caregivers (mean age = 51.4) of 104.15 (SD = 11.88), with a low score of 75.0 and a high score of 131.0. A higher SPSI-R score (short or long form) reflects a greater tendency to use effective problem-solving skills. Note that the mean total raw score is calculated to be 15.0, according to the technical manual (D’Zurilla et al., 2002). In a related study of ALS caregivers (average age = 58), Murphy (2003) measured problem-solving abilities with the SPSI-R and the resulting mean total raw score was 14.22 (SD = 2.66), which converts to a standard score of 100 (D’Zurilla et al., 2002).

Caregivers had a mean total score of 97.95 (SD = 26.10) on the 39-item Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS), which is scored by adding the sums of its 12 subscales. On the BMMRS the highest possible raw score is 176 and the lowest possible score is 36, with lower scores reflecting a tendency to be more religious and spiritual. For example, question 9 states, “I believe in a God who watches over me.” The possible answers range from 1 (strongly agree) to 4 (strongly disagree). The ALS caregivers’ total raw scores ranged from 54 to 169.

The Life Orientation Test-Revised (LOT-R) is a ten-item measure of individual differences in optimism, providing one overall score representing the degree to which an individual is optimistic. The higher the score (range 10-50), the more optimistic the caregiver. Plus, it is possible to obtain separate subscores for the constructs of optimism (items 1, 4, 10) and pessimism (items 3, 7, 9), and the remaining four items are distracters
ALS Caregivers obtained an average total score of 33.76 (SD = 4.22) on the LOT-R, a mean of 11.52 (SD = 2.49) on the optimism items, and a mean of 7.35 (SD = 3.38) on the pessimism items.

Caregivers had a mean score of 35.62 (SD = 8.66, range, 11 to 47) on the Adult State Hope Scale (SHS), a six-item dispositional self-report measure of an individual’s ongoing goal-directed thinking, that is the state hope (Snyder et al., 1996). The SHS reflects the authors’ theorized agency and pathways components of hope. Summing the three agency and the three pathways items derives the total State Hope Scale score (range, low of 6 to a high of 48). The mean scores for agency thinking (i.e., motivational component of hope) and pathways thinking (i.e., planning component) were comparable, that is 17.29 (SD = 4.91) and 18.33 (SD = 4.41), respectively.

The Level of Care Index (LCI) is a descriptive measure of the caregivers’ perceptions of the amount of time they spend providing care and the kind of care (i.e., functional and instrumental) required by the patient. Caregivers scored a mean total of 9.67 (SD = 4.32, range 1-17) on the LCI. The majority (64.9%) reportedly spends up to 40 hours a week in the primary caregiver role, providing more assistance with the instrumental activities of daily living such as managing the patient’s finances (M = 4.54, SD = 2.09) than with functional activities such as feeding the patient (M = 2.54, SD = 2.21).

ALS patients’ functional capabilities were assessed by their physicians using the ALS Functional Rating Scale-Revised (ALSFRS-R), which provided an objective report of the type of caregiver assistance required by each patient in 12 functional domains. On a scale of 0 (total dependence) to 48 (normal functioning), ALS patients’ mean rating was
30.97 (SD = 9.87, range = 8 to 46), and the most problematic activities were assessed to be handwriting, cutting food, dressing/hygiene, walking, and climbing stairs.

The World Health Organization Quality of Life – Abbreviated Form (WHOQOL-BREF) provides total scores in four quality of life domains, reflecting the international WHO authors’ conceptual framework which emphasizes the holistic and multi-dimensional nature of the quality of life. As such, these domains do not measure symptoms of disease, but are intended to measure a respondent’s perceived position in life in context (i.e., social, physical, environmental, and psychological) and to render a self-assessment of the effects of disease and impairment within context on one’s daily activities and behavior. There are two items that are not included in the domains: question 1 examines an individual’s overall quality of life, and question 2 asks about an individual’s overall health. Yet the WHOQOL Group (1997) discourages equating the quality of life construct with terms like mental status, health status, life satisfaction, or well-being.

For each domain, the possible range of answers is 0 to 100, with the higher scores denoting higher quality of life. ALS caregivers scored an average of 73.21 (SD = 12.73) on the environmental QOL domain, which tapped into such facets as financial resources and satisfaction with physical environment. On the physical health QOL domain, caregivers averaged 71.59 (SD = 16.34); 68.46 (SD = 13.75) on the psychological QOL domain; 66.86 (SD = 16.75) on the social relations QOL domain. The mean score for overall quality of life was 4.05 (SD = .58, range 0 to 5), and for overall rating of health the mean was 3.63 (SD = .82).
Inferential Statistics

Inferential data collected from the Social Problem Solving Inventory-Revised: Short Form (SPSI-R:S), the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS), the Life Orientation Test-Revised (LOT-R), the Adult State Hope Scale (SHS), the Dyadic Adjustment Scale (DAS), and the World Health Organization Quality of Life-Abbreviated Form (WHOQOL-BREF) were summarily analyzed using correlational methods and regression analyses to determine the predictive value of those variables. The strength of the correlations between the various predictors (social problem solving, religiousness/spirituality, optimism, hope, and relationship satisfaction) and caregivers’ quality of life (the criterion variable) generally determines the accuracy of the predictions among variables.

Correlational Analyses

Table 3 presents the correlations of the resiliency factors in this study with the four domains of the WHOQOL-BREF.

*Social problem solving.* A moderate and likely stable positive correlation exists between social problem solving, as measured by the total score of the SPSI-R: S, and the psychological quality of life domain ($r = .550$, $p < .01$, two-tailed), as measured by the WHOQOL-BREF. A smaller positive relationship exists between social problem solving and the social relationships domain ($r = .323$, $p < .05$, two-tailed). Thus, it appears that ALS caregivers’ tendency to endorse effective problem-solving skills is associated with high quality of life within the psychological domain (i.e., assessing bodily image, negative/positive feelings, self-esteem, spirituality, and cognition) and the social
relationships domain (i.e., assessing personal relationships, social support, and sexual activity).

**Hope.** A number of positive relationships between hope and the four quality of life domains are supported by the data: (1) there is a moderate but significant positive relationship between hope and the psychological quality of life domain ($r = .569$, $p < .01$, two-tailed); (2) a small but significant positive relationship between hope and the social relationships quality of life domain ($r = .442$, $p < .01$, two-tailed); (3) a small, significant, positive correlation between hope and the environment quality of life domain ($r = .354$, $p < .01$, two-tailed); and (4) a small, positive correlation between hope and the physical health quality of life domain ($r = .280$, $p < .05$, two-tailed). Although the relationships are small, the data suggest that caregivers who score high on the Adult State Hope measure tend to endorse a positive quality of life in each of the four domains.

**Optimism.** This resiliency construct, measured by the Life Orientation Test – Revised (LOT-R), was positively correlated with the psychological quality of life domain ($r = .360$, $p < .01$, two-tailed) and with the social relationships domain ($r = .314$, $p < .05$, two-tailed). These findings represent small relationships, but they suggest that high scores in optimism were associated with high scores in at least two quality of life domains.

**Religiousness/Spirituality.** The Brief Multidimensional Measure of Religiousness/ Spirituality (BMMRS) was negatively correlated with quality of life, as follows: (1) physical domain, $r = -.183$ ($p = .174$, two-tailed); (2) psychological domain, $r = -.255$ ($p = .056$, two-tailed); (3) social relationships domain, $r = -.193$ ($p = .150$, two-tailed); and (4) environment domain, $r = -.054$ ($p = .689$, two-tailed). The BMMRS
measures both concrete and abstract dimensions of public and private religiosity, in addition to subjective spirituality. Thus, non-statistically-significant negative correlations are as likely as not to mean that the average caregiver is merely questioning or reevaluating religious beliefs and spiritual values, within the context of the ALS experience.

Relationship satisfaction. The Dyadic Adjustment Scale, measuring spousal caregivers’ intimate relationship satisfaction, was positively correlated with the social relationships quality of life domain, $r = .356(p < .05, \text{two-tailed})$. This finding represents a small relationship, but it is significant and suggests that the caregiver’s satisfaction with the dyad relationship is an important factor when rating quality of life as it relates to a positive adjustment to the altered relationship within the context of the ALS-caregiving experience.

Level of Care Index and ALS Functional Rating Scale-Revised. In general, caregivers have perceptions of the amount of time and care their care recipients need in a given day or week. These perceptions were measured by the Level of Care Index (LCI) for 35 caregiver-patient dyads, and were correlates with the corresponding functional capabilities of the patients, as measured by their physicians using the ALS Functional Rating Scale-Revised (ALSFRS-R). There was a small, inverse correlation between the LCI and the ALSFRS-R ($r = -.168, p = .333, \text{two-tailed}$), meaning that the caregiver’s report of a high level of care was associated with the physician’s report of low levels of patient functional abilities. Although the relationship is relatively small and not statistically significant, this finding nonetheless supports Murphy’s (2003) post hoc
analysis which suggests that caregivers’ perceptions of the extent of care required by ALS patients are generally consistent with objective medical evidence.

Regression Analyses

Hierarchical multiple regression analyses were conducted to determine if the resiliency factors (i.e., hope, social problem solving, optimism, relationship satisfaction, and religiousness/spirituality) predicted caregivers’ quality of life in the four domains. The order of entry of the variables into the four regression equations was: hope, social problem solving, optimism, relationship satisfaction, and religiousness/spirituality. The order of regression analyses was consistent with the WHOQOL-BREF domain number: physical health (domain 1), psychological (domain 2), social relationships (domain 3), and environment (domain 4).

Regression with physical health domain as the criterion variable. Hierarchical multiple regression was conducted to determine if the resilience variables predicted ALS-caregivers’ quality of life in the physical health domain. The order of entry of the variables into the regression equation was: hope, social problem solving, optimism, relationship satisfaction, and religiousness/spirituality. The results revealed that, although the trend of relationships tended to be positive, the variables being explored were not significant predictors of caregivers’ quality of life in domain 1. The resiliency variables, individually and collectively, accounted for less than 7% of the physical health domain’s variance (adjusted $r^2 = .066$), with hope accounting for 6.1%.

Regression with psychological domain as the criterion variable. Hierarchical multiple regression was conducted to determine if the resilience variables predicted ALS-
caregivers’ quality of life in the psychological domain. The order of entry of the variables into the regression equation was: hope, religiousness/spirituality, optimism, social problem solving, and relationship satisfaction. The results revealed that the five resilience variables significantly predicted caregivers’ quality of life in domain 2, with hope and religiousness/spirituality accounting for 46.4% and 5.7% of the total variance in psychological quality of life, respectively [F (2, 30) = 18.408, p < .001]. Table 4 presents summary results of the regression analysis.

*Regression with social relationships domain as the criterion variable.*

Hierarchical multiple regression was conducted to determine if the resilience variables predicted ALS caregivers’ quality of life in the social relationships domain. The order of entry of the variables into the regression equation was: hope, relationship satisfaction, optimism, religiousness/spirituality, and social problem solving. The results revealed that these factors do predict caregivers’ quality of life in domain 3. In fact, collectively the 5 variables account for almost 40% of the variance in social relationships quality of life (adjusted $r^2 = .391$). Moreover, the best fit model is represented by caregivers’ hope, relationship satisfaction, and optimism [F (3, 29) = 7.622, p < .001]. Table 5 presents summary results of the regression analysis.

*Regression with environment domain as the criterion variable.* Hierarchical multiple regression was conducted to determine if the resilience variables predicted ALS-caregivers’ quality of life in the environment domain. The order of entry of the variables into the regression equation was: hope, social problem solving, optimism, religiousness/spirituality, and relationship satisfaction. The results revealed that caregivers’ hope is the one significant predictor of caregivers’ quality of life in domain 4, accounting for 14.3%
of the variance in environment quality of life \[ F (1, 31) = 6.321, p < .05 \]. Table 6 presents summary results of the regression analysis.

**Hypotheses: Relevant Findings**

*Hypothesis 1.* Hope, optimism, social problem-solving skills, relationship satisfaction, and religiousness/spirituality will be significant predictors of the four quality of life domains of caregivers of patients with ALS. As shown in Table 3, there are significant positive relationships between the four WHOQOL-BREF quality of life domains and four of the five resiliency assessments. Small to moderate positive correlations exist between hope and the four domains, as follows: domain 1, \( r = .280 \) (\( p < .05 \), two-tailed); domain 2, \( r = .569 \) (\( p < .001 \), two-tailed); domain 3, \( r = .442 \) (\( p < .01 \), two-tailed); and domain 4, \( r = .354 \) (\( p < .01 \), two-tailed). As for relationship satisfaction there is a small, positive correlation between the Dyadic Adjustment Scale and the social relationships domain (\( r = .356 \), \( p < .05 \), two-tailed). Significant small to moderate positive correlations exist between social problem solving and the psychological domain (\( r = .550 \), \( p < .001 \), two-tailed) and the social relationships domain (\( r = .323 \), \( p < .05 \), two-tailed). Finally, there are small positive relationships between optimism and social relationships (\( r = .314 \), \( p < .05 \), two-tailed) and optimism and the psychological quality of life domain (\( r = .360 \), \( p < .01 \), two-tailed). In contrast, there is a small inverse relationship between the four quality of life domains and caregivers’ religiousness/spirituality.

Hypothesis one was also analyzed using regression analysis. The results revealed that the best overall predictor of caregivers’ quality of life in domains 1 through 4 was
hope, as measured by the Adult State Hope Scale. However, hope predicted only a small portion (6.6%) of the variance in caregivers’ quality of life represented by physical health, and just 6.1% of the variance in the environment quality of life. All of the resiliency variables contributed to the variance in domain 2, together predicting nearly 55% of caregivers’ psychological quality of life. Caregivers’ social relationships quality of life was adequately predicted by high scores in hope, relationship satisfaction, and optimism. Small contributions to the variance by religiousness/spirituality and social problem solving also predicted quality of life in the social relationships domain. Thus, hypothesis one was generally supported by the correlation and regression data in both analyses.

**Hypothesis 2.** Positive problem orientation and rational problem solving will be positively correlated with the relationship satisfaction of spousal caregivers of patients with ALS. Pearson correlation coefficients measuring the relationships between the subscales of the Dyadic Adjustment Scale (DAS) and the SPSI-R:S subscales suggest a moderate, significant inverse relationship between spousal caregivers’ rational problem-solving scores and their scores on the dyadic satisfaction subscale of the DAS ($r = -.519$, $p < .01$, two-tailed). However, there is no evidence of a significant relationship between positive problem orientation and relationship satisfaction. It should be noted that the SPSI-R:S inventory was not completed by all participants, because the measure was inadvertently omitted from the study packets of some early respondents. Thus, analysis of social problem-solving skills data should be interpreted conservatively and considered exploratory at this time. Still, preliminary findings do not support hypothesis two.

**Hypothesis 3.** ALS caregivers’ religiousness/spirituality will be positively
correlated with caregivers’ state hope and dispositional optimism (i.e., positive life orientation). The relationships between hope and religiousness/spirituality and between optimism and religiousness/spirituality are not significant. However, Pearson correlation coefficients measuring the relationship between optimism and the components of the State Hope Scale reveal a small but stable positive correlation between agency and optimism ($r = .326, p < .05$, two-tailed). Based on the current data, hypothesis three is partially supported.

Summary of Results

It is believed that this study is the first to explore the concept of resiliency in caregivers of patients with ALS, within the theoretical framework of positive psychology. Seligman and Csikszentmihalyi (2000), pioneer positive psychologists, have proposed that resiliency is a lifespan process of amassing and assimilating unique human strengths and virtues. Furthermore, they contend that resiliency is the interaction of certain core human strengths and virtues that balance and sustain individuals through crises, even over an extended period of time. Thus, one research question that this study aimed to answer was whether or not resiliency, as operationalized in the positive constructs of hope, optimism, social problem solving, relationship satisfaction, and spirituality, is significantly evident in a sample of ALS caregivers. The positive psychology model for this study assumed that resilient caregivers (1) possess future-oriented worldviews (i.e., hope and optimism), (2) have premorbid satisfying and empowering relationships with the care recipients, (3) are grounded in spiritual beliefs and practices, and (4) have the ability to skillfully solve problems. In general, the data from the sample participants ($n =$
provide preliminary support for the resiliency model and its assumptions.

A second research question was considered: how well do the core resiliency factors (i.e., hope, optimism, social problem solving, relationship satisfaction, and spirituality), separately and/or collectively, predict physical and psychological quality of life in ALS caregivers? The literature suggests that the resiliency factors are interrelated (Thompson & Snyder, 2003; Tsang & McCullough, 2003; Bryant & Cvengros, 2004) and have positive predictive power in promoting subjective psychological well-being. The data collected from the sample participants (n = 58) in this study are generally consistent with other findings that suggest that there are significant interconstruct relationships among the resiliency variables and the presence of these variables appears to promote psychological hardiness and positive quality of life.
Significant Findings

It was hypothesized that hope, optimism, social problem-solving skills, relationship satisfaction, and religiousness/spirituality will be significant predictors of the four quality of life domains (i.e., physical health, psychological well-being, social relationships, and environment) for caregivers of patients with ALS. According to the data, there are significant positive relationships between the World Health Organization Quality of Life: Abbreviated Form (WHOQOL-BREF) and four of the five resiliency assessments. Religiousness/spirituality, as measured by the BMMRS, has an inverse relationship with each of the quality of life domains.

According to the data, hope appears to be the best predictor of ALS caregivers’ quality of life, being the one variable that has small to moderate yet significant positive relationships with all four quality of life domains. Hope also contributes from 6.1% to 46.4% of the variances of the domains of quality of life. This finding is consistent with positive psychology literature on the role of hopeful thinking in the process of dying from a terminal illness. Gum and Snyder (2002) found that hope, as measured by the dispositional Hope Scale, is associated with many positive outcomes in different life situations. In hope theory, pathways thinking refers to a person’s perception that workable paths or plans can be identified in order to reach a desired goal (Snyder et al., 1996). High-hope individuals are able to develop one path or alternate paths to a goal with confidence. Agency thinking refers to a person’s perception of having the motivation to choose a path and sustaining the motivation to change courses when a
particular path is blocked (Snyder et al., 1996). In general, high-hope individuals are self-motivated to choose and effectively use a chosen pathway. In addition, they can remain motivated and redirect their mental and physical energies to follow another more feasible pathway or pursue an alternate goal, as needed. Snyder (2000) theorizes that hope plays an important part in the way family members cope with losing a loved one and bereavement. Thus, with regard to caregivers’ quality of life, higher dispositional hopeful thinking is related to outcomes that are similar to the WHOQOL-BREF domains, such as positive psychological well-being (i.e., psychological domain), better social functioning (i.e., social relationships domain), more positive physical health outcomes/health behaviors (i.e., physical health domain), and adaptive adjustment to chronic illness (i.e., environment domain) (Gum & Snyder, 2002).

Social problem solving, as a resiliency construct in this study, has less overall significant predictive ability than expected with respect to caregivers’ quality of life across the four domains. Prior research supported the notion that social problem-solving played a key role in predicting distress among caregivers. In a sample of 116 adult caregivers of Alzheimer’s patients, effective problem solving, as measured by the Social Problem Solving Inventory – Revised (SPSI-R), was significantly related to three measures of distress (Rothenberg, Nezu, & Nezu, 1995). Elliott, Shewchuk, and Richards (1999) assessed the problem-solving abilities of 66 family member caregivers of patients with spinal cord injuries. The authors found that caregivers who tended to solve problems impulsively and carelessly were associated with patients that had difficulty accepting their disability. Thus, it was hypothesized in the current study that ALS caregivers’ social problem-solving abilities would have a greater predictive impact
on the four domains of quality of life.

Nonetheless, the current data suggest that ALS caregivers who are high scoring social problem-solvers are more likely to have high scores in at least the psychological and social relationships quality of life domains. Although social problem solving has not been explored in depth with caregivers in the ALS population, the current finding is consistent with a recent study. Murphy (2003) found that ALS caregivers who reported low psychological morbidity and high quality of life were likely to have a tendency to implement effective social problem solving, as measured by the Social Problem Solving Inventory-Revised (SPSI-R). In the present study, caregivers’ social problem-solving accounts for less than 2% of the total variance of psychological quality of life. This finding is not consistent with Murphy’s (2003) study, in which social problem solving explained 15% of the variance of quality of life, as measured by the Quality of Life Index (QOLI) (Frisch, Cornell, Villanueva, & Retzlaff, 1992). Yet, the current results indicate a significant positive relationship between social problem-solving and the psychological domain of the WHOQOL-BREF, a finding that supports Murphy’s (2003) results showing a significant relationship between SPSI-R and the QOLI.

Perhaps social problem solving is best viewed as a mediator variable that describes how, rather than when, aspects of quality of life will occur by accounting for the relationship between the resiliency variables and the four quality of life variables. For example, the data suggest that when caregivers’ hope increases, quality of life increases. In fact, it could be argued that this finding depends on how well social problem solving mediates the relationship, given that social problem solving is significantly correlated with hope ($r = .477$, $p < .01$, two-tailed).
In this study, high scores in optimism, as measured by the Life Orientation Test-Revised (LOT-R), predict ALS caregivers’ psychological and social relationships quality of life. Optimism is under explored in the literature on ALS caregivers. However, the current data is consistent with Atienza, Stephens, and Townsend’s (2002) investigation which examined the effects of role-related stress and dispositional optimism on the well-being of 296 adult daughter caregivers, who were also wives, mothers, and employees. Their results suggest that dispositional optimism contributes to adult daughter caregivers’ general well-being (Atienza et al., 2002). Additionally, the authors found that dispositional optimism may reduce the negative effects of specific role stress, including wife stress and caregiver stress, on psychological well-being (i.e., depressive symptoms and life satisfaction).

Optimism theorists support the premise that dispositional optimism mediates between external events and how a person perceives those events (Seligman & Csikszentmihalyi, 2000). In the current study, the external events would be characterized by the diagnosis of ALS and the related caregiver stressors. Optimistic caregivers exhibit an ability to perceive negative external events in such a way that focuses on successful outcomes (Bryant and Cvengros, 2004). Also, high optimistic caregivers are prone to experience the constructs that are incorporated into domain 3 of the WHOQOL-BREF, such as enhanced personal relationships, social support, and sexual activity. Thus, they are likely to report higher quality of life in the social relationships domain.

Relationship satisfaction, not surprisingly, was a significant predictor of the ALS caregivers’ social relationships quality of life domain (incorporating personal relationships, social support, and sexual activity). The current study measured
relationship satisfaction among a heterogeneous sample of ALS caregivers (spouses and others) using all subscales of the Dyadic Adjustment Scale (DAS) and the findings suggest that high relationship satisfaction is associated with high quality of life in the social relationships domain. Additionally, when only ALS spousal caregivers were measured, the findings also suggested that high relationship satisfaction predicted high quality of life in the social relationships domain. This finding is consistent with other studies investigating general caregiver populations. For example, Chang, Noonan, and Tennstedt (1998) reported that high relationship satisfaction was related to low depressive symptoms in a sample of caregivers of elderly care recipients. Thompson and Snyder (2003) agree that relationship satisfaction contributes to psychological well-being, which in turn may predict quality of life across populations.

In contrast, among the ALS caregivers population, Murphy (2003) found that relationship satisfaction (i.e., the quality of the caregiver-care recipient relationship), as measured by the 10-item Dyadic Satisfaction subscale of the DAS, was not a significant predictor of quality of life among spousal caregivers or other caregivers of patients with ALS. However, her findings suggested that relationship satisfaction was a significant predictor of psychological morbidity, as measured by the Brief Symptom Inventory (BFI) (Derogatis & Melisaratos, 1983). Note that Murphy’s (2003) criterion variable, quality of life, was measured by the Quality of Life Index (QOLI; Frisch, Cornell, Villanueva, & Retzlaff, 1992), which yields one overall life satisfaction score for each subject, whereas the WHOQOL-BREF, which measures quality of life in the current study, yields four separate quality of life domain scores and does not assume that quality of life is unidimensional or interchangeable with well-being.
Religiousness/spirituality, represented by the total score of the BMMRS, is a predictor of quality of life in the psychological domain, accounting for 5.7% of the total variance of that domain. This finding is not surprising, given the fact that spirituality, religion, and personal beliefs are principal components incorporated within domain 2 of the WHOQOL-BREF. Furthermore, it is consistent with other research investigating the quality of life of ALS patients and ALS caregivers. For example, Bremer et al. (2004) suggest that religiosity plays a major role in the self-perceived positive quality of life of individuals with ALS. With regard to ALS caregivers, Murphy (2003) found that spirituality was a predictor of caregivers’ quality of life.

The fact that the construct religiousness/spirituality is not a significant predictor of the remaining domains might be explained by the construction of the instrument. The BMMRS is multidimensional and focuses on a broad range of religious and spiritual domains that are only moderately correlated with one another, suggesting that they are separate and distinct constructs (Fetzer & NIA, 1999). As such, responses to these domains generate twelve subscales, and up to 48 possible relationships with four quality of life criterion variables. That much data would appear not only to require a more comprehensive statistical model, but also a larger sample size.

However, the religiousness/spirituality subscales were further examined for dimensions of that measure which might somehow play a predictive role in the quality of life of ALS caregivers. Preliminary findings of a regression analysis of selected subscales (forgiveness, private practices, organized religion, and daily spiritual experiences) suggest that the organized religion subscale is a predictor of the psychological quality of life, accounting for 8% of the total variance.
Hypothesis two stated that positive problem orientation (PPO) and rational problem solving (RPS) will be positively correlated with the relationship satisfaction of spousal caregivers of patients with ALS. At this time, preliminary findings do not support hypothesis two. In summary, (1) the correlation between PPO and overall relationship satisfaction is a negative one ($r = -.244$, $p = .229$, two-tailed); (2) the relationship between PPO and the dyadic satisfaction subscale of the Dyadic Adjustment Scale (DAS) is also negative ($r = -.351$, $p = .08$, two-tailed); and (3) there is a significant inverse relationship between spousal caregivers’ RPS scores and their scores on the dyadic satisfaction subscale ($r = -.519$, $p<.01$, two-tailed). One alternative explanation for these unexpected findings is the fact that PPO and RPS, the two constructive dimensions of social problem solving, are primarily significant predictors of adaptive coping in the presence of specific stressful events (D’Zurilla & Chang, 1995). The PPO scale assesses one’s tendency to view problems as challenges as opposed to threats (i.e., dispositional hope) and assumes optimism in one’s ability to reach effective solutions (Kurylo, Elliott, DeVivo, & Dreer, 2004). The RPS scale also assumes hope and optimism in one’s ability to approach problems in a rational, systematic, and thorough manner, within the framework of the problem solving model, i.e., define the problem, generate alternatives, evaluate alternatives, implement solutions, and evaluate outcomes (D’Zurilla et al., 2002). Thus, the negative correlations between PPO/RPS and relationship satisfaction in this sample of caregivers suggest a tendency toward maladaptive coping or poor adjustment to the stress of the ALS patient-caregiver dyad, thereby compromising the caregivers’ effective social problem-solving abilities. Ultimately, reduced motivation or inhibition of adaptive problem-solving strategies
increases the probability of psychological distress (Nezu, Nezu, Houts, Friedman, & Faddis, 1999). Given the small sample size, an analysis of the social problem-solving skills data should be interpreted conservatively and considered exploratory.

Hypothesis three holds that ALS caregivers’ religiousness/spirituality will be positively correlated with caregivers’ state hope and dispositional optimism (i.e., positive life orientation). Based on the current data, the third hypothesis is partially supported, given the positive relationship between optimism and the components of the State Hope Scale which reveal a small but significant correlation between agency thinking and optimism ($r = .326, p < .05, \text{two-tailed}$). This finding is consistent in principle with positive psychology theorists who found that optimism is equally associated with pathways thinking and agency thinking (Bryant and Cvengros, 2004). Carver and Scheier (2003) found that the positive emotions that sustain motivation and inspire confidence in high-hopers are really a function of the construct optimism.

On the other hand, the relationships between hope and religiousness/spirituality and between optimism and religiousness/spirituality are not significant. This lack of evidence may be explained by the small sample size or by the fact that the BMMRS is virtually a combination of 12 separate and distinct constructs in one instrument, making it difficult to tease apart any significant relationships that may exist with such intrinsic constructs as hope and optimism. Yet data in this study support the predictive role of religiousness/spirituality in caregivers’ quality of life, especially in the psychological and social relationships domain. These are domains in which state hope and dispositional optimism are also important, sharing the total variance of these aspects of quality of life. Thus, further investigation into the validity of hypothesis three appears to be warranted.
Limitations of the Study

Several aspects of this study must be considered as potential limitations. For instance, the recruitment strategy involved solicitation by each Clinic Director of a convenience sample of caregivers known to the director and staff, which may compromise the external validity of study findings. Those caregivers who agreed to participate may have been disposed to report higher positive affect than they actually felt because they wanted to be perceived as model caregivers by the clinic staff. Thus, their socially desirable responses could positively skew the results. A selection bias is also possible within the ALS clinics. Murphy (2003) found that 92.5% of the eligible caregivers in one ALS clinic self-selected or participated because they perceived that their involvement in that research would be beneficial to future caregivers.

Another possible threat to external validity could be that study participants recruited from within the clinic setting may differ perceptually from those caregivers who are not part of an ALS network because of the extensive attention and social support they receive from the staff. Thus, they may perceive their circumstances as more hopeful, endorse a higher quality of life, and report less psychological distress than non-clinic-attending caregivers who will not be represented in the study. On the other hand, the social support aspect of the ALS clinic may be a potential clinical intervention for caregivers and patients who are not currently registered with a clinic.

The sample’s ethnic and racial composition is another potential limitation of this study. Although every effort was made to recruit a representative sample of the ALS population of the demographic areas sampled, it is likely that the generalizability of the findings with respect to resiliency constructs may be limited by an overrepresentation of
Caucasian caregivers in the sample. Such was the case in an earlier study on quality of life of ALS caregivers (Murphy, 2003).

From a temporal perspective, the case may be that on any given assessment day, a participant may have had a stressful week before arriving at the clinic and is thereby exhibiting temporary subjective distress. In other words, that caregiver’s responses, on that day, may not be a true reflection of an otherwise overall satisfaction with quality of life. Therefore, caution should be taken in generalizing negative affect findings to all ALS spousal caregivers.

Another potential limitation involves the measuring instruments. All of the measures in this study employ a self-report instrument, which is generally characteristic of research in positive psychology (Tsang & McCullough, 2004). However, given the wide variability of individual differences across the complex constructs being measured, self-report instruments are potentially limited in their ability to capture all aspects of the protective benefits of resiliency.

A potential limitation exists whenever the selected measures do not have pre-existing predictive relationships between the variables of interest and the criterion (i.e., outcome) variables being measured (Kazdin, 1998). For example, the self-report instruments used to measure the resiliency constructs in this study have not been previously employed with the ALS caregiver population, with one possible exception. That exception is the QOL study conducted by Murphy (2003), in which the investigator used the SPSI-R (a longer version of the SPSI-R:S) to assess ALS caregivers’ social problem-solving skills. That study provided credible evidence that social problem-solving skills are the best predictor of ALS caregivers’ quality of life and psychological
morbidity. Since the current study is exploratory, and since the conceptualization of resiliency among ALS caregivers is in its infancy, some measurement threats to construct validity are unavoidable.

It is believed that the significance of the ANOVA results would increase (i.e., $p < .05$) with the increase of the sample size (e.g., $n > 58$). Additionally, interpretations of these findings, including the presence or absence of identified predictive relationships, may not be accurate given the phenomenological nature of the variables that were assessed.

Clinical Implications

It is reasoned that since the resiliency variables inform caregivers’ subjective, emotional experiences and innate abilities, their adaptive thinking and behavior (i.e., self-reported QOL) may vary according to the dynamics of the caregiving experience and the stage of the ALS patient’s illness. Thus, the role of the ALS caregiver is not a passive one, rather it is a dynamic process strongly influenced by the severity of the disease. With regard to the progression of the caregiving experience, Shewchuk, Richards, and Elliott (1998) found in a prospective study that the inaugural year of caregiving tends to be complex, dynamic, and distressful. Over time, many ALS family caregivers are resilient to psychological morbidity and manage to cope well with the process. Others appear to be overwhelmed by their circumstances (i.e., cannot quite adjust to their changing roles), and thus often go on to develop clinically significant symptomatology with reduced quality of life. Shewchuk et al. (1998) advocate for identifying those characteristics that predispose caregivers to negative outcomes, then developing early
cognitive-behavioral interventions that are designed to equip them with emotion regulation tools, task management skills, and coping strategies. Shewchuk and Elliott (2000) further advocate for interventions that are effective and low cost for families who may have limited access, limited resources, and who often are not interested in formal psychological/psychiatric services. Thus, conceptualizing spousal/family caregiver responsibilities and needs within a positive psychology framework provides at least a useful perspective for identifying predictive risk factors early on in the process and for developing cognitive-behavioral interventions that actively address Shewchuk’s and colleagues’ concerns.

Prompted by the data in the current study, the early intervention proposed here is strengths based and focuses on constructs of resiliency (i.e., hope, optimism, spirituality, relationship satisfaction, and social problem solving) as predictors of quality of life in spousal and other family caregivers of patients with ALS. The primary goals of this intervention are to maximize caregiver effectiveness and to optimize caregiver quality of life. It is a variation of the social problem-solving therapy and training model prescribed by Nezu et al. (1999), a model adapted earlier by Houts, Nezu, Nezu, and Bucher (1996) for family caregivers of physically ill persons at home. In this proposed variation, the traditional problem-solving components of the ALS caregiver resiliency model are: (1) positive problem orientation (PPO), which assumes the constructs of hope, optimism, and religiousness/spirituality, and (2) rational problem-solving skills (RPS; i.e., problem definition and formulation; generation of alternatives; decision making; solution implementation and verification). The final component of this training model is
empowerment through education, external support, and acceptance as a member of the ALS patient’s health care team.

Given the research scope of this study and the variety of clinical implications in the findings, it is not appropriate or possible to discuss this proposed intervention model in its entirety. Furthermore, it subsumes a large variety of possible integrations of cognitive-behavioral (CBT), positive psychology, and supportive therapy techniques among its therapeutic tools. However, it is possible to present an outline of the model that was inspired by the results of the current study and earlier research conducted through the years by Nezu, Nezu and their various colleagues.

ALS Caregiver Resiliency Training Model

1. Screening. The process likely begins with a routine, informal clinical screening for symptoms of caregiver distress, through observation and self-reports. For example, when a veteran caregiver accompanies the ALS patient to a clinic visit, it could be a matter of course for the clinic director to simply inquire about the person’s physical and mental health status and listen for signs of adaptive coping or subjective distress in any of several domains of functioning (physical, psychosocial, marital, sexual, spiritual, etc.). New caregivers could be asked to complete a short Social Problem Solving Inventory (SPSI-R:S) during one of the initial visits to the ALS clinic. It might also be useful to ask the ALS patient, “How is your [spouse/other] doing?” Surely, the patient can tell if the caregiver appears stressed out by day-to-day problems, major chores, or tasks related to providing care (Houts et al., 1996).
2. *Positive problem orientation* (PPO) refers to the mindset when a person is predisposed to being hopeful in appraising problems as challenges and has an attitude that is optimistic regarding the expectation that any problem-solving efforts will lead to a successful outcome (Houts et al., 1996). Caregivers who exhibit dysfunctional problem orientation in the screening phase might accept a referral to the mental health professional on the ALS clinical team, who could then help the caregiver determine if there is distress or not and what cognitive-behavioral (CBT) techniques might be appropriate. There are a variety of evidence-based approaches, some self-directed, that are effective in fostering hope and optimism and facilitating movement toward positive problem orientation (Nezu et al., 1999).

3. *Rational problem solving.* Next, the rational problem-solving skills (RPS) component of this resiliency model addresses the specific cognitive abilities of caregivers to define the problem and then to creatively assemble and manage the external resources necessary to determine and implement the best available solution. Therefore, caregivers who report that they are having difficulty with concentration, identifying real problems, or generating ideas to solve problems would also be referred for training or coaching in how to break down larger problems into smaller, manageable parts. Thus, the complexity of the problem is minimized, allowing the caregiver to engage in more positive oriented thinking that is broad based, creative, and flexible (Nezu et al., 1999).

4. *Empowerment.* The final component of the ALS caregiver resiliency training model is empowerment through education, avenues of external support, and being a member of the ALS patient’s health care team. The factors that enable the empowerment component are derived primarily from the Houts et al.(1996) family caregiver model of
problem-solving. The authors believed that family members who care for patients at home need expert information and training if the patients’ needs are to be met and if home care is to be an effective extension of professional health care. In the resiliency model, education is caregiver-focused and provides caregivers with the expert information and level of problem-solving training they need to feel confident that they know what to do when an obstacle gets in the way. In addition, they are in control of the process and in control of their quality of life.

Recognizing the presence of external support and the ability to communicate need for support is a real strength and another measure of empowerment. This support may come from the patient (i.e., relationship satisfaction), other family members, religiousness/spirituality connections, coworkers, other ALS caregivers, the patient’s health care team, etc. A final form of empowerment in this model is the act of being accepted as a consultant on the patient’s ALS health care team with regard to medical treatment plan, diet, medication compliance, emergency treatment, mental health, etc. Ideally, the caregiver resiliency model’s clinical implications exist in its potential to empower caregivers with the problem-solving skills to cope with terminal illness and the dying process, and it may help to moderate caregiver stress (Houts et al., 1996).

Conclusion

Based on the research, most caregivers will experience some degree of psychological distress in reaction to the stress induced by a loved one receiving a life-threatening diagnosis, such as ALS. As such, ALS caregivers are more or less thrust into their roles of providing care, without much time to adjust to the diagnosis or how it will
impact their lives. Ultimately, how a person perceives and internalizes the caregiving experience is a critical determinant of that person’s quality of life in response to disease-specific caregiving stress. It is believed that those ALS caregivers who demonstrate resiliency report a higher quality of life as they adapt to their caregiving experience.

The results of the current study at least contribute to positive psychology research by proposing that the presence of resiliency in new ALS caregivers can be detected early in the experience, as easily as at-risk factors. In turn, at-risk caregivers can be identified and referred for early cognitive-behavioral interventions, designed to build upon their resiliency skills, increasing the likelihood that they will adapt to the stress of ALS and enjoy a good quality of life.

The caregiving outcomes and career trajectories of ALS family and spousal caregivers are as different as the unique daily experiences regularly observed between and within other caregiver populations (Le et al., 2003; Shewchuk & Elliott, 2002). The caregiving experience includes both positive and negative elements, and it is difficult to determine which elements will have the greater impact on the quality of life of a given caregiver (Le et al., 2003).

In general, it is beyond the scope of this study’s cross-sectional design to analyze transitions in the stages of ALS caregiving, as the disease progresses with certainty toward death. Future research design should involve prospective longitudinal studies, which would be more suitable to examining these transitions and the role resiliency factors may play in promoting quality of life among spousal caregivers over time.

It is hoped that the findings in this study have been useful in increasing clinicians’ understanding of the diverse psychosocial issues that impact ALS caregivers’ quality of
life during this caregiving process and useful in understanding how certain resiliency
factors may aid in the prediction of quality of life.
References


Simmons, Z. (2004). Key determinants of quality of life in ALS. In M. Lyon (Chair), *Amyotrophic lateral sclerosis and other motor neuron disorders.* Symposium conducted at the meeting of the 15th International Symposium on ALS/MND, Philadelphia, PA.


Table 1

Demographic Characteristics of ALS Caregivers

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
<th>%</th>
</tr>
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<tbody>
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<td>Age</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>12.85</td>
<td>2.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in Relationship</td>
<td>28.87</td>
<td>16.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>42</td>
<td></td>
<td>72.4</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
<td></td>
<td>27.6</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td></td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>Asian, Pacific Islander</td>
<td>4</td>
<td></td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>Hispanic, non-white</td>
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<td></td>
<td>3.4</td>
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</tr>
<tr>
<td>Caucasian</td>
<td>51</td>
<td></td>
<td>87.9</td>
<td></td>
</tr>
<tr>
<td>Relationship to ALS Patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse, Domestic Partner</td>
<td>42</td>
<td></td>
<td>72.4</td>
<td></td>
</tr>
<tr>
<td>Parent, child, sibling, other</td>
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<td></td>
<td>27.6</td>
<td></td>
</tr>
<tr>
<td>Time as primary caregiver</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>3-11 months</td>
<td>23</td>
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<td>39.7</td>
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<td>1-3 years</td>
<td>24</td>
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<td>41.4</td>
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<td>4-6 years</td>
<td>3</td>
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<td>5.2</td>
<td></td>
</tr>
<tr>
<td>7-10 years</td>
<td>2</td>
<td></td>
<td>3.4</td>
<td></td>
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<tr>
<td>Variables</td>
<td>Mean</td>
<td>SD</td>
<td>N</td>
<td>%</td>
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<tr>
<td>---------------------------------</td>
<td>------</td>
<td>----</td>
<td>-----</td>
<td>----</td>
</tr>
<tr>
<td><strong>Caregiver Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work at home</td>
<td>9</td>
<td></td>
<td>15.5</td>
<td></td>
</tr>
<tr>
<td>Work outside home</td>
<td>37</td>
<td></td>
<td>63.8</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
<td></td>
<td>6.9</td>
<td></td>
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<tr>
<td>Student, other</td>
<td>8</td>
<td></td>
<td>13.7</td>
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<tr>
<td><strong>Household Income (thousands)</strong></td>
<td></td>
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<td></td>
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<tr>
<td>Less than 20</td>
<td>4</td>
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<td>6.9</td>
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<tr>
<td>20-39</td>
<td>14</td>
<td></td>
<td>24.1</td>
<td></td>
</tr>
<tr>
<td>40-59</td>
<td>14</td>
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<td>24.1</td>
<td></td>
</tr>
<tr>
<td>60-79</td>
<td>8</td>
<td></td>
<td>13.8</td>
<td></td>
</tr>
<tr>
<td>80 and above</td>
<td>5</td>
<td></td>
<td>8.6</td>
<td></td>
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<tr>
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<td>13</td>
<td></td>
<td>22.4</td>
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Table 2

*Descriptive Statistics: ALS Caregivers’ Scores*

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Minimum</th>
<th>Maximum</th>
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<tr>
<td>Adult State Hope Scale</td>
<td>36.07</td>
<td>8.65</td>
<td>36</td>
<td>11</td>
<td>47</td>
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<tr>
<td>ALSFRS</td>
<td>31.14</td>
<td>10.34</td>
<td>40</td>
<td>8</td>
<td>48</td>
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<tr>
<td>BMMRS</td>
<td>98.00</td>
<td>25.87</td>
<td>115</td>
<td>54</td>
<td>169</td>
</tr>
<tr>
<td>Dyadic Adjustment Scale</td>
<td>98.39</td>
<td>25.10</td>
<td>131</td>
<td>0</td>
<td>131</td>
</tr>
<tr>
<td>Level of Care Index</td>
<td>9.60</td>
<td>4.31</td>
<td>16</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>LOT-R</td>
<td>33.77</td>
<td>4.19</td>
<td>19</td>
<td>24</td>
<td>43</td>
</tr>
<tr>
<td>SPSI-R: S</td>
<td>104.17</td>
<td>11.01</td>
<td>48</td>
<td>83</td>
<td>131</td>
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<td>WHOQOL-BREF</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Physical Domain</td>
<td>71.98</td>
<td>16.47</td>
<td>56</td>
<td>38</td>
<td>94</td>
</tr>
<tr>
<td>Psychological Domain</td>
<td>68.58</td>
<td>13.66</td>
<td>69</td>
<td>31</td>
<td>100</td>
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<tr>
<td>Social Relations Domain</td>
<td>67.33</td>
<td>16.99</td>
<td>75</td>
<td>25</td>
<td>100</td>
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<tr>
<td>Environmental Domain</td>
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<td>12.91</td>
<td>62</td>
<td>38</td>
<td>100</td>
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<tr>
<td>Overall QOL (Question 1)</td>
<td>4.07</td>
<td>.59</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Overall Health (Question 2)</td>
<td>3.63</td>
<td>.81</td>
<td>3</td>
<td>2</td>
<td>5</td>
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</table>

*Note.* ALSFRS (ALS Functional Rating Scale); BMMRS (Brief Multidimensional Measure of Religiousness/Spirituality); LOT-R (Life Orientation Test – Revised); SPSI-R: S (Social Problem Solving Inventory –Revised: Short Form); WHOQOL-BREF (World Health Organization Quality of Life – Abbreviated Form).
Table 3

*Bivariate Pearson Product-Moment Correlations of Resiliency Factors with Domains of WHOQOL-BREF*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Physical Domain</th>
<th>Psychological Domain</th>
<th>Social Relationships</th>
<th>Environment Domain</th>
</tr>
</thead>
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<tr>
<td>Hope</td>
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<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.280*</td>
<td>.569**</td>
<td>.442**</td>
<td>.354**</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.035</td>
<td>.000</td>
<td>.001</td>
<td>.007</td>
</tr>
<tr>
<td>Relationship Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.150</td>
<td>.109</td>
<td>.356*</td>
<td>.188</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.293</td>
<td>.445</td>
<td>.010</td>
<td>.188</td>
</tr>
<tr>
<td>Social Problem Solving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.193</td>
<td>.550**</td>
<td>.323*</td>
<td>.236</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.293</td>
<td>.000</td>
<td>.045</td>
<td>.149</td>
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<tr>
<td>Religiosity/Spirituality</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.183</td>
<td>-.255</td>
<td>-.193</td>
<td>-.054</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.174</td>
<td>.056</td>
<td>.150</td>
<td>.689</td>
</tr>
<tr>
<td>Optimism</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.148</td>
<td>.360**</td>
<td>.314*</td>
<td>.003</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.275</td>
<td>.006</td>
<td>.018</td>
<td>.982</td>
</tr>
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</table>

*Note.* WHOQOL-BREF (World Health Organization Quality of Life: Abbreviated Form).

*p < .05, two-tailed. **p < .01, two-tailed.*
Table 4

*Summary of Hierarchical Regression Analysis for Variables Predicting Caregivers’ Psychological QOL (Domain 2 from WHOQOL-BREF)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SE_B$</th>
<th>$\beta$</th>
<th>$t$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SHS</td>
<td>1.114</td>
<td>0.208</td>
<td>0.693</td>
<td>5.359</td>
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<tr>
<td><strong>Model 2</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SHS</td>
<td>1.091</td>
<td>0.197</td>
<td>0.679</td>
<td>5.546</td>
</tr>
<tr>
<td>BMMRS</td>
<td>-0.161</td>
<td>0.075</td>
<td>-0.265</td>
<td>-2.164</td>
</tr>
</tbody>
</table>

*Note. $R^2 = .48$ for Model 1; $\Delta R^2 = .07$ for Model 2. BMMRS (Brief Multidimensional Measure of Religiousness/Spirituality); WHOQOL-BREF (World Health Organization Quality of Life: Abbreviated Form); SHS (State Hope Scale).*
### Table 5

**Summary of Hierarchical Regression Analysis for Variables Predicting Caregivers’ Social Relationships QOL (Domain 3 from WHOQOL-BREF)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SHS</td>
<td>0.741</td>
<td>0.307</td>
<td>0.398</td>
<td>2.415</td>
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<td><strong>Model 2</strong></td>
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</tr>
<tr>
<td>SHS</td>
<td>0.780</td>
<td>0.282</td>
<td>0.419</td>
<td>2.770</td>
</tr>
<tr>
<td>DAS</td>
<td>0.238</td>
<td>0.091</td>
<td>0.397</td>
<td>2.627</td>
</tr>
<tr>
<td><strong>Model 3</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>SHS</td>
<td>0.361</td>
<td>0.307</td>
<td>0.194</td>
<td>1.178</td>
</tr>
<tr>
<td>DAS</td>
<td>0.238</td>
<td>0.083</td>
<td>0.397</td>
<td>2.852</td>
</tr>
<tr>
<td>LOT-R</td>
<td>1.568</td>
<td>0.616</td>
<td>0.419</td>
<td>2.547</td>
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</tbody>
</table>

*Note. $R^2 = .16$ for Model 1; $\Delta R^2 = .16$ for Model 2; $\Delta R^2 = .13$ for Model 3. BMMRS (Brief Multidimensional Measure of Religiousness/Spirituality); WHOQOL-BREF (World Health Organization Quality of Life: Abbreviated Form); SHS (State Hope Scale); DAS (Dyadic satisfaction Scale); LOT-R (Life Orientation Test-Revised).*
Table 6

Summary of Hierarchical Regression Analysis for Variables Predicting Caregivers’ Environment QOL (Domain 4 from WHOQOL-BREF)

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>0.247</td>
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<td>2.514</td>
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<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>SHS</td>
<td>0.598</td>
<td>0.303</td>
<td>0.396</td>
<td>1.975</td>
</tr>
<tr>
<td>SPSI-R:S</td>
<td></td>
<td>0.249</td>
<td>0.029</td>
<td>0.143</td>
</tr>
</tbody>
</table>

Note. \( R^2 = .17 \) for Model 1; \( \Delta R^2 = .00 \) for Model 2. WHOQOL-BREF (World Health Organization Quality of Life: Abbreviated Form); SHS (State Hope Scale); SPSI-R:S (Social Problem Solving Inventory – Revised: Short Form).
SAMPLE INFORMED CONSENT FORM

TITLE OF STUDY
Resiliency Factors: Predictors of Quality of Life in Family Caregivers of Patients with Amyotrophic Lateral Sclerosis

PURPOSE
The purpose of this research is to determine the relationship, if any, between hope, optimism, social problem-solving skills, relationship satisfaction, religiosity/spirituality and the quality of life in caregivers of patients with ALS.

You are being asked to participate in this research study because you meet the criteria for eligibility, which include: (1) being age 18 years and over, (2) the primary caregiver and spouse or cohabitating partner of a patient diagnosed with ALS, (3) have been providing primary care for your spouse for at least three months, and (4) fluent in English at or above the 6th grade level (e.g., able to understand the informed consent form). If you have a history of a severe psychiatric disorder, or if you are unwilling, and unable to sign the informed consent form, you can not be in this study.

INVESTIGATOR(S)
Name: Principal Investigator - Stephanie H. Felgoise, PhD, ABPP
Department: Director, PsyD Program in Clinical Psychology
Address: Philadelphia College of Osteopathic Medicine
4190 City Avenue
Philadelphia, PA 19131-1693
Phone: 215-871-6543

Name: Responsible Investigator, Beatrice H. Chakraborty, M.S.
Department: Doctoral Student, PsyD-Clinical Psychology
Address: Philadelphia College of Osteopathic Medicine
4190 City Avenue
Philadelphia, PA 19131-1693
Phone: 215-871-6442
The doctors and scientists at Philadelphia College of Osteopathic Medicine (PCOM) do research on diseases and new treatments. The quality of life study you are being asked to volunteer for is part of a larger research project.

Even though this research project is to study caregivers’ quality of life, no one can say that any treatment that results from this study will be better than the usual treatment.

If you have any questions about this research, you can call Dr. Felgoise at (215) 871-6543.

If you have any questions or problems during the study, you can ask Dr. Simmons, who will be available during the entire study. If you want to know more about Dr. Felgoise’s background, or the rights of research subjects, you can call Dr. Frederick Goldstein, Chairperson, PCOM Institutional Review Board at (215) 871-6859.
DESCRIPTION OF THE PROCEDURES

The Clinic Director or one of the ALS clinical staff persons whom you know will explain the study to you. If you are interested in participating, you will be introduced to a research assistant who will give you eight short questionnaires to fill out. These questionnaires will ask about your emotional mood, the role of religion in your life, your goals for the present, your relationship with your spouse, your attitude towards life in general, how you solve problems, and how you rate your current feelings of well-being. There are no correct, or wrong answers, and it should only take about 35-40 minutes to answer all questions. Feel free to complete the forms in the clinic, while your spouse or partner is participating in a separate quality of life study. However, if you do not have time answer the questions in the clinic, then you may take the questionnaires home, complete them, and mail them back to the principal investigator of this study in a self-addressed, stamped envelope which we will provide for your convenience.

Our research assistants are advanced doctoral students in clinical psychology, and are being supervised by a licensed psychologist, who is a core faculty member of the Philadelphia College of Osteopathic Medicine.

POTENTIAL BENEFITS

You may not benefit directly from being in this study. However, there are potential benefits to society. For example, the information obtained from this study may aid the investigators in understanding the physical, emotional, spiritual, and quality of life aspects of providing primary care to patients with ALS. You may benefit from the opportunity to speak with an objective person, should you care to, about your thoughts and feelings. Yet, no benefit is guaranteed.

RISKS AND DISCOMFORTS

There are no known risks or discomforts from being in the study.

You may experience emotional discomfort and become upset due to thinking about your loved one with ALS and your personal caregiving experience. However, you may decline to respond to a particular question or a questionnaire, but you may be asked by an investigator why you chose not to respond.

ALTERNATIVES

There are no known alternative studies being conducted at this time.

PAYMENT

You will not receive any payment for being in this study.
Appendix B

Demographics Questionnaire

Each of these questions relates to the person who provides home-based primary care to the patient with ALS. Please complete each question by filling in the blank or checking the single best answer.

Study ID #: ________________________________ Date: ____/_____/_______

Age: ______ yrs.

How long have you been a primary caregiver for the patient with ALS?

_____ Years ________ Months

Relationship to patient with ALS

_____ Spouse

_____ Domestic partner, married

_____ Domestic partner, unmarried

How long have you been in a spousal relationship with the patient?

_____ Yrs. ______ Mos.

Racial Background

___ White/Caucasian
___ Hispanic/Latino
___ African American
___ Asian/Pacific Islander
___ Other ___
___ Prefer not to answer

Household Income

___ Less than $20,000
___ $20,000 - $39,999
___ $40,000 - $59,999
___ $60,000 - $79,999
___ $80,000 or more
___ Prefer not to answer

Employment Status: (check all that apply)

Presently: ___ Work at home ___ Work outside of home ___ Part-time ___ Full time

Before ALS: ___ Work at home ___ Work outside of home ___ Part-time ___ Full time

History of psychiatric treatment and/or hospitalization: ___ Yes ___ No
Appendix B

**Adult State Hope Scale**

**Goals Scale for the Present**

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes how you think about yourself right now and put that number in the blank before each sentence. Please take a few moments to focus on yourself and what is going on in your life at this moment. Once you have this "here and now" set, go ahead and answer each item according to the following scale:

\[
\begin{array}{cccccccc}
1 &=& 2 &=& 3 &=& 4 &=& 5 &=& 6 &=& 7 &=& 8 = \\
\text{Definitely} &=& \text{Mostly} &=& \text{Somewhat} &=& \text{Slightly} &=& \text{Slightly} &=& \text{Somewhat} &=& \text{Mostly} &=& \text{Definitely} \\
\text{False} &=& \text{False} &=& \text{False} &=& \text{False} &=& \text{True} &=& \text{True} &=& \text{True} &=& \text{True} \\
\end{array}
\]

_____ 1. If I should find myself in a jam, I could think of many ways to get out of it.

_____ 2. At the present time, I am energetically pursuing my goals.

_____ 3. There are lots of ways around any problem that I am facing now.

_____ 4. Right now, I see myself as being pretty successful.

_____ 5. I can think of many ways to reach my current goals.

_____ 6. At this time, I am meeting the goals that I have set for myself.

Appendix B

**LOT-R**

*Life Orientation Test - Revised*

**Directions**

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. **There are no "correct" or "incorrect" answers.** Answer according to your own feelings, rather than how you think "most people" would answer.

---

A = I agree a lot  
B = I agree a little  
C = I neither agree nor disagree  
D = I Disagree a little  
E = I Disagree a lot

1. In uncertain times, I usually expect the best.  
2. It's easy for me to relax.  
3. If something can go wrong for me, it will.  
4. I'm always optimistic about my future.  
5. I enjoy my friends a lot.  
6. It's important for me to keep busy.  
7. I hardly ever expect things to go my way.  
8. I don't get upset too easily.  
9. I rarely count on good things happening to me.  
10. Overall, I expect more good things to happen to me than bad.

---

Appendix B

WHOQOL-BREF

ABOUT YOU
Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your gender? Male Female

What is your date of birth? Day / Month / Year

What is the highest education you received? None at all Primary school Secondary school Tertiary

What is your marital status? Single Separated Married Divorced Living as married Widowed

Are you currently ill? Yes No

If something is wrong with your health what do you think it is? ______________ illness/problem

INSTRUCTIONS
This assessment asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

<table>
<thead>
<tr>
<th>Completely</th>
<th>Not at all</th>
<th>Not much</th>
<th>Moderately</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you get the kind of support from others that you need?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

<table>
<thead>
<tr>
<th>Completely</th>
<th>Not at all</th>
<th>Not much</th>
<th>Moderately</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you get the kind of support from others that you need?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>(4)</td>
</tr>
</tbody>
</table>

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.
Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

<table>
<thead>
<tr>
<th>Question</th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(G1) How would you rate your quality of life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how much you have experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 (F1.4) To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4 (F11.3) How much do you need any medical treatment to function in your daily life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5 (F4.1) How much do you enjoy life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6 (F24.2) To what extent do you feel your life to be meaningful?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following questions ask about how completely you experienced or were able to do certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 (F2.1) Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11 (F7.1) Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12 (F18.1) Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13 (F20.1) How available to you is the information that you need in your day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14 (F21.1) To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Neither</th>
<th>Good</th>
<th>Very Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 (F9.1) How well are you able to get around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

The following question refers to how often you have felt or experienced certain things in the last two weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Seldom</th>
<th>Quite Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>26 (F8.1) How often do you have negative feelings such as blue mood, despair, anxiety, depression?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Did someone help you to fill out this form? …...........................................................................................................

How long did it take to fill this form out? …...........................................................................................................

Do you have any comments about the assessment?

...........................................................................................................................................................................

THANK YOU FOR YOUR HELP.
Appendix B

Brief Multidimensional Measure of Religiousness/Spirituality: 1999

**Daily Spiritual Experiences:** The following questions deal with possible spiritual experiences. To what extent can you say you experience the following:

1. I feel God’s presence.
   1 - Many times a day
   2 - Every day
   3 - Most days
   4 - Some days
   5 - Once in a while
   6 - Never or almost never

2. I find strength and comfort in my religion.
   1 - Many times a day
   2 - Every day
   3 - Most days
   4 - Some days
   5 - Once in a while
   6 - Never or almost never

3. I feel deep inner peace or harmony.
   1 - Many times a day
   2 - Every day
   3 - Most days
   4 - Some days
   5 - Once in a while
   6 - Never or almost never

4. I desire to be closer to or in union with God.
   1 - Many times a day
   2 - Every day
   3 - Most days
   4 - Some days
   5 - Once in a while
   6 - Never or almost never

5. I feel God’s love for me, directly or through others.
   1 - Many times a day
   2 - Every day
   3 - Most days

6. I am spiritually touched by the beauty of creation.
   1 - Many times a day
   2 - Every day
   3 - Most days
   4 - Some days
   5 - Once in a while
   6 - Never or almost never

**Meaning**

7. The events in my life unfold according to a divine or greater plan.
   1 - Strongly agree
   2 - Agree
   3 - Disagree
   4 - Strongly disagree

8. I have a sense of mission or calling in my own life.
   1 - Strongly agree
   2 - Agree
   3 - Disagree
   4 - Strongly disagree

**Values/Beliefs**

9. I believe in a God who watches over me.
   1 - Strongly agree
   2 - Agree
   3 - Disagree
   4 - Strongly disagree

10. I feel a deep sense of responsibility for reducing pain and suffering in the world.
    1 - Strongly agree
    2 - Agree
    3 - Disagree
    4 - Strongly disagree
Forgiveness: Because of my religious or spiritual beliefs:

11. I have forgiven myself for things that I have done wrong.
   1 - Always or almost always
   2 - Often
   3 - Seldom
   4 - Never

12. I have forgiven those who hurt me.
   1 - Always or almost always
   2 - Often
   3 - Seldom
   4 - Never

13. I know that God forgives me.
   1 - Always or almost always
   2 - Often
   3 - Seldom
   4 - Never

Private Religious Practices

14. How often do you pray privately in places other than at church or synagogue?
   1 - More than once a day
   2 - Once a day
   3 - A few times a week
   4 - Once a week
   5 - A few times a month
   6 - Once a month
   7 - Less than once a month
   8 - Never

15. Within your religious or spiritual tradition, how often do you meditate?
   1 - More than once a day
   2 - Once a day
   3 - A few times a week
   4 - Once a week
   5 - A few times a month
   6 - Once a month
   7 - Less than once a month
   8 - Never

16. How often do you watch or listen to religious programs on TV or radio?
   1 - More than once a day
   2 - Once a day
   3 - A few times a week
   4 - Once a week
   5 - A few times a month
   6 - Once a month
   7 - Less than once a month
   8 - Never

17. How often do you read the Bible or other religious literature?
   1 - More than once a day
   2 - Once a day
   3 - A few times a week
   4 - Once a week
   5 - A few times a month
   6 - Once a month
   7 - Less than once a month
   8 - Never

18. How often are prayers or grace said before or after meals in your home?
   1 - At all meals
   2 - Once a day
   3 - At least once a week
   4 - Only on special occasions
   5 - Never

Religious and Spiritual Coping: Think about how you try to understand and deal with major problems in your life. To what extent is each of the following involved in the way you cope?

19. I think about how my life is part of a larger spiritual force.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all

20. I work together with God as partners.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all
21. I look to God for strength, support, and guidance.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all

22. I feel God is punishing me for my sins or lack of spirituality.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all

23. I wonder whether God has abandoned me.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all

24. I try to make sense of the situation and decide what to do without relying on God.
   1 - A great deal
   2 - Quite a bit
   3 - Somewhat
   4 - Not at all

25. To what extent is your religion involved in understanding or dealing with stressful situations?
   1 - Very involved
   2 - Somewhat involved
   3 - Not very involved
   4 - Not involved at all

Religious Support: These questions are designed to find out how much help the people in your congregation would provide if you need it in the future.

26. If you were ill, how much would the people in your congregation help you out?
   1 - A great deal
   2 - Some
   3 - A little
   4 - None

27. If you had a problem or were faced with a difficult situation, how much comfort would the people in your congregation be willing to give you?
   1 - A great deal
   2 - Some
   3 - A little
   4 - None

28. How often do the people in your congregation make too many demands on you?
   1 - Very often
   2 - Fairly often
   3 - Once in a while
   4 - Never

29. How often are the people in your congregation critical of you and the things you do?
   1 - Very often
   2 - Fairly often
   3 - Once in a while
   4 - Never

Religious/Spiritual History

30. Did you ever have a religious or spiritual experience that changed your life?
   _____No  _____Yes

   IF YES: How old were you when this experience occurred? ________________

31. Have you ever had a significant gain in your faith?
   _____No  _____Yes

   IF YES: How old were you when this occurred? ________________

32. Have you ever had a significant loss in your faith?
   _____No  _____Yes

   IF YES: How old were you when this occurred? ________________
Commitment

33. I try hard to carry my religious beliefs over into all my other dealings in life.
   1 - Strongly agree
   2 - Agree
   3 - Disagree
   4 - Strongly disagree

34. In an average week, how many hours do you spend in activities on behalf of your church or activities that you do for religious or spiritual reasons?

Organizational Religiousness

35. How often do you go to religious services?
   1 - More than once a week
   2 - Every week or more often
   3 - Once or twice a month
   4 - Every month or so
   5 - Once or twice a year
   6 – Never

36. Besides religious services, how often do you take part in other activities at a place of worship
   1 - More than once a week
   2 - Every week or more often
   3 - Once or twice a month
   4 - Every month or so
   5 - Once or twice a year
   6 - Never

Religious Preference

37. What is your current religious preference?
   _______________________
   If protestant, which specific denomination is that? _______________________

Overall Self-Ranking

38. To what extent do you consider yourself a religious person?
   1 - Very religious
   2 - Moderately religious
   3 - Slightly religious
   4 - Not religious at all

39. To what extent do you consider yourself a spiritual person?
   1 - Very spiritual
   2 - Moderately spiritual
   3 - Slightly spiritual
   4 - Not spiritual at all

* Fetzer Institute, 1999
Appendix B

**LEVEL OF CARE INDEX**

The primary caregiver of the patient with ALS is the person who provides the majority of daily care for the patient, but does so informally (i.e., is not paid to provide the care). The following questions ask about the amount and type of care you are currently providing as the primary caregiver of a patient with ALS.

1. Thinking of all the help that you provide, how many hours do you spend in an average week providing care?

   1. ____ 0-8 hours per week
   2. ____ 9-20 hours per week
   3. ____ 21-40 hours per week
   4. ____ 41 or more hours, or “constant care”

2. Please check off all activities that you help the person with ALS perform:

   ___ Getting in and out of bed and chairs
   ___ Getting dressed
   ___ Getting to and from the toilet
   ___ Bathing or showering
   ___ Continence care with bowel or bladder or use of diapers
   ___ Assistance with feeding
   ___ I do not help with any of these

3. Please check off all activities that you help the person with ALS perform:

   ___ Managing finances
   ___ Housework
   ___ Preparing meals
   ___ Transportation (driving or arranging for transportation)
   ___ Arranging and supervising outside services
   ___ Grocery shopping
   ___ Giving medications
Appendix B

**DYADIC ADJUSTMENT SCALE**
*(SPANIER, 1976)*

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list:

<table>
<thead>
<tr>
<th>Item</th>
<th>Almost Always Agree</th>
<th>Almost Always Agree</th>
<th>Occasionally Disagree</th>
<th>Frequently Disagree</th>
<th>Almost Always Disagree</th>
<th>Always Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Handling family finances</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2. Matters of recreation</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>3. Religious matters</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>4. Demonstrations of affection</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>5. Friends</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>6. Sex relations</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>7. Conventionality (correct or proper behavior)</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>8. Philosophy of life</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>9. Ways of dealing with parents or in-laws</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>10. Aims, goals, and things believed important</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>11. Amount of time spent together</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>12. Making major decisions</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>13. Household tasks</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>14. Leisure time interests and activities</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>15. Career decisions</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>More</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. How often do you discuss or have you considered divorce, separat'n/terminat'g relat'nship?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. How often do you/your mate leave the house after a fight?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. In general, how often do you think that things between you &amp; your partner are going well?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Do you confide in your mate?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
20. Do you ever regret that you married, or lived together?  
0 1 2 3 4 5

21. How often do you and your partner quarrel?  
0 1 2 3 4 5

22. How often do you and mate "get on each other's nerves?"  
0 1 2 3 4 5

23. Do you kiss your mate?  
4 3 2 1 0

24. Do you and your mate engage in outside interests together?  
4 3 2 1 0

25. Have a stimulating exchange of ideas  
Never 1 2 3 4 5

26. Laugh together  
0 1 2 3 4 5

27. Calmly discuss something  
0 1 2 3 4 5

28. Work together on a project  
0 1 2 3 4 5

29. Being too tired for sex 0 Yes 1 No

30. Not showing love 0 Yes 1 No

31. The numbers on the following line represent degrees of happiness in your relationship. Number 3 ("happy") represents the degree of happiness of most relationships. Please circle the number that best describes the degree of happiness, all things considered, of your relationship?

0 1 2 3 4 5 6

Extremely Fairly A little Happy Very Extremely Perfect
Unhappy Unhappy Unhappy Happy Happy

32. Which of the following statements best describes how you feel about the future of your relationship?

5. I want desperately for my relationship to succeed, and would go to almost any length to see that it does.

4. I want desperately for my relationship to succeed, and will do all I can to see that it does.

3. I want desperately for my relationship to succeed, and will do my fair share to see that it does.

2. It would be nice if it succeeded, but I can’t do much more than I am doing now to help it succeed.

1. It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep it going.

0. My relationship can never succeed, and there is no more that I can do to keep the relationship going.
Appendix C

Data Collection Procedure and Instructions for Collectors

The Quality of Life (QOL) Study Group of the Milton S. Hershey Medical Center and PCOM collaborators are conducting a multicenter research study to refine and validate an ALS specific QOL Questionnaire. The fact that patients are generally accompanied to clinic appointments by their primary caregivers, presents a great opportunity to conduct a concurrent QOL study with their caregivers. The purpose of the later study is to explore the relationships among the caregivers’ level of hope, optimism, spirituality, relationship satisfaction, and social problem solving skills, and the predictive impact of these variables on the caregivers’ quality of life.

Research assistants (RA) are advanced doctoral students in clinical psychology, and are being supervised by a licensed psychologist, who is a core faculty member of PCOM. RA’s will be asked to obtain or verify informed consent from caregivers, administer the questionnaires, and assure the return of the data packets to the principal investigator at PCOM. The following instructions have been developed to support the data collectors and to assure consistent data collection across the study sites. Therefore it is imperative that this protocol is followed as closely as possible. Deviations from same should be documented in the participant’s data collection check list, as changes may affect the outcome of the study.

Data Collection Packet Contents

- Data Collection Checklist
- Informed consent form
- Demographics questionnaire
- WHOQOL-BREF
- LOT-R
- SPSI-R: S
- Adult Hope Scale
- The Level of Care Index
- DAS
- BMMRS: 1999

1. Selecting Participants

At the beginning of each clinic day, the neurologist will identify potential caregiver participants and determine eligibility, using the eligibility checklist located in the front of each data collection packet:
Inclusion criteria for participation are:

1. Age 18 years and over.
2. Spouse or domestic partner and functioning as the primary caregiver for an individual with clinically definite, clinically probable, or clinically probable – laboratory supported ALS, as diagnosed by the attending neurologist using El Escorial Criteria (Brooks et al., 1998). Primary caregivers are spouses, or domestic household partners who assume primary responsibility for (1) the patient’s emotional support, (2) helping with activities of daily living, (3) administration of medications, (4) provision of any special nutrition plan, and (5) help with other aspects of physical care during the course of the disease (Le et al., 2003).
3. Must have been providing primary care for a spouse with ALS for at least three months.
4. Fluency in English at the 6th grade level or higher, as determined by self-identification and ability to comprehend the informed consent.
5. Willing and able to provide informed consent.

Exclusion criteria are:

1. Lack of willingness or inability to give informed consent.
2. Dementia of the patient with ALS, as determined by the attending neurologist. Note that ALS with dementia is atypical of the course of ALS disease progression (McCluskey, 2000), and generates a host of unique caregiving issues that are not within the design of this study.
3. Caregivers of patients who have ALS comorbid with severe medical problems (e.g., cancer), or a psychiatric disorder (e.g., schizophrenia), as determined by the attending neurologist. These conditions have unique caregiving issues that cannot be addressed within the scope of this study.
4. Caregivers with a history of severe psychiatric disorders.

Once eligibility is determined proceed to introduce the study to the caregiver.

2. Introducing the Study to the Caregivers

Inviting caregivers to participate in the study is an important step. It is most important to inform caregivers about the purpose of this study, and why their participation is important. From experience, it has been found helpful if the person introducing the study is someone the caregiver knows, such as the neurologist or the nurse clinician. After one of the latter has explained the rationale and purpose of the study to the caregiver, and the caregiver displays interest in participating, the neurologist will introduce the caregiver to the research assistant(s) who will be administering the questionnaires. The following is a suggested personal introduction to participants:
“Mr/Mrs/Ms. Caregiver, as Dr. [Namee] indicated, my name is J. Doe and I am a doctoral student in clinical psychology at Philadelphia College of Osteopathic Medicine (display your student identification badge). This clinic is one of a number of ALS clinics participating in a Quality of Life study. We are asking all spousal/partnered caregivers of ALS patients to complete several questionnaires in the clinic today. Your participation is entirely voluntary and will take approximately 35-40 minutes of your time. Ultimately, we are looking to better understand the quality of life of our patients’ caregivers, and how that may affect the quality of life of our patients. I will leave this (informed consent) with you to read over, and I will return in a few minutes to answer any questions you may have, and to see if you wish to participate. If you choose not to participate that will be fine and it will not affect the care of your loved one in the clinic.”

Research assistants, please note that the Clinic Director/neurologist may elect to send a letter introducing the study, and a copy of the informed consent to caregivers prior to a pending clinic visit. This approach may be advantageous in obtaining participant cooperation and minimizing the caregivers’ time and energy once they arrive at the clinic. Such a letter can easily be included in any preclinic mailing that the patient and caregiver already receive, or sent separately. (See Appendix D).

3. Obtaining Informed Consent

The person who obtains the informed consent will vary based on the IRB guidelines for informed consent at your study site (e.g., Pennsylvania Hospital). All participants must read and sign an informed consent form. After the participant reads the form, ask if there are any questions. Reassure the participant that all information is confidential, that the participant may stop participating at any point in the data collection, and that choosing to participate or stop participating will have no impact on the care of the patient or the caregiver. The informed consent form must be signed by the participant and dated in permanent black ink, before any data is collected or questionnaires are given.

The form must also be signed and dated by an IRB authorized person at your study site. Please make copies of the signed informed consent form and distribute as mandated by your IRB, making sure to enclose one copy with the completed data packet to be returned to the principal investigator at PCOM.

4. Facilitating Self-Administered Questionnaires

On the Master Caregiver Quality of Life Registration Form, record the participant’s name, data collection packet number, date, and data collector’s name. A separate room, or private space should be reserved for participants to complete the
questionnaires. Perhaps you could arrange for beverages (i.e., coffee, tea) to be available to make participants as comfortable as possible.

Simultaneous studies are being conducted at the ALS clinics: the *ALSQOL study*, and the *Caregiver QOL study*. In most instances the data collector will be the same for both studies. Spouses or partner-caregivers will have been asked to leave the room anyway, while you complete the questionnaires for the *ALSQOL study*, with the ALS patients. Therefore, give the caregivers a pen and the *Caregiver QOL* data collection packets to complete while they are waiting for the patients. Remind participants that completion of the questionnaires will only take a short time. Anticipate 35 to 40 minutes. Remember, too, that if the caregiver does not have time to complete the questionnaires during the clinic visit, it is acceptable to let the person take the forms home to fill them out. In that case, as long as you have a signed informed consent from the participant, give the person the questionnaires, and a self-addressed envelop to return the completed forms to the principal investigator at PCOM. Encourage the person to complete and return the forms within one week.

It is preferred that you hand the packet to the participants in the order that you want the questionnaires completed. Most participants will not change the order. Have the packet secured with a large clip or something similar so that it does not fall apart if accidentally dropped. Clipboards may greatly facilitate the process of data collection:

- Demographics questionnaire
- WHOQOL-BREF
- LOT-R
- SPSI-R:S
- Adult Hope Scale
- The Level of Care Index
- DAS
- BMMRS: 1999

Remind the participants that there is no right or wrong answer to any question, and that they do not need to spend a lot of time on any one item, but they should not skip any question.

5. **Important Data Collection Points**

- If a participant asks your opinion about the content of a question, resist the temptation to offer your personal interpretation. Instead, it is suggested that you validate the person’s concern with: “I understand this is important to you. However, please complete the questionnaire just as you understand it, for purposes of our study. Afterwards, feel free to talk with (clinic designee’s name, or the principal investigator) about your concern.”

- The Caregiver QOL questionnaires are not intended to evoke emotional discomfort. However, it sometimes happens that when thinking about their roles
as caregivers, participants may be overwhelmed by the prospect. If they express a need to you for emotional comfort, please gently refer them to the clinic designee for psychological support.

- Always thank the participant for volunteering to be part of the research process, before and after they complete the questionnaires.

6. **Completion of Data Collection**

- Retrieve the Caregiver QOL data collection packet from the participant, checking to make sure the questionnaires are fully completed, and that the participant has a copy of the signed informed consent form. Obtain the ALSFRS-R of the ALS spousal care-recipient from the Clinic Director, and include a copy of that scale with the caregiver’s data.

- Complete and sign the data collection checklist. Place all completed data packets for that clinic day in the envelope supplied. Seal the envelope and return it to the principal investigator at PCOM.

- The designated person at PCOM will return the data packets as soon as possible to the responsible investigator of the Caregiver QOL study in overnight delivery mailers provided for that purpose.
Appendix D

SAMPLE RECRUITMENT LETTER

Dear Mr/Mrs. Caregiver:

I am writing to you to inform you of a research project being conducted by investigators from the Philadelphia College of Osteopathic Medicine, at three ALS clinics across the state of Pennsylvania, including our Hershey Medical Center’s ALS Clinic. The purpose of this research is to determine the relationship, if any, between hope, optimism, social problem-solving skills, relationship satisfaction, religiosity/spirituality and the quality of life in spousal and cohabitating caregivers of patients with ALS.

Approximately 150 caregivers will be asked to fill out a series of short questionnaires relevant to specific aspects of daily living that contribute to a caregiver’s quality of life. Ideally, caregivers will complete the questionnaires while visiting the ALS clinic with patients, and it will take about 35-40 minutes. However, the researchers have also made provisions for the forms to be completed at the caregiver’s home, and returned by mail.

You are being asked to participate in this research study because you meet the minimum criteria for eligibility, which include: (1) being age 18 years and over, (2) the primary caregiver and spouse/partner of a patient diagnosed with ALS, (3) have been providing primary care for your mate for at least three months, and (4) fluent in English.

If you agree to participate, you will be asked to read and sign an informed consent form. Then you will be given the questionnaires which focus on your emotional mood, the role of religion in your life, your goals for the present, your relationship with your spouse, your attitude towards life in general, how you solve problems, and how you rate your current feelings of well-being. Your written responses will be stored in a locked file cabinet in the principal investigator’s office. Further, your name and identity will not be used in this study, or any published results.

This study may not benefit you personally. However, if you agree to participate, you will be adding to the body of knowledge about the specific experiences and needs of spouses providing primary care to patients with ALS. If you are interested in participating, please let me know prior to [ALS patient name] next clinic visit. If you have any questions about this research study, you may contact me directly.

Respectfully yours,

Zachary Simmons, M.D.
Appendix E

Data Collection Check List

Check the following before sealing the data collection envelope:

__ Information entered on your site’s Master Quality of Life registration Form

__ Informed consent verified

__ Copies of Informed consent distributed according to rules of your Institutional Review Board

__ Demographic sheet completed and enclosed

__ ALSFRS-R completed by Clinic Director and enclosed

__ Study questionnaires: _____ enclosed ____ taken home by participant

Problems during data collection?

_____ No  _____ Yes

If YES, describe

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

Comments, suggestions concerning data collection: ____________________________

____________________________________________________________________________________

____________________________________________________________________________________

Data Collector’s Signature ____________________________________________

Date ______________________________
Appendix F

Master Caregiver Quality of Life Registration Form

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