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Spirituality and Psychological Well-Being Among ALS Caregivers:
Hope and Perceived Stress as Mediators

A thesis
presented to
the faculty of the Department of Psychology
East Tennessee State University

In partial fulfillment
of the requirements for the degree
Master of Arts in Psychology

by
Bridget R. Jeter
May 2016

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Keywords: ALS, Caregiver, Spirituality, Well-being, Hope, Perceived Stress

ABSTRACT

Spirituality and Psychological Well-Being among ALS Caregivers:

Hope and Perceived Stress as Mediators

by

Bridget R. Jeter

The empirical study of the salutary relationship between spirituality and psychological well-being is burgeoning. Theory suggests that within the context of ALS caregiving, spirituality may lead to hope and less perceived stress, ultimately contributing to increased well-being. Cross-sectional mediation-based analyses were conducted on data from 85 ALS caregivers throughout the U.S., The Netherlands, and Belgium. Participants were 78.8% female, 92.9% Caucasian, 48.2%, spent over 100 hours per week caregiving, and the average age was 55.2 years. Ritualistic spirituality was not related to well-being. Theistic spirituality was directly, positively related to well-being. Existential spirituality was deleteriously related to well-being. However, when hope and perceived stress were considered as mediators, the effect changed and contributed salutarily to well-being when operating through hope and perceived stress alone. This study may be the first to model spirituality and well-being in ALS caregivers, thus more research to investigate the psychological process of caregiving is warranted.

DEDICATION

This study is dedicated to my mother, Deborah Manuel Reeves, who was diagnosed with ALS in February 2011 and passed away on June 1, 2013 at the age of 51. From the very beginning she gave her lot and blessed me with the wings to fly!

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Furthermore, I want to offer my deepest appreciation to my mother's caregivers who served as true models of hope and courage for my mother and me during the progression of her illness. Without their tireless effort, flexibility, and time, the continuation of graduate school and this resulting project, would not have become a reality for me.

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CHAPTER 1

INTRODUCTION

Spiritual connections and religious beliefs and practices, have been important to US citizens and individuals world-wide for centuries. Recently, a comprehensive study including over 230 countries and territories worldwide reported that, in 2010, 5.8 billion or 84% of the world's inhabitants consider themselves as religiously affiliated (Pew Research Center, 2012). As of 2013, 90% of US citizens believe in God or a universal spirit, 56% say that religion is very important in their own lives and 59% state that they are a member of a church or synagogue (Gallup Poll, 2013).

Considering the prevalence of spiritual and religious beliefs in the US and worldwide, the importance of spiritual and religious concerns should, likewise, not be overlooked in relationship to individuals' psychological well-being. Empirical studies examining the relationship between spirituality/religiousness and psychological well-being are burgeoning (Hill & Pargament, 2008; see also Koenig, King, & Carson, 2012). Although many of these studies have found salutary relationships between spirituality/religiousness and psychological well-being, fewer studies have focused solely on delineating the *mechanisms* of the spirituality-psychological well-being connection. Experts have suggested that not only may there be a direct effect, but there may also be psychological, social, or physiological factors that mediate the relationship between spirituality/religiousness and psychological well-being (Hill & Pargament, 2008).

Spirituality/religiousness may be a central factor in the promotion of coping in the context of situations that are high in stress, such as health related incidences (Koenig & Larson, 2001).

Spirituality/religion have been found to have beneficial effects in a variety of aspects of health and healthcare (Koenig et al., 2012), including medical rehabilitation (George, Larson,

Koenig, & McCullough, 2000; Webb, 2003; Webb, Toussaint, Kalpakjian, & Tate, 2010). Spirituality/religion may not only contribute to positive psychological characteristics such as hope, forgiveness, and compassion (Toussaint, Webb, & Keltner, 2012), but may have a significant impact on the process of healing, adjusting to, and coping with disability related health conditions (Koenig & Larson, 2001; Simmons, 2013; Webb, 2003). Likewise, spirituality/religion may positively impact caregivers' psychological well-being as they adjust to the stress and burdens associated with caring for individuals with disability related and chronic health conditions such as Amyotrophic Lateral Sclerosis (ALS; Hebert, Dang, Schulz, 2007; Calvo et al., 2011).

A subsequent examination of the literature will further evaluate the role of spirituality on psychological well-being, in general, and more specifically in terms of ALS caregiving. However, in order to achieve a better understanding of the ALS caregiving experience, knowledge of the disease is crucial. Second, the existing ALS caregiving literature will be examined in relationship to psychological well-being factors such as caregiver burden, caregiver distress, and caregiver-patient interactions. Third, in addressing psychological well-being among ALS caregivers, the potential mediators of hope and perceived stress will be highlighted. Last, the relationship between spirituality and ALS caregiving will be examined in the context of the overall model of spirituality and psychological well-being with hope and perceived stress as mediators.

Spirituality

A review of the literature by Toussaint et al., (2012) found that, to date, of about 600 studies, 70% report at least one positive association between religiousness, spirituality, and better mental health. Similarly, in a review of the literature, Koenig and Larson (2001) found positive

associations in 12 of 14 studies evaluating hope, optimism, and purpose and meaning in relationship to religion. Of the three studies reported to have utilized the best scientific methodology, individuals who were more religious also had greater levels of hope and optimism. Koenig and Larson suggest that religiousness may promote a positive worldview and meaning in life which may, in turn, contribute to a “sense of purpose and direction that enhances hope and motivation” (p. 72). Religiousness may also promote social support, forgiveness, compassion, and, overall, bolster well-being especially during times of stress (see Toussaint et al., 2012).

Many experts have suggested that spirituality/religiousness may be multidimensional in nature, yet much of the literature has not measured spirituality/religiousness in a consistent nor multidimensional manner (Hebert, Weinstein, Martire, & Schulz, 2006; Hill & Pargament, 2008; Webb, Toussaint, & Dula, 2014). To date, the empirical literature has not been unified in the measurement of spirituality/religiousness, often utilizing items such as church attendance, denominational affiliation, and self-reported beliefs, which may only be measuring one aspect of spirituality (Pargament, 2013; Seeman, Dubin, & Seeman, 2003). Even as the empirical investigations of spirituality and religiousness in the context of health and well-being have burgeoned, there is more work to be done.

In an acknowledgement of prior literature and an effort to better operationalize both spirituality and religiousness, Webb et al. (2014) have redefined the term *spirituality* to be an overarching construct that includes three interrelated components: 1) structured religious activities (religiousness; ritualistic spirituality), 2) non-religious, but otherwise spiritual activities (non-structured, deity focused; theistic spirituality), and 3) non-theistic, but otherwise transcendent activities related to searching for meaning and purpose (existential spirituality). Therefore, there may be a distinction between spirituality and religiousness in that religiousness

itself operates as one of three dimensions of spirituality. This model of spirituality assumes that *optimal* spirituality embodies characteristics of all three components and that each of the components overlap with each other to some degree and in a way that is both multidirectional and proportional, such that higher levels of one dimension would be associated with lower levels of another dimension. This is the first model of its kind to explicitly delineate and incorporate all three dimensions of spirituality into the same model (Webb et al., 2014).

Spirituality and Psychological Well-Being

Although experts have long been examining the relationship between spirituality/religiousness and psychological well-being, less is known about the mechanisms through which spirituality may influence such. Psychological well-being may be conceptualized as the absence of physical health somatic symptoms such as sleep difficulties, indigestion, and headaches, as well as the absence of mental health symptoms such as depression and anxiety (e.g., Hirsch, Sirois, & Lyness, 2011; Vella, Milligan, & Bennett, 2013; Wang & Castañeda-Sound, 2008). Conceptual and theoretical models have been developed in order to guide the literature with a more complete understanding of the spirituality-psychological well-being relationship. As examples, George, Ellison, and Larson (2002), Baetz and Toews (2009), and Koenig and Larson (2001) have each proposed models of the spirituality-mental health relationship.

George and colleagues (2002) examined the relationship between religious involvement and overall health. George and colleagues suggest that the two most salient dimensions of religious involvement in regards to health are attendance at religious services and religious coping. Weekly attendance at religious services has not only been found to be related to physical health and longevity, but mental health, as well (Koenig et al., 1997). Religious coping has

strong associations with illness recovery and survival, such that those that lean upon their religion during times of illness recover more quickly, better tolerate medical procedures, and ultimately are more likely to survive illness (Koenig et al., 1997). The mechanisms through which religion positively influences health are thought to be health practices, social support, psychosocial resources such as self-esteem, self-efficacy, and mastery, and a sense of coherence or meaning. Additionally, George and colleagues recognize the need to fully examine the relationships and pathways such hypothesized mechanisms have among religion and mental and physical health.

Baetz and Toews (2009) have suggested that the positive association between spirituality/religion and well-being is mediated by biological, psychological, and social elements. The biological elements include genetic factors that have been found to contribute to increased spirituality and religiousness and physiological mechanisms that play a role within the spirituality and mental health relationship. The psychological elements include extrinsic orientation which describes individuals who utilize religion for “security, solace, sociability, distraction, status, and self-justification” and intrinsic orientation which describes individuals who have found “their reason for being through their religious beliefs” (p. 293). Social elements involve mechanisms that promote health related behaviors and discourage health-compromising behaviors, such as alcohol abuse, drug abuse, and other risky activities.

Koenig and Larson (2001) offer a model of spirituality/religiousness and mental health that is comprised of three components. First, both spirituality and religiousness foster psychological qualities which may give rise to a more meaningful worldview, such as hope, optimism, purpose, meaning, and motivation. These positive characteristics may be especially important in times of significant stress. Second, spirituality/religiousness promotes pro-social

values such as forgiveness, humility, compassion, mercy, and gratitude, which supplants self-serving ideals; encouraging a focus toward others. Third, spirituality/religion may bolster social support, marital and familial relationships, and community networks, which may play supportive roles in times of trial and distress. It is through these mechanisms (e.g., hope) by which spirituality/religiousness may enhance the means by which an individual copes with stress and may buffer against emotional disorders, ultimately contributing to increased mental health and well-being. That is, spirituality may lead to hope, which may lead to less stress, which may lead to better psychological well-being (see Figure 1a).

Moreover, Koenig and Larson (2001) recognize the importance of spirituality/religiousness in situations of severe and prolonged stress. They have also suggested that the effects of spirituality/religiousness may vary according to what type of stress is being experienced. Caregiving for chronically and terminally ill patients, such as those with ALS, may be one such circumstance in which spirituality may contribute to the caregiver's psychological well-being. However, a model of spirituality and psychological well-being in ALS caregivers has not been examined to date. A May 2015 literature search of PsycINFO and PubMed of spiritual* and amyotrophic lateral sclerosis and caregiv* resulted in two applicable empirical studies which had examined spirituality/religiousness in ALS caregivers and, in general, found a salutary relationship between spirituality/religiousness and caregivers' quality of life (Calvo et al., 2011; Pagnini et al., 2011). As such, an examination of the association between spirituality and psychological well-being among ALS caregivers is warranted.

Amyotrophic Lateral Sclerosis

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive neuromuscular disease that has a survival rate of two to four years after symptom

onset (Andersen et al., 2012). There is no known cure. Due to the nature of the disease and the way in which series of muscles gradually succumb to impairment and eventually render the patient unable to move and/or speak, although cognitive and sensory function remains intact, the burden of care gradually, but extensively, shifts to family members, friends, and/or other medical providers (Clarke & Levine, 2011).

The mean age of onset is between 43 – 52 years of age for familial cases, which account for 5% to 23% of all ALS cases, and 58 – 63 years of age for sporadic cases (Andersen et al., 2012). Diagnosis often occurs only after symptoms, such as loss of muscle control, have caused enough awkwardness and concern during daily activities to seek explanations. Due to difficulties with differential diagnosis, medical professionals may request and evaluate any number of tests to rule out a variety of potential conditions before confirming a diagnosis of ALS. Thus, it is difficult, if not impossible, to know the actual time of onset and, on average, takes 10 – 18 months from onset of symptoms to receive a confirmation of ALS diagnosis (Andersen et al., 2012; Shook & Pioro, 2009). Andersen et al. (2012), state that “psychologically, the absence of a definitive diagnosis, even of a disorder carrying a poor prognosis, causes distress and anxiety” (p. 361). Symptomology varies from patient to patient, as well, contributing to difficulty in diagnosis and overall uncertainty and distress related to the disease (Shook & Pioro, 2009). Common symptoms include difficulty grasping items, such as a coffee cup or buttoning clothes, and awkwardness in walking, increased rate of tripping, falling for no obvious reason, and changes in walking style, such as heaviness in the feet or dropped toes (Clarke & Levine, 2011). In 25% of cases, the onset involves bulbar weakness (i.e., weakness in the muscles controlling speech, swallowing, and chewing). In all cases, bulbar weakness will occur at some point during the illness, but is typically considered to have mid to late onset in the progression. Only through

electrophysiological evidence, such as electromyography and sensory nerve conduction, can a neurologist make a diagnostic determination of ALS (Andersen et al., 2012; Clarke & Levine, 2011).

As muscle atrophy progresses, other symptoms are presented throughout the course of the disease until point of death. Table 1 provides a clinical summary of ALS symptoms and a related, but not exclusive, list of assistive needs. ALS is characterized by the three D's, dysarthria (difficulty speaking), dysphagia (difficulty swallowing), and dyspnea (difficulty breathing), which occur in sequence on the continuum of progression (Brooks et al., 1996; Clarke & Levine, 2011). Patients experience increased muscle spasticity (Andersen et al., 2012), which causes muscles to become rigid and stiff, especially considering decreased muscle use, and commonly experience exaggerated fasciculations (muscle twitching). Dysphagia may also lead to the decreased ability to swallow whole foods, modified or thinned foods and even water, increasing the need for tube feeding or percutaneous endoscopic gastrostomy (PEG). While PEG does improve nutrient intake, there is no evidence of increased quality of life or increased survival (Andersen et al., 2012). Unless intervention occurs through use of a device, such as a BiPAP (Biphasic Positive Airway Pressure) or tracheotomy, the patient will succumb to respiratory failure, due to loss of muscle function in the diaphragm (Albert et al., 2009; Clarke & Levine, 2011). Importantly, in addition to the aforementioned physical symptoms associated with muscle atrophy, at least 50% of patients also experience uncontrollable expressions of emotion related to Pseudobulbar Affect (PBA), such as laughing, crying, yawning, or smiling, regardless of positive or negative bulbar motor symptoms (Andersen et al., 2012).

As muscle atrophy increases, required lifestyle changes progress. Over the course of the illness, independent mobility decreases and reliance upon various equipment and support from

family members, friends, and healthcare professionals becomes mandatory. Often the process of finding the right equipment or fit, or method of being lifted or handled, is a process of trial and error, but also a process of change and adaptation (King, Duke, & O'Connor, 2009). Considering the potential short timeframe between onset of symptoms and further muscle deterioration, rapid adaptation may be necessary for both the patient and caregiver(s) (Clarke & Levine, 2011). The caregiver may experience strain related to increased responsibilities, including physical movement of the patient, patient feeding, management of equipment such as a ventilator, and illness-related financial burden. During this process, it should be noted, the caregiver(s) may rely on the patient's independence of mind for instruction and guidance regarding what accommodation is further required (Fried-Oken et al., 2006; King et al., 2009). The process, as described, may be mentally and physically fatiguing for both the patient and caregiver (Andersen et al., 2012).

Table 1

A Summary of Clinical Symptoms and Projected Needs in ALS

Symptoms	Early States	Late Stages	Leading to:	May require:
Muscular Symptoms			Loss of voluntary movement and function	
Example of lower motor neuron involvement	Awkward fine hand movement, with weakness, twitching, or cramping Painless, progressive limb weakness typically asymmetric (flaccid muscle weakness-> paralysis) Muscle twitching (fasciculations) Muscle wasting (atrophy)	Typically progresses regionally to upper arms, neck, shoulders, and lower extremities Severely limited mobility and painful joint complications due to spasticity Increased and sensed by patient as cramping Continued widespread wasting of upper and lower extremities	Inability to do basic functions or care for self Inability to move or walk	Less restrictive clothing, help buttoning, help writing Cane -> Walker -> Wheel chair (various types) Adjusted transportation Lifting recliner -> Hoyer Lift -> Mechanical Hospital Bed
Example of upper motor neuron involvement	Spasticity (tight and stiff muscles) -> spastic muscle weakness Hyperreflexia (exaggerated reflexes) with spontaneous clonus Babinski sign	Widespread, spasticity in walking and manual dexterity Widespread Foot and hand deformities (foot drop, claw hand), secondary joint contractures		Adjusted bathing, toileting area, & living quarters Shoe inserts -> Foot & ankle braces
Respiratory symptoms	Poor nocturnal sleep with excessive daytime sleepiness, headaches on awakening from nocturnal hypoventilation (sleep)	Progressive inability to cough or clear secretions from the airway	Respiratory tract infections and aspiration of food and saliva	Adjusted bedding & pillows Mechanical suction devices
	Dyspnea with exertion, inability to sleep in supine position	Dyspnea at rest, respiratory muscle failure, increased breathing difficulties	Respiratory failure as primary cause of death	BiPAP -> Tracheostomy (requires surgery)

Table 1, continued

Symptoms	Early States	Late Stages	Leading to:	May require:
Bulbar palsy symptoms (affecting speech and swallowing)	Nasal speech with loss of volume -> slow spastic slurred or garbled speech (dysarthria)	Progressive	Inability to speak	Assistive communication devices (manual to computerized)
	Loss of tongue mobility -> difficulty chewing, swallowing with choking (dysphagia), weight loss, fatigue	Progressive inability to eat and swallow	Malnutrition and starvation	Altered softened foods -> Liquids -> PEG (feeding tube, requires surgery)
	Excessive salivation (sialorrhea) and drooling			Mechanical suction devices
	Hyperactive gag reflex Facial weakness, head drop (ptosis)	Inability to protect airway Loss of facial expression	Aspirations	Head support -> Neck brace (careful not to affect breathing ability)
	Fascial fasciculations Brisk jaw jerks Involuntary emotional expression disorder (laughing or crying outbursts), exaggerated emotional response		Erratic affective behavior	

Table 1, continued

Symptoms	Early States	Late Stages	Leading to:	May require:
Cognitive symptoms	Alert and oriented (generally)	Fear, anxiety, depression		
	Mild impairment (relatively common) - may be related to nocturnal			
	Dementia (rare) - fronto-temporal dementia may occur with bilateral frontal lobe neurodegeneration			
	Typically unaffected			
	Extra ocular muscle movements			
	Bladder and bowel control			
	Sensory function (ability to see, smell, taste, hear, and feel touch)		Able to feel and perceive pain	
	Autonomic function	Excessive nocturnal sweating		
	Mind, personality, intelligence, and memory			

Adapted from Clarke & Levine (2011), p. 208-209

For years, ALS patients have been esteemed as mentally resilient or heroically stoic individuals who seem to be free from psychological symptoms such as hopelessness and depression (Brown & Mueller, 1970; McLeod & Clarke, 2007). It has only been during the last 10 years that the scientific literature has challenged such a notion. The literature does, however, agree on the fact that evaluating psychosocial constructs in ALS patients has largely been overlooked, likely due to the focus on the physical components of the disease and the search for a cure (e.g., Boerner & Mock, 2012; McLeod & Clarke, 2007; Pagnini, 2013). Studies evaluating similar constructs in *caregivers* of ALS patients solely, have been even more meager, but

preliminary evidence suggests that hopelessness and associated depression may be higher in caregivers than patients (Trail et al., 2003).

Psychological Well-Being among ALS Caregivers

The research literature regarding psychological well-being among ALS caregivers is lacking compared to examples from other areas of chronic illness research. There are few studies that solely examine ALS caregiver characteristics and outcomes external to the corresponding ALS patient dyad (i.e., the ALS patient and the ALS caregiver). A July 2015 search of the scientific literature within PsycINFO and PUBMED initially revealed a total of 78 unique peer reviewed journal articles. The search terms included caregiv* [title] and amyotrophic lateral sclerosis. Of the 78 results, 16 of those examined psychosocial constructs within and among ALS caregiving and caregivers. For purposes of the following review, this literature has been grouped and categorized according to various ALS caregiver related psychosocial topics such as caregiver burden, caregiver distress, and patient interaction with the caregiver.

Caregiver burden

Over the past 10 years, researchers have been curious as to possible differences in ratings from caregivers versus patients concerning burden of care. The seminal article in this regard was published by Hecht et al. (2003), which examined objective and subjective burden of care in 37 ALS caregivers and their corresponding patients. Measures included the Burden Scale for Family Caregivers (BSFC) used to measure subjective burden, the Cost of Care Index (CCI) used to measure economic burden, and average time spent caregiving. The study found that the mean BSFC scores were low compared to scores from caregivers of dementia, neuropsychiatric disease, and internal-geriatric disease patients. The authors explain this finding by suggesting that ALS caregivers have increased motivation at the beginning of the caregiving stint which

may lower perceived stress scores initially, but would gradually worsen as the disease progressed. The study also found that women rated higher than men for subjective burden of care. Furthermore, the study found that the subjective burden of care and ALS-FRS (ALS Functional Rating Scale) were significantly correlated, and that the subscales of “physical and emotional health” and “personal and social restrictions” were essential dimensions (p. 331). The ALS-FRS was also positively and highly correlated to the daily average time spent by ALS caregivers in caregiving activities. Considering these findings, Hecht et al. made the call for the appropriateness of developing interventions and offering psychological treatment for both patients *and* caregivers.

Adelman et al. (2004) followed Hecht et al. (2003) by addressing potential discrepancies between patients and caregiver ALS-FRS ratings at the end of life. Because caregivers may serve as “proxies” (p. 1769) for the patient when providing data for the ALS-FRS (i.e., as the disease progresses, ALS patients are increasingly less able to communicate effectively with acquaintances), the ability to give accurate function ratings is imperative, especially toward the end of life. In addition to the ALSFRS – R (revised), the Zarit Burden Interview was given to 69 caregivers and their patients, as well as the Visual Analogue Scale (VAS) which assesses mood and attitudes. The study found that, over multiple settings, caregivers accurately reported ALSFRS-R ratings and that the patients were in agreement especially concerning pain, control over ALS, optimism, and will to live. However, there was a reduced amount of agreement concerning patient suffering and caregiver burden, as caregivers rated patient suffering higher than patients rated it themselves. Similarly, patients rated caregivers as having more burden than caregivers rated it themselves. Additionally, the more caregivers feel burdened, the more likely they are to report higher patient suffering.

Chio, Gauthier, Calvo, Ghiglione, and Mutani (2005) examined subjective burden in 60 ALS patients and their caregivers utilizing the ALS-FRS, the Caregiver Burden Inventory (CBI), the McGill Quality of Life Questionnaire (MQOL), the Zung Depression Scale (ZDS), and the Self-Perceived Burden Scale (SPBS). Chio et al. found that CBI total scores, which measured time dependence, emotional, social, physical, and domains, were positively significantly related to ALS-FRS scores. This finding indicates that as the disease progresses over time, the rise of caregiver burden is anticipated. The authors indicate, as Hecht et al. (2003) had proposed, that caregiver burden increasing over time and being “in excess of the patients’ clinical impairment” is one element that sets ALS apart from other chronic illnesses (Chio et al. 2005, p. 1781). Interestingly, perceived burden did not decrease when additional or substitute caregivers were available. Additionally, as found in Hecht et al. (2003), subjective burden (CBI scores) were higher in women than men and especially in the social burden category, and elucidates the notion that women and men may have different motivations for caregiving and cope with the caregiving experience in different ways. Furthermore, only 12% of caregivers reported depressive symptoms which corresponded to patients’ reports. Finally, patients had an accurate awareness of their clinical status which corresponded to their perceived impact on their caregivers, which is alternative to findings reported by Adelman et al. (2004).

Caregiver distress

One may intuitively suspect that in patients who may face progressive loss of ability and increased physical impairment over time, that depression would be high. One might expect similar results concerning caregivers. However, research results have been mixed. Rabkin, Wagner, and Del Bene (2000) interviewed 56 ALS patients and 31 caregivers. Participants responded to surveys assessing depression, quality of life, and caregiver burden. Even though

most of the patients had been diagnosed with ALS for over one year, their depression scores were not elevated. Additionally, depression and ratings of distress were not related to time since diagnosis, physical manifestations of illness, or with disease progression. However, depressive symptoms, hopelessness, suffering, and fatigue were found in those who desired hastened death. Yet, taking steps toward preparing for death, as measured by the Schedule of Attitudes Toward Hastened Death (SAHD), was negatively associated with psychological distress suggesting that making such preparations is actually a means of coping rather than distress. In this study, caregivers tended to be similarly depressed as the patients. Additionally, there was a positive association between caregiver perceived burden and caregiver ability to find meaning, which was suggested by Folkman (2010) as a means of positive coping. Finally, and perhaps most importantly, the correlations between patients and caregivers were high for distress levels such as severe depression, anxiety, and quality of life. These results support the conclusion that levels of distress in one party may affect distress levels in the other.

Another study addressing the psychosocial attributes of both patients and caregivers was performed by Trail, Nelson, Van, Appel, and Lei (2003). The study involved 27 ALS patients and 19 caregivers who completed a variety of measures including depression, quality of life, functional rating, and attitude scales. The results suggested that severity of disability was not necessarily related to depression. However, the study did find that caregivers reported more depressive symptoms than patients.

Rabkin, Rabkin, Albert, Rowland, and Mitsumoto (2009) longitudinally studied the prevalence of depression among ALS caregivers. Participants included 80 patients and 71 caregivers who completed the Patient Health Questionnaire (PHQ-9), Beck Depression Inventory (BDI-II), Manne scales of positive and negative Dyad support, two measures of caregiver burden

(Zarit) and satisfaction (Folkman), ALSFRS –R, Chalder Fatigue Scale, and 21 items from Folkman’s Ways of Coping Scale. Patients and caregivers were interviewed on a monthly basis until tracheostomy or death. The results indicate that caregivers reported depressive symptoms at the beginning of the study and remained constant throughout despite an increase in patients’ symptoms or outcome. The authors eloquently make the case for caregiver distress rather than pathological depression. Qualitative examples, in this study, of caregivers’ experiences provide more details regarding what caregivers deal with throughout disease progression. Caregiver symptoms of depression were correlated with perceptions of lack of support from their patients and lack of problem solving or avoiding challenges associated with caring for the patient.

Mock and Boerner (2010) examined depressive symptoms, benefit finding, and sense making in 60 ALS patients and their caregivers. The participants reported on measures of health and “symptom severity, personality factors, situational appraisal and coping, well-being, and depression” (p. 117). They also answered open ended questions regarding sense making and benefit finding. The study found that if there was no patient benefit finding, then the spousal pair had more depressive symptoms if the caregiver did not endorse benefit finding than if the caregiver did endorse benefit finding. As such, benefit finding may be a more important characteristic than sense making, as in this study only benefit finding was observed to act as a buffer against depressive symptoms in the spousal dyad.

Caregiver distress is a near inevitable consequence of caring for a patient with ALS. Olsson, Markhede, Strang, and Persson (2010) examined well-being and quality of life in 35 ALS patients and their caregivers (specifically next of kin) over the course of two years. Although findings suggest that depression and quality of life did not change in ALS patients over time, there was an increase in depression scores for caregivers. Furthermore, there were no

differences in quality of life and well-being among patients and their caregivers. However, as seen in earlier studies (e.g., Adelman et al., 2004), next of kin reported poorer well-being for their patients than was self-reported, yet the opposite was not the case. Patients did not underestimate well-being in their counterparts.

Pagnini et al. (2010) also investigated burden and similar constructs in ALS caregivers. Participants for this study included 40 patients and their caregivers who were assessed for caregiver health worries, burden (ZBI), depression (BDI-II), anxiety (STAI), perception of support (MGQoL), and functional ability (ALSFRS-R). The study found that burden in caregivers was positively associated with caregiver depressive symptoms and negatively with patient functional ability. There was also a positive relationship between anxiety and burden in caregivers and a negative association between burden and social support perception. However, in this case, severity of illness was directly related to burden, anxiety, and somatic symptoms related to depression in caregivers. The authors questioned why somatic expression of depression was the only BDI factor associated with the ALSFRS-R, but failed to deduce that ALS patients tend to have difficulty sleeping, therefore the same is extended to the caregivers. Furthermore, perceptions of social support were negatively associated with caregiver burden and symptoms of anxiety and depression. Also, an examination of caregiver worries highlighted their own health fears.

Last, Pagnini et al. (2012) evaluated the relationship of distress in caregivers and respiratory function in ALS patients. 40 ALS patients and 40 of their caregivers (informal) participated in interviews to assess the Peak Cough Flow (PCF), Forced Vital Capacity (FVC), and social support in patients and burden (ZBI), depression (BDI-II), and anxiety (STAI) in caregivers. The study found that the patient's perception of social support and distress in their

caregivers were related to their respiratory function. Specifically, patients' FVC and PCF ratings were negatively associated with their caregiver's level of depression, anxiety, burden and positively associated with perceived social support. While there is no evidence to determine directionality, it is intuitive to conclude that as patients' capacity to breathe deteriorates, burden on caregivers naturally increases. However, the authors suggest that the opposite may also be the case. If caregivers are overly burdened, experience depressive and anxiety related symptoms, less care may be paid to the details of caring for a patient that experiences these difficulties, therefore affecting these physical ratings. Much more research is necessary to tease apart the directionality of respiratory function and caregiver distress, but one concept that can be concluded from prior literature is that the caregiver-patient relationship is of utmost concern.

Patient interaction with the caregiver

Only recently have researchers questioned ALS patients' emotional lability, patient attitudes, and perceived support offered by the patient. In an exploratory study, Goldstein, Atkins, Landau, Brown, and Leigh (2006) evaluated psychological distress in 50 spouse/partner caregivers in a longitudinal study. The study's primary goal was to measure the change in levels of psychological distress in caregivers (spouse/partner) over time and how distress might be predicted. Findings indicated that caregivers' overall distress increased over time, perhaps resulting from both depression and caregiver burden. Symptom severity was not associated to caregivers' distress scores; however, patients' emotional lability may engender more psychological distress in caregivers.

Chio et al. (2010) examined neurobehavioral symptoms and their relationship to ALS caregivers' burden and quality of life in 70 patient and caregiver dyads, who were interviewed and assessed for neurobehavioral symptoms (particularly frontotemporal conditions), emotional

status, and quality of life. The Frontal Systems Behavior Scale (FrSBE) measured apathy, disinhibition, and executive dysfunction. The most common behavioral impairment of the patient, according to caregiver reports, was apathy, yet patients remained unaware of their problematic apathetic behavior. Furthermore, these patient symptoms impacted their caregiver's emotional state. As such, patients' neurobehavioral symptoms were related to increased caregiver depressive symptoms and caregiver perceived burden. Patients' neurobehavioral symptoms were significantly negatively related to caregiver quality of life. A more in-depth examination of subscales found that both patient apathy and patient executive dysfunction were related to an increase in psychological distress in caregivers.

Lillo, Mioshi, and Hodges (2012) examined ALS patient behavioral changes and physical disability as predictors of caregiver burden in 140 caregivers, each of whom completed survey measurements of neuropsychiatric symptoms and activities such as memory, skills, self-care, mood, beliefs, sleep, eating habits, abnormal behavior, motor behaviors, and lack of motivation (CBI-R), as well as measures of motor function (ALSFRS-R), depression, anxiety, and stress (DASS-21), and the Zarit Burden Interview (ZBI). The study found that caregiver burden is predicted by level of caregiver stress and patient behavioral changes rather than any other variables including severity of disability. Furthermore, the most important determinant of caregiver burden was abnormal patient behavior, namely apathy.

Boerner and Mock (2012) continued their line of research several years later with a separate investigation into patient suffering and caregiver well-being. Participants included 52 patient and caregiver dyads who completed surveys including measures of ALS-FRS, depression (CES-D), patient support (QRI), caregiver affect (PANAS), and caregiver benefit finding, which was assessed through open-ended questions. Evidence of the patient showing support for the

caregiver was the only factor associated with positive affect in caregivers. However, patient distress was the only significant predictor of negative affect in caregivers. Severity of illness or disability in patients was associated with neither positive nor negative affect in caregivers. Furthermore, if the patient was perceived as being unsupportive to the caregiver while personally experiencing a mild degree of suffering, caregivers were unable to find benefit. This notion sheds light on the patient-caregiver relationship, as not only may the caregiver's level of psychological distress impact the patient as has been previously suggested (Pagnini et al., 2012; Rabkin et al., 2000), but the patient's behavior and perceived level of support given to the caregiver by the patient may impact the caregiver.

In summary, previous work examining psychological well-being among ALS caregivers suggests that the severity of disease or disability is not what is significant in relationship to the caregiver's overall quality of life and well-being, but rather the patient's behavior, the caregiver's perception of support from the patient, and the caregiver's perceived burden of care and distress. Furthermore, it may be that the caregiver's psychological well-being influences the psychological and physical well-being of the patient.

Addressing Psychological Well-Being Among ALS Caregivers

As researchers have only recently begun to investigate caregiving in the context of ALS, the literature is lacking in several areas including examining factors that may contribute to constructive coping and psychological well-being among caregivers (Pagnini, 2010). One means of guiding the next steps in addressing these limitations is the examination of factors associated with psychological well-being and coping within *other* areas of chronic illness. Much of the literature in this regard is focused on caregiving in the context of Alzheimer's disease and dementia and reveals a common theme of evaluating the relationships among perceived stress

and coping. Aside from the concept of *subjective burden of care* (see above), perceived stress has not been explicitly evaluated in ALS caregiving.

Stress and Coping among Caregivers

Pearlin, Mullan, Semple, and Skaff, (1990) describe the nature of caregiving and the conceptual components involved in the environmental nature of stress, its appraisal, mediators, and outcomes, including in the context of some families' valuation of caring for members at home, rather than institutionalization. Pearlin et al. (1990, p. 583) illustrate the potential significance of these caregiving relationships by stating:

“Considering how quotidian caregiving is, it hardly seems the stuff out of which severe stress springs. Under some circumstances, however, caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an extraordinary and unequally distributed burden.”

Pearlin et al. go on to describe that Alzheimer's disease is one such ailment. Consequently, a significant portion of caregiving research in the context of chronic illness and disease has been devoted to the Alzheimer's population. The impairments that befall those with ALS, which generate a need for informal caregiving, also appear to fit the above description.

Components. In the context of Alzheimer's disease caregiving, Pearlin et al. (1990) developed a model of caregiver stress, which harkens back to Lazarus and Folkman's (1984) seminal model. Through the acknowledgement of stress as a process rather than an independent phenomenon, relational attributes within the stress framework are identified. The proposed model is comprised of four integral components or domains including stress context, stressors,

mediators of stress, and outcomes of stress. Likewise, these relational domains are also comprised of various components. As such, stressors may be identified as primary versus secondary stressors. Primary stressors in the context of caregiving involve those stressors that directly involve the needs of the patient and secondary stressors are those which arise as a result of the primary stressors (e.g., job strain, economic hardships, family strain).

Mediators. Lazarus and Folkman's (1984) stress process model, as adapted for Alzheimer's disease caregiving by Pearlin et al. (1990), states further that there are likely a number of intervening variables, as not all those that may experience stress in caregiving will endorse problematic outcomes. As such, coping was identified as a principal influence within this model that may directly and indirectly influence problematic outcomes. Coping may be measured in number of ways and through a variety of variables. Pearlin et al. (1990) operationally defined coping as having three functions "management of the situation giving rise to stress, management of the meaning of the situation such that its threat is reduced, and management of the stress symptoms that result from the situation" (p. 590). That is to say, coping can occur at various junctures within the model. Additionally, hope may serve as a mechanism which addresses each of these coping functions, such that coping and hope share a "dynamic, interdependent relationship" (Folkman, 2010, p. 903).

Haley, Levine, Brown, and Bartolucci (1987) cross-sectionally examined a model of stress and coping among caregivers of dementia patients and found that although caregiver stressors may increase as severity of patient symptoms increase (e.g., behavioral concerns, inability for self-care, and declines in cognitive function), caregivers may not always respond negatively. Similar to previous findings (e.g., Rabkin et al., 2000; Trail et al., 2003), Haley et al. found that objective measures of severity of patient illness were not strongly related to

depression, life satisfaction, and health in the caregivers. However, the caregivers' perceptions or appraisals of the severity of the patients' illness were related to the caregivers' levels of depression; greater perceived stress regarding disability-related problems was related to more symptoms of depression. Likewise, increased problem solving related coping, social support, and participation in social activities contributed to higher levels of beneficial, self-reported health outcomes, suggesting that individual differences are important factors in determining overall well-being in dementia caregivers.

Stress and burden have also been studied in caregivers of spinal cord injury and stroke patients. Dreer, Elliott, Shewchuk, Berry, and Rivera (2007) examined family caregivers of patients with spinal cord injuries. Participants included 121 home-based caregivers of a family member with spinal cord injury who completed measures associated with severity of disability, depression, health, and problem-solving characteristics. The results suggested that while patient health and severity of disability were not significantly related to the level of caregiver depressive symptoms, difficulties related to problem-solving abilities and style did predict depression in caregivers. Thompson, Bundek, and Sobolew-Shubin (1990) interviewed 40 caregivers of stroke patients and assessed a number of measures including adjustment, patient functioning, caregiver perceptions of burden, the caregiver-patient relationship, and control, meaning, and hope. Results showed that the number of strokes a patient experienced correlated positively with the level of caregiver depressive symptoms. Level of impairment in the patients, lack of family harmony, and lack of hope in caregivers accounted for a 53% of the variance in caregiver symptoms of depression. As such, caregivers are more depressed when patients' impairments are worsened, when there is family discord, and when the caregiver has a decreased sense of hope. Furthermore, caregivers' perceptions of increased stress and burden worsened these outcomes.

Colgrove, Kim, and Thompson, 2008 examined spirituality in relationship to caregiving stress and caregivers' physical and mental health in caregivers of cancer patients. Participants included 403 spousal cancer patient caregivers and provided self-report information on a measure of spirituality within chronic illness, caregiving stress (Pearlin Stress Scale), mental and physical health. The study found that spirituality did moderate the relationship between caregiving stress and physical and mental health. However, in the context of mental health, spirituality had a stress-buffering effect, whereas in the context of physical health spirituality had a stress-aggravating effect. Additionally, the higher the levels of spirituality, the stronger the moderating effect in both conditions. Colgrove and colleagues note that "highly spiritual cancer caregivers may perceive caregiving as part of their spiritual duties" and thus contributing to the inattention to their own physical health needs (p. 95).

Hope

Hope has only been recently evaluated and studied as a focus of psychological research, particularly in relationship to health. C.R. Snyder's life work was in the pursuit of hope-related investigation (2000; 2002), and he concluded that the unifying characteristic of hope is one of future orientation that is also object-directed, as personified by poet Samuel Coleridge's *Work without Hope*, penned in February 21, 1825:

All Nature seems at work. Slugs leave their lair—

The bees are stirring—birds are on the wing—

And Winter slumbering in the open air,

Wears on his smiling face a dream of Spring!

And I the while, the sole unbusy thing,

Nor honey make, nor pair, nor build, nor sing.

Yet well I ken the banks where amaranths blow,
Have traced the fount whence streams of nectar flow.
Bloom, O ye amaranths! bloom for whom ye may,
For me ye bloom not! Glide, rich streams, away!
With lips unbrightened, wreathless brow, I stroll:
And would you learn the spells that drowse my soul?
Work without Hope draws nectar in a sieve,
And Hope without an object cannot live.

In 1991, Snyder, Irving, and Anderson described hope as “a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy) and (b) pathway (planning to meet goals)” (p. 287). Thus, their model of hope is comprised of goals, agency, and pathway, which are interrelated cognitive mechanisms (Snyder, 2000).

Specifically, goals are targets of mental action sequences, but must be of sufficient importance to “occupy a person’s conscious thought” (Snyder, 2000, p.9). Additionally, goals fall within an area on a continuum from absolutely attainable to completely unattainable. However, in order to achieve a goal or set of goals, one must perceive that one is capable of bringing about at least one route to the goal(s). This “pathway thinking” is the “mental capacity we can call on to find one or more effective ways to reach our goals” (Snyder, 1994, p. 8). Agency, on the other hand is defined as “the motivational component to propel people along their imagined routes to goals” (Snyder, 2000, p. 10). This determination drives the process by which a person might attain a desired goal (Snyder et al., 1991).

Similarly, Lopez (2013) operationally defines hope by declaring that, often, future expectations are the object of one’s “longing” and that “in our minds, our beliefs firm up links

between ourselves and the future, priming people for hope” (p. 18). Hopeful individuals share core beliefs, perhaps, though not of necessity, bolstered by spirituality or religiousness (see Koenig & Larson, 2001), that (1) the future will be better than the present and (2) individuals believe in their own power to make the future better than the present (Lopez, 2013).

Hope and Health. Elliott, Witty, Herrick, and Hoffman (1991) examined the relationship of hope, including subscales of agency and pathways, on psychological adjustment, including depression, in a sample of 57 individuals who had acquired physical disabilities after a traumatic injury. Hope significantly predicted both depression and psychosocial impairment, which included an assessment of alertness, communication, affective displays, and mobility in social situations, such that higher levels of hope were associated with lower levels of depression and psychosocial impairment.

Horton and Wallander (2001) examined hope, social support, mental and physical health related symptoms, and caregiver stress in mothers of children with cerebral palsy, spina bifida, or insulin-dependent diabetes mellitus. Results suggested that neither the child’s diagnosis nor severity of the child’s disability were related to maternal distress; rather, it was the mother’s perception of the stress and burden placed on her that was associated with her ability to adjust, which is in agreement with similar ALS patient-caregiver literature (e.g., Chio et al., 2005; Hecht et al., 2003). Hope accounted for a significant amount of the variance in distress over and above that which was accounted for by disability-related stress. Furthermore, when disability-related stress was high, its effects on maternal distress were buffered by hope. The relationship did not prove the same when stress was low. Finally, hope was individually related to maternal distress.

In a related study, Irving, Snyder, and Crowson (1998) evaluated the ways in which healthy, college-aged women might view cancer facts and produce hope-specific coping

strategies in relation to cancer risk, detection, course of illness, and impact. In regards to cancer prevention strategies and hopefulness, women with higher hope produced more hopeful coping responses through imagining responses regarding risk, detection, course, and impact of cancer. The implications of this study are relevant to adaptive health behaviors which may be bolstered by goal-directed thinking as provided by hope.

Spirituality and Hope. In contemplating the role of hope as a means of coping or buffering against deleterious effects of perceived stress, generally, one must also consider the factors that may predict hope in individuals. As such, some researchers suggest that hope may be a means through which religiousness or spirituality affects well-being (Koenig & Larson, 2001; Snyder, Sigmon, & Feldman, 2002). Specifically, Chang et al., (2013) found that hope, as operationalized by Snyder (2002), fully mediated both religiousness and spirituality in their relationships with depressive symptoms in primary care adult patients. Additionally, when the investigators tested an alternative model of religiousness and spirituality mediating agency and pathway hope and depressive symptoms, no support was found for significant indirect effects. Chang et al., (2015) also found that hope mediated the relationship between multidimensional spirituality and depressive symptoms in college students in a salutary direction. Taken separately and collectively, these findings not only emphasize the importance of both aspects of hope and their distinctive association with religiousness and spirituality, but the predictive nature of religiousness and spirituality in regards to hope. A July 2015 search of the literature (PsycInfo and PUBMED) revealed that this is the first study of its kind assessing these variables in an ALS caregiver sample. Search terms included “caregiv*”, “amyotrophic lateral sclerosis”, “hope”, “spirit*”, and/or “relig*”.

Other studies have also found spirituality, in general, to play a predictive role in association to hope as a buffer of both depressive symptoms and stress (Mascaro & Rosen, 2005; Mascaro & Rosen, 2006; Ciarrochi & Heaven, 2012). In sum, much research suggests that spirituality may be one factor that plays a role in bolstering hope, which may in turn aid in one's psychological well-being.

Spirituality and Caregiving

Recent polling suggests that a sizeable proportion of Americans (39%) annually provide informal, or unpaid, caregiving to an individual with a significant health condition (Pew Research Center, 2013). This statistic has increased from 30% in 2010. Providing care for another individual can be both physically and mentally taxing and, in primary caregivers, may actually worsen their physical and mental health (National Alliance for Caregiving, 2004; National Alliance for Caregiving, 2009; Pew, 2013). A national poll from 2004 reported that 73% of caregivers utilize prayer (an example of ritualistic spirituality) as a means of coping with caregiving demands and associated stress (National Alliance for Caregiving, 2004). Furthermore, praying was the coping mechanism most widely reported by participants in this survey. Unfortunately, this line of questioning was omitted from the 2009 poll (National Alliance for Caregiving, 2009). Nevertheless, this finding highlights the necessity of investigating spiritual/religious issues among informal caregivers.

Hebert, Weinstein, and Schulz (2006) have asserted that while the spirituality/religion and well-being literature has burgeoned, much less has been done to investigate these constructs in the context of informal caregiving. As well as presenting the results from a review of the literature in this area, Hebert and colleagues (2006) provide groundwork upon which to guide future studies. Out of the 83 articles reviewed, the most frequently studied caregiver group was

that of dementia patients. The most utilized measures of well-being were depression, emotional distress, and burden. Additionally, the religion/spirituality dimensions that were most commonly measured were attitudes and beliefs, behaviors, religious denomination, and coping; however, 66% of the studies only measured one dimension. After evaluating and compiling 222 associations between six different spirituality/religion dimensions and nine different measures of well-being, 78% of the associations were non-significant or mixed and 19% indicated improved well-being. Predicated upon these findings and a growing body of literature that has found salutary relationships between spirituality/religion and physical and mental health (see also Koenig et al., 2012), Hebert et al., (2006) suggested areas in which future studies might base their examination in order to better address ambiguity in the literature.

First, Hebert and colleagues (2006) suggest evaluating the mechanisms through which spirituality/religion affect health and well-being. Some of these proposed mechanisms include coping resources and positive emotions. Second, the multidimensional nature of spirituality/religion must be operationally defined, measured, and validated. Indeed, many of the studies included in their review measured aspects of religious behavior (i.e., ritualistic spirituality) which may not generalize to a broader conceptualization of spirituality. Third, researchers should be clear about the outcomes that are expected as a result of including spiritual/religious components within their studies and, in particular, the directionality of the expected associations. Fourth, it is essential to adequately describe the circumstances of the caregiving situation in which the spirituality/religion and well-being constructs are examined, including the perceived burden or stress as experienced by the caregiver. Additionally, Hebert and colleagues (2006) suggest that spirituality/religion influenced outcomes may be nuanced depending on the type and severity of the health related problem requiring informal care.

Spirituality and ALS Caregiving

Not only have experts in the field of spirituality made the call for more research regarding the multidimensionality of spirituality/religiousness and psychological well-being, but experts in the field of ALS have made the call for more research of psychological constructs, including the role spirituality and hope (e.g., Pagnini, 2013). However, whereas a current model of spirituality/religiousness in ALS caregiving does not currently exist, a model must be devised based on the literature that does currently exist in more general areas, such as Koenig and Larson's (2001) model of spirituality and mental health. It may be that within the context of an ongoing stressful situation as is ALS caregiving, the spirituality/religiousness of the caregiver may contribute to a bolstering or maintaining of hope. Hope may serve as a function of coping and therefore facilitating a decrease in the appraisal of stress within the ALS caregiving situation and ultimately contributing to an increase in psychological well-being.

Summary

In sum, the burden and stress associated with caring for individuals with chronic illnesses such as ALS patients is significant, and caregivers may be at risk for increased symptoms of depression, symptoms of anxiety, and other deleterious health and well-being related outcomes. In line with a model of the association between spirituality and health, including well-being, proposed by Koenig and Larson (2001) in conjunction with a model of perceived stress as operationalized by Pearlin et al., (1991), coping factors may defend against primary stressors associated with the patients' disease and impairments and the secondary stressors that come about as a consequence of the caregiving process. As the patient and caregiver(s) experience the constant and progressive declines in function associated with ALS, both parties evaluate and reevaluate, adjust and readjust to the mandatory changes and hope may function as a perpetual or

ongoing means of coping with the stress associated with these changes. Additionally, spirituality/religiousness may be a facilitator of the hope that is necessary for coping with the perceived stress associated with ALS caregiving, consequently leading to increased psychological well-being for the caregiver.

Purpose and Hypotheses

The purpose of this study is to aid the investigation of challenges associated with ALS caregiving. The general hypothesis of this study is that spirituality will be associated with psychological well-being among ALS caregivers and that this relationship will be mediated by hope and perceived stress. The general bivariate hypothesis states that higher levels of spirituality will be associated individually with higher levels of hope, as well as better psychological well-being, and lower levels of perceived stress. Each of the independent and dependent variables will be inter-correlated such that positive psychological constructs will be related to better psychological well-being. The specific hypotheses for this study are as follows (see Figure 1):

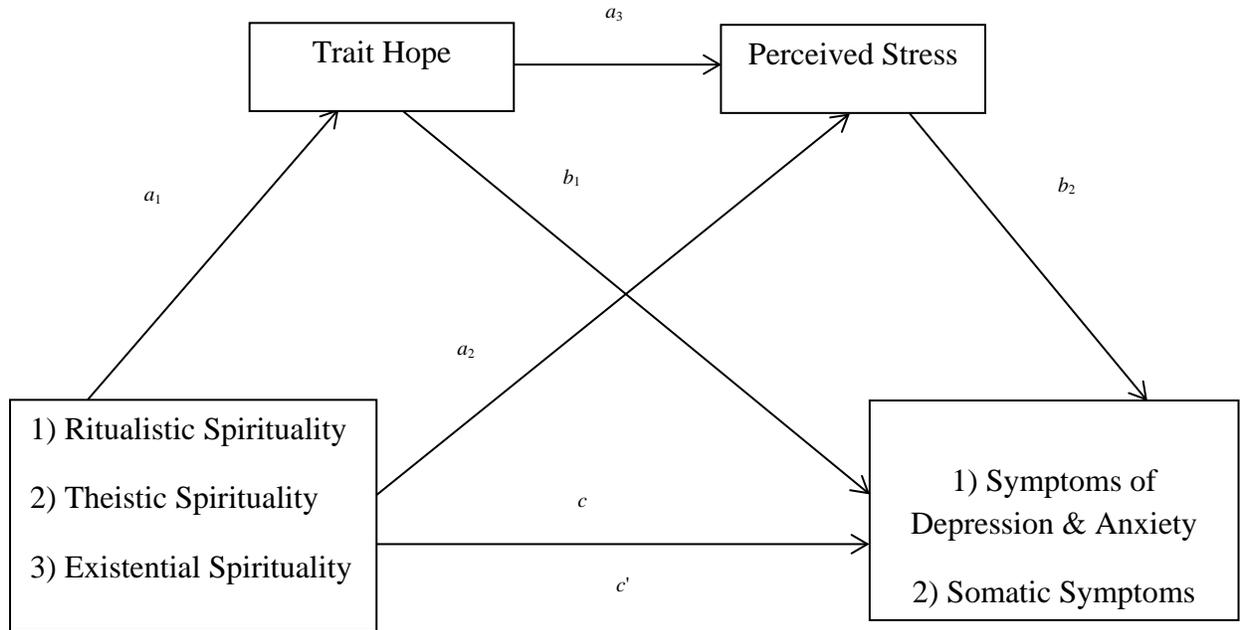
Hypothesis 1: After controlling for demographic variables and the ALSFRS-R, as it will be related to psychological well-being at the bivariate level, spirituality (i.e., ritualistic, theistic, and/or existential) will be directly associated with psychological well-being (i.e., depression, anxiety, and/or somatic symptoms) and this association will also operate indirectly through hope. That is, higher levels of spirituality will be associated with higher levels of hope which, in turn, will be associated with better psychological well-being.

Hypothesis 2: After controlling for demographic variables and the ALSFRS-R, as it will be related to psychological well-being at the bivariate level, spirituality will be directly

associated with psychological well-being and indirectly associated therewith through perceived stress. That is, higher levels of spirituality will be associated with lower levels of perceived stress which, in turn, will be associated with better psychological well-being.

Hypothesis 3: Spirituality will be indirectly associated with psychological well-being sequentially through hope and perceived stress, in a serial fashion. That is, higher levels of spirituality will be associated with higher levels of hope which, in turn, will be associated with lower levels of perceived stress and consequent better psychological well-being.

Hypothesis 4: The association between spirituality and psychological well-being and the indirect role(s) of hope and perceived stress will vary according to the multidimensional nature of spirituality and the particular aspect of psychological well-being under consideration. This is an exploratory hypothesis. For example, existential spirituality may be directly and indirectly related to psychological well-being through hope and perceived stress in a salutary fashion, whereas ritualistic spirituality may be directly related to psychological well-being in a salutary fashion, and indirectly through hope, but not perceived stress. Additionally, it may be that there is a deleterious relationship between ritualistic spirituality and perceived stress. Theistic spirituality may be directly and indirectly related to psychological well-being, in a salutary fashion, through perceived stress, but not hope.



- a_1 = direct association of Spirituality and Hope
- a_2 = direct association of Spirituality and Perceived Stress
- a_3 = direct association of Hope and Perceived Stress
- b_1 = direct association of Hope and Psychological Well-being
- b_2 = direct association of Perceived Stress and Psychological Well-being

- ab = total indirect effect
- a_1b_1 = specific indirect effect of Spirituality on Psychological Well-being through Trait Hope
- a_2b_2 = specific indirect effect of Spirituality on Psychological Well-being through Perceived Stress
- $a_1a_3b_2$ = specific indirect effect of Spirituality on Psychological Well-being through Trait Hope and Perceived Stress

- c = total effect of Spirituality with Psychological Well-being, without accounting for any Mediator Variables
- c' = direct effect of Spirituality with Psychological Well-being, after accounting for all Mediator Variables

Figure 1: The Association of Spirituality with Psychological Well-being: Trait Hope and Perceived Stress as Mediators

CHAPTER 2

METHODS

Participants

Participants include ALS caregivers (N=173; $n=85$) from areas across the United States (90.59%; $n=77$) (e.g., North Carolina, Wisconsin, California), Belgium (3.53%; $n=3$), and the Netherlands (5.88%; $n=5$). The sample of ALS caregivers was mostly female (78.82%; $n = 67$), Caucasian (92.94%; $n = 79$), married (82.35%; $n = 70$), with an average age of 55.20 ($SD = 11.6$). Additionally, 56.47% of the participants ($n = 48$) were the wife of the person being cared for, 20.00% ($n = 17$) were the husband of the person with ALS being cared for, and 48.24% of participants ($n = 41$) spent over 100 hours per week caring for a person diagnosed with ALS. The study was limited to participants aged 18 years and over and English speaking individuals who are currently serving caregiving functions for ALS patients.

Table 2

Demographic Information

Characteristic	Sample
	(n = 85)
ALSFRS -R	
<i>M</i>	33.44
(<i>SD</i>)	(12.92)
Sex: N (%)	
Male	18 (21.20)
Female	67 (78.80)
Age:	
<i>M</i>	55.20
(<i>SD</i>)	(11.58)
Ethnicity: N (%)	
Caucasian	79 (92.90)
Other	6 (7.10)
Marital Status: N (%)	
Married	70 (82.40)
Single (never married)	2 (2.40)
Separated / Divorced	4 (4.70)
Other	7 (8.2)

Table 2, continued

Relation to patient: N (%)

Husband	17 (20.00)
Wife	48 (56.50)
Daughter	8 (9.40)
Father	1 (1.20)
Mother	2 (2.40)
Sister	2 (2.40)
Friend	1 (1.20)
Other	5 (5.90)

Months/Years spent caregiving: N (%)

1 - 6 months	11 (12.90)
6 - 12 months	5 (5.90)
1 - 2 years	15 (17.50)
2 – 3 years	12 (14.10)
3 – 5 years	11 (12.90)
5 – 10 years	7 (8.20)
10+ years	3 (3.50)

Table 2, continued

Hours spent caregiving per week: N (%)	
1 – 10 hours	13 (15.30)
11 – 20 hours	6 (7.10)
21 -30 hours	6 (7.10)
31 – 40 hours	4 (4.70)
41 – 60 hours	3 (3.50)
61 – 80 hours	5 (5.90)
81 – 100 hours	5 (5.90)
Over 100 hours	41 (48.2)

Participants for this study were recruited through dissemination of study information via email and social media messaging to various ALS Association chapter support groups (e.g., Evergreen Chapter, DC/MD/VA Chapter, Greater New York Chapter) and other ALS related organizations (e.g., Les Turner Foundation, The ALS League of Belgium, MND Association – London). Chapter or organization leaders were asked for their help in disseminating information related to the study through their organization social media outlets, email, monthly/quarterly newsletters, or in person. Participants either completed self-report measures through online administration utilizing www.SurveyMonkey.com, which is an encrypted and secure source for online survey administration (Survey Monkey, 2013), or they completed the survey in paper format, as some organizations requested paper packets for their members to complete and return through the mail. This study was approved by the Institutional Review Board prior to data collection.

Measures

Demographics and the ALSFRS-R

Demographic information that was collected during this study included age, sex, ethnicity, relationship to patient and survey type (i.e., paper or online administration). Age, sex, and relationship to patient status are characteristics which, in prior research, are related to caregiver burden (e.g., Chio et al., 2005; Hecht et al., 2003; Olsson et al., 2010). There may also be significant differences in the characteristics and motivation of individuals completing an online survey compared to those filling out paper surveys (e.g., ALS caregivers filling out paper surveys may be more likely to be receiving group support services than those filling out online surveys), as well as differences in the characteristics of those from Europe (i.e. Belgium and the Netherlands) versus participants from the United States. As such, preliminary data analysis found no significant differences between paper versus online survey participants, nor between varying countries' participants. Additionally, information regarding the perceived up-to-date health status of the caregiver's associated patient as reported by the caregiver was included in bivariate analysis and as a covariate in multivariable analysis, as the level of patient disease progression may have an impact on study variables. Age, sex, and ethnicity were also included as covariates in the multivariable analysis.

The measurement tool that is most commonly utilized by the ALS care providers to assess patients' disease progression is the ALS Functional Rating Scale – Revised (ALSFRS-R) (Brooks et al., 1996). The ALSFRS-R (total score possible range = 12 - 60) incorporates items regarding dyspnea, orthopnea, and need for mechanical ventilation assistance, whereas the original ALS-FRS did not include these items. The ALSFRS-R retains the appropriate properties of the original scale and adds better assessment of respiratory function, while maintaining the

overall good performance and validity of the original scale. The ALSFRS-R is a 13-item self-report measure that encompasses four domains of patient function (i.e., gross motor tasks, fine motor tasks, bulbar functions, and respiratory function). Participants rate the items on a 5-point Likert scale that vary depending on the specific item (e.g., regarding speech: “0 – Loss of useful speech”, “1 – Speech combined with non-vocal communication”... “4 – Normal speech processes”; regarding respiratory insufficiency: “0 – Invasive mechanical ventilation by intubation or tracheostomy”, “1 – Continuous use of BiPAP during the night and day”... “4 – None”). A sample of 387 patients were evaluated with the ALSFRS-R in concert with a Phase II-III clinical trial (Cedarbaum et al., 1999), and internal consistency (Cronbach’s alpha) was found to be acceptable ($\pm = .71$). In the current study, reliability estimates were good ($\pm = .88$). Of note, alphas above .90 are generally considered as excellent, above .80 generally considered good, and above .70 considered as acceptable (DeVellis, 2012; George & Mallery, 2003; Kline, 2013).

Spirituality

The RiTE Measure of Spirituality (RiTE) was used to assess multidimensional spirituality-related characteristics (Webb et al., 2014). The RiTE (possible range, per subscale = 1 - 5) is a 30-item self-report measure that consists of three subscales of ten items each: 1) ritualistic spirituality or a structured connection with deity, 2) theistic spirituality or a non-structured connection with deity, and 3) existential spirituality or a non-theistic search for meaning and purpose. Each item is scored on a five-point Likert scale anchored by “1=Strongly Disagree” and “5=Strongly Agree”. The measure has shown good psychometric properties in a large sample of college students at a mid-sized university in Southern Appalachia (Webb et al., 2014; see also Chang et al., 2015, for a clinical sample). In the development of the RiTE (Webb et al., 2014), reliability estimates reported for the subscales were: ritualistic ($\pm = .92$), theistic (\pm

= .98), and existential ($\pm = .91$). Similarly, examination of validity found appropriate convergence and divergence with the Spiritual Well-Being Scale (Paloutzian & Ellison, 1982), the Religious Orientation Scale (Allport & Ross, 1967), and the Social Desirability Scale (Crowne & Marlowe, 1960). As such, our study found excellent reliability estimates for the RiTE subscales including ritualistic ($\pm = .95$), theistic ($\pm = .98$), and good reliability estimates for existential ($\pm = .89$) spirituality.

Hope

Self-reported levels of hope were measured by utilizing the 12-item Trait Hope Scale (Snyder et al., 1991). The scale (possible range = 1 - 8) uses an eight-point Likert scale with the anchors being “1 = definitely false” and “8 = definitely true”. Four items represent the agency component of hope (e. g., “I energetically pursue my goals.”) and four are representative of pathways (e. g., “Even when others get discouraged”, “I know I can find a way to solve the problem”). The remaining four items are “fillers.” Snyder et al. (1991) measured internal consistency using six different samples of college students and two samples of individuals in psychological treatment, one inpatient and one outpatient. Cronbach’s alphas were adequate ranging from .74-.84 for the total scale, .71-.76 for the agency subscale, and .63-.80 for the pathways subscale. Additionally, good convergent/divergent validity was found with the Life Orientation Test (i.e., a measure of general individual differences in optimism and pessimism); $r = .60$ and $r = .50, p < .005$, the Generalized Expectancy for Success Scale ($r = .55$ and $r = .54, p < .005$), and the Hopelessness Scale ($r = -.51, p < .001$) (Snyder et al., 1991). Discriminant validity was found with the Manifest Anxiety Scale ($r = -.47, p < .001$) and the State-Trait Anxiety Inventory ($r = -.58, p < .005$) (Snyder et al., 1991). The Trait Hope Scale has been tested extensively in regards to health populations and health outcomes (Snyder, 2002). Additionally,

the Trait Hope Scale should not be confused with a state-based measure of hope, such that the Trait Hope Scale measures an individual's level of hope over time and across situations, which is applicable to the current study. A state-based measure of hope assesses an individual's hope only in the moment that they are responding to the measure, which may be helpful in measuring an individual's change in hope as a result of a particular treatment (Snyder, 2002). Our current study found internal reliability estimates to be satisfactory for the subscales and total scale: pathways ($\pm = .77$), agency ($\pm = .70$), and total scale ($\pm = .82$).

Perceived Stress

Perceived stress was measured using the Perceived Stress Scale (possible range = 1 – 5) (Cohen, Kamarck, & Mermelstein, 1983), which is a 10-item self-report measure of the degree to which an individual appraises life situations as stressful. Participants rated stress-related feelings and thoughts (e.g., “In the last month”, “how often have you felt nervous and “stressed?”; “In the last month, how often have you felt that things were going your way?”) that they experienced over the past month using a five-point Likert scale ranging from “0 = never” to “4 = very often”. Participants for psychometric analysis included two college student samples ($n = 332$, $n = 114$) and one adult smoking-cessation sample ($n = 64$). Cronbach's alphas for the three samples were .84, .85, and .86 respectively. A separate college student sample ($n = 82$) was used for test-retest reliability after two days and the correlation for this sample was $r = .85$. Test-retest reliability was measured again in six months in an adult community sample ($n = 64$) and the correlation was $r = .55$. Moderate convergent validity was found with the College Student Life Events Scale when a subjective impact (of the corresponding life event) score rating was given ($r = .35$, $p < .01$; $r = .24$, $p < .01$; $r = .49$, $p < .01$), which is closely tied to an individual's perception of that event rather than a particular number of life events. Divergent validity was

found in association with depressive symptomology after taking into account the relationship between perceived stress and physical symptomology by taking partial correlations ($r = .16, p < .01$; $r = .17, p < .07$) (Cohen et al., 1983). Likewise, divergent validity was found in association with physical symptomology after taking into account the relationship between perceived stress and depressive symptomology by taking partial correlations ($r = .31, p < .01$; $r = .38, p < .01$) (Cohen et al., 1983; see also Taylor, 2015). The current study found internal consistency estimates for the perceived stress scale to be excellent at $\pm = .91$.

Psychological Well-Being

For the purpose of this study, psychological well-being will be conceptualized as considering both somatic symptomology, measured by the Physical Health Questionnaire (Schat, Kelloway, & Desmarais, 2005), and general mental health, measured by the depression and anxiety subscales of the DASS-21 (Lovibond & Lovibond, 1995). Generally, psychological well-being is thought to encompass the absence of the endorsement of somatic symptoms, as well as the absence of the endorsement of symptoms of depression and anxiety (Hirsch, Sirois, & Lyness, 2011; Vella, Milligan, & Bennett, 2013; Wang & Castañeda-Sound, 2008). Previous studies have also conceptualized psychological well-being in a similar fashion (e.g. Roothman, Kirsten, & Wissing, 2003; Wissing & van Eeden, 2002).

The Physical Health Questionnaire (PHQ) (Schat et al., 2005) was utilized to assess somatic symptoms of physical health. The PHQ (possible range = 1 - 7) is a 14-item self-report measure and includes a 7-point Likert scale rating, ranging from “1-Not at all” to “7-All the time”. Participants are asked to rate how they have been feeling physically within a specified period of time (i.e., “over the past 6 months”; “How often have you woken up during the night?”; “How often have you suffered from an upset stomach (indigestion)?”). In a study of two samples

of college students ($n = 129$ and $n = 187$), internal consistency was adequate for the Gastrointestinal Problems subscale ($\pm = .84$ and $\pm = .86$), Headaches subscale ($\pm = .90$ and $\pm = .90$), Sleep Disturbance subscale ($\pm = .81$ and $\pm = .81$), and Respiratory Illness subscale ($\pm = .70$ and $\pm = .77$), respectively. Discriminant validity was found in association with job performance which ranged from $r = -.12$ to $r = .10$, $p < .001$ (Schat et al., 2005). Convergent validity was found in association with the General Health Questionnaire (GHQ) which ranged from $r = .23$ to $r = .62$, $p = .001$ (Schat et al., 2005). The current study found good internal reliability estimates for the subscales and total scale: sleep ($\pm = .76$), headaches ($\pm = .93$), gastrointestinal ($\pm = .87$), and respiratory ($\pm = .82$), and total scale ($\pm = .89$).

General mental health was measured using the Depression Anxiety Stress Scales 21 (DASS-21), which is a short form of the DASS 42-item measure (Lovibond & Lovibond, 1995). The DASS-21 (possible range = 1 - 4) is made up of three 7-item self-report scales and measures three constructs: depression, anxiety, and stress. It utilizes a 4-point Likert scale ranging from “0 – Did not apply to me” to “3 – Applied to me very much or most of the time”. The participants are to rate the statements in regards to what they have experienced throughout the past week (e.g., “I found it hard to wind down”; “I felt that I was rather touchy”). For the purposes of this study, the stress subscale measure was not included with the analyses due to conceptual overlap with the perceived stress measure. Gloster et al.’s (2008) investigation of the DASS-21 in older primary care patients suggests that the full three-factor scale is an excellent tool to predict depression and anxiety especially in older patients as to guard against fatigue of questionnaire taking. Additionally, the factors or sub-scales can be administered separately or in pairs depending on the necessity of the information collected, the setting administered, or depending on the needs of the patients/respondents (Gloster et al., 2008; Osman et al., 2012; Szabo, 2010,

Tran, Tran & Fisher, 2013). Sinclair and colleagues (2012), surveyed 503 individuals throughout the US to investigate the psychometric qualities of the DASS-21 scale in an extended and diverse manner. Discriminant validity was demonstrated in association with the Physical Health Component Summary measure of the SF-8 Health Survey ranging from $r = -.16$ to $r = -.34$ for the separate subscales of the DASS-21 (i.e., depression, anxiety, and stress). Convergent validity was demonstrated in association with the Mental Component Summary score of the SF-8 Health Survey with $r = -.58$ to $r = -.69$ for the separate subscales of the DASS-21. Convergent validity was also found in association to the Rosenberg Self-Esteem Scale ranging from $r = -.49$ to $r = .64$ also for the separate DASS-21 subscales (Sinclair, Siefert, Slavin-Mulford, Stein, Renna, & Blais, 2012). In the current study, internal reliability estimates for the depression and anxiety subscales were excellent for depression ($\pm = .92$) and acceptable for anxiety ($\pm = .76$).

Statistical Analyses

For the purpose of examining whether multidimensional spirituality, hope, and perceived stress are related to psychological well-being among caregivers of patients with ALS, including the mediating properties of hope and perceived stress, a series of multivariable analyses were conducted. Bivariate correlations were calculated in order to examine zero-order associations among all variables in order to address multicollinearity and to preserve statistical power. To prevent the confounding influence of multicollinearity, or redundant constructs, a cutoff of $r = .70$ was used to remove a problematic variable, unless previous conceptual theory and psychometric development suggest otherwise (Tabachnick & Fidell, 2001). As such, there were two sets of bivariate correlations which were just at the cutoff. The relations between perceived stress and depression and anxiety ($r = .77$) and between perceived stress and somatic symptoms ($r = .68$) were right above or close to the cutoff value of $r = .70$, but were not considered

problematic nor redundant variables. Conceptually and theoretically, it is likely that individuals who endorsed perceived stress items were also more likely to endorse somatic symptoms, as well as symptoms of depression and anxiety. However, that is not to imply that these scales measured the exact same elements and therefore remained part of the study. In order to conserve statistical power, those demographic variables observed to be non-significant at the bivariate level of analysis (see Table 3) were not employed in the subsequent multivariable analyses.

Multivariable analyses were conducted using the statistical mediation methods as described by Hayes (2013); in particular, the PROCESS Macro or mediation analysis operating in serial (Hayes, 2012; Hayes, Preacher, & Myers, 2011) was utilized (see Figure 1). The analyses were based on three dimensions of spirituality as characterized in the RiTE (i.e. ritualistic, theistic, and existential spirituality) as independent variables (IVs) and the two psychological well-being outcomes (i.e. somatic symptoms [PHQ], depression and anxiety together [DASS-21]) as the dependent variables (DVs), accounting for the indirect effects of hope and perceived stress as mediator variables (MVs) – requiring six separate analytical models.

Through mediation analysis, a variety of potential effects can be observed 1) a total effect, 2) a direct effect, 3) full mediation, 4) partial mediation, and 5) an indirect only effect. Software developed to determine adequate sample size for statistical power, such as G*Power (Faul, Erdfelder, Lang, & Buchner, 2007), cannot be utilized in regards to mediation analysis as it was not designed to accommodate the inherent analytical complexities of these techniques. However, there is a commonly accepted general rule regarding sample size for regression-based analyses (i.e. 10-15 participants per IV) (Field, 2009). As such, based on 3 IVs, 2 MVs, and 7 potential covariates, a target of 120 - 180 participants was needed to achieve sufficient statistical power for the proposed analyses. Additionally, Hayes' (2012) techniques use bootstrap

resampling to assess indirect effects. The bootstrapping rate, or the rate by which the data were resampled, was set at 10,000 (as recommended by Hayes), to best estimate the distribution of the population under investigation. In assessing for indirect effects, this resampling process not only negates the need to assume normal distribution of the data, but it also enhances the statistical power for detecting indirect effects – allowing for relatively smaller samples (Hayes et al., 2011).

Missing Data

In order to compensate for missing data within the sample (of 8,415 scale responses, 36 responses were missing) and to increase statistical power, we utilized person-mean imputation (i.e., participants who completed at least 50% of the items of a particular scale were included in the person-mean imputation of scores; Downey & King, 1998). This process allows particular participants' responses to be considered, despite having missed items or not completed the scales to entirety. Person-mean imputation involves calculating an individual participant's mean score for items responded to on a particular scale and replacing the missing data on the remaining items of that scale with said mean score. Replacing the missing items with the mean score of the non-missing items creates a total score whose mean score equals the mean of the non-missing items and thus, a total mean score. Person-mean imputation was not used on all scales and was only used for those constructs where missing information was conceptually reasonable to estimate. As such, person-mean imputation was used for the measures of multidimensional spirituality, hope, perceived stress, symptoms of depression and anxiety, and somatic symptoms and was not used for demographic variables or the broad assessment of functioning among the ALS patients. When person-mean imputation was used for a particular scale, rather than using the summed score for further analysis, the total mean score was used. A total of eleven

participants' responses were preserved for the analyses after having utilized person-mean imputation as a method to address missing data.

CHAPTER 3

RESULTS

Bivariate Associations

In order to examine zero-order associations between study variables, a bivariate correlation matrix was constructed (see Table 3). For our sample, there were 62 potential associations between the independent variables (i.e. ritualistic spirituality, theistic spirituality, and existential spirituality), mediator variables (i.e., trait hope and perceived stress), and dependent variables (i.e. symptoms of depression and anxiety, and somatic symptoms), as well as demographic variables (e.g. sex, age, ethnicity, ALSFRS-R score). Of these, 15 were significant ($r_s = -.68$ to $.77$), and are described below ($p < .05$, unless indicated otherwise).

Table 3

Bivariate Associations and Descriptive Statistics for Dependent Variables (n = 85)

Variable	Perceived Stress Scale	Trait Hope	Depression & Anxiety	Somatic Symptoms	n: <i>M (SD)</i>
Sex ^a	.23*	-.08	.13	.24*	Male=18 Female=67
Age in years	-.17	.05	-.17	-.26*	55.20 (11.58)
Ethnicity ^b	.11	-.03	.07	.20†	Caucasian=79 Other=6
ALSFRS-R ^c	-.24*	.18	-.33**	-.39***	33.44 (12.92)
Ritualistic Spirituality	-.15	.10	-.17	-.17	3.40 (1.08)
Theistic Spirituality	-.08	.10	-.18†	-.17	3.82 (1.23)
Existential Spirituality	-.19†	.30**	-.05	-.03	4.51 (.37)
Perceived Stress Scale	--	-.47***	.77***	.68***	2.88 (.73)
Trait Hope Scale	-.47***	--	-.34***	-.45***	3.16 (.35)
Depression & Anxiety	.77***	-.34***	--	.77***	1.51 (.55)
Somatic Symptoms	.68***	-.45***	.77***	--	2.82 (1.05)

Effect size (strength of association) of *r*: .10=small, .30=medium, .50=large (Cohen, 1988)

† $p < .10$; * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

^aMale = 1; Female = 2

^bAmerican Indian = 1; Asian = 2; Black/African American = 3; Native Hawaiian/Other Pacific Islander = 4; White/Caucasian = 5; Hispanic = 6; Latino = 7

^cSee Appendix A for ALSFRS-R coding

Regarding demographic variables, sex was correlated with both the perceived stress scale and somatic symptoms, such that female sex (1 = male; 2 = female) was related to higher levels of perceived stress and higher levels of somatic symptoms. Age was negatively correlated with somatic symptoms, such that as age increased somatic symptoms were fewer. Ethnicity was positively correlated with somatic symptoms, such that those who identified as an ethnicity other than Caucasian (1 = White/Caucasian; 2 = other) reported increased somatic symptoms. The *ALSFRS-R* was significantly, negatively correlated with the perceived stress scale, symptoms of depression and anxiety, and somatic symptoms, such that poorer ALS related functioning (lower *ALSFRS-R* scores) was associated with higher levels of perceived stress, symptoms of depression and anxiety, and somatic symptoms among the caregivers.

Ritualistic spirituality was not correlated with any of the other variables. Theistic spirituality was negatively correlated at the $p < .10$ level with symptoms of depression and anxiety, such that higher levels of theistic spirituality were associated with fewer symptoms of depression and anxiety. Existential spirituality was negatively associated with the perceived stress scale at the $p < .10$ level, such that higher levels of existential spirituality were associated with lower levels of perceived stress. These two relationships are correlated at the $p < .10$ level; however, they would likely reach a greater level of significance within a larger sample. Existential spirituality was positively associated ($p \leq .01$) with the trait hope scale, such that higher levels of existential spirituality were associated with higher levels of trait hope.

Perceived stress, trait hope, symptoms of depression and anxiety, and somatic symptoms were all significantly correlated with each other, such that higher levels of trait hope were negatively associated with perceived stress, symptoms of depression and anxiety, and somatic

symptoms. Symptoms of depression and anxiety were positively associated with perceived stress and somatic symptoms, and somatic symptoms were positively associated with perceived stress.

Multivariable Associations

Each of the models presented in Table 4 and Table 5 (see also Figure 1 for diagram) represent the consolidated results of the analyses (Preacher & Hayes, 2008) combining the three dimensions of spirituality measured in this study (i.e., ritualistic, theistic, and existential) as predictors of psychological well-being (i.e., fewer symptoms of depression and anxiety and fewer somatic symptoms), as mediated by trait hope and perceived stress, among caregivers of patients with ALS. Each table displays the unstandardized regression coefficients and p values for each pathway within the models (i.e., a_1 , a_2 , a_3 , b_1 , b_2 , c , and c'). Additionally, Tables 4 and 5 present 95% Bias Corrected Confidence Intervals (CI) for each indirect pathway.

Table 4

*The Association of Spirituality with Depression and Anxiety: Trait Hope and Perceived Stress
as Mediators*

	Ritualistic Spirituality		Theistic Spirituality		Existential Spirituality				
	coefficient	<i>p</i> value	coefficient	<i>p</i> value	coefficient	<i>p</i> value			
<i>a</i> ₁	-.02	ns	.01	ns	.29	*			
<i>a</i> ₂	-.10	ns	.04	ns	-.08	ns			
<i>a</i> ₃	-.83	***	-.83	***	-.83	***			
<i>b</i> ₁	.01	ns	.01	ns	.01	ns			
<i>b</i> ₂	.59	****	.59	****	.59	****			
<i>c</i>	.04	ns	-.11	ns	.04	ns			
<i>c'</i>	.09	ns	-.12	*	.22	†			
	Effect	95CI		Effect	95CI		Effect	95CI	
<i>ab</i>	-.05	-.20	.09	.01	-.12	.14	-.18	-.54	.06
<i>a</i> ₁ <i>b</i> ₁	-.00	-.02	.01	.00	-.01	.02	.00	-.08	.09
<i>a</i> ₂ <i>b</i> ₂	-.06	-.20	.08	.02	-.10	.14	-.05	-.32	.17
<i>a</i> ₁ <i>a</i> ₃ <i>b</i> ₂	.01	-.06	.08	-.01	-.08	.04	-.14*	-.35	-.03

n = 85; Initial Model $R^2 = .17^*$; Full Model $R^2 = .68^{****}$

† $p < .10$; * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$; **** $p \leq .0001$; ns = non-significant

See Figure 1 for graphic representation of pathways

Analyses adjusted for age, sex, ethnicity, and ALSFRS-R score.

Table 5

*The Association of Spirituality with Somatic Symptoms: Trait Hope and Perceived Stress**as Mediators*

	Ritualistic Spirituality		Theistic Spirituality		Existential Spirituality				
	coefficient	<i>p</i> value	coefficient	<i>p</i> value	coefficient	<i>p</i> value			
a_1	-.02	ns	.01	ns	.29	*			
a_2	-.10	ns	.04	ns	-.08	ns			
a_3	-.83	***	-.83	***	-.83	***			
b_1	-.61	*	-.61	*	-.61	*			
b_2	.72	****	.72	****	.72	****			
c	.10	ns	-.26	*	.14	ns			
c'	.15	ns	-.26	*	.54	*			
	Effect	95CI		Effect	95CI		Effect	95CI	
ab	-.05	-.27	.15	.01	-.20	.19	-.41	-.92	.00
a_1b_1	.01	-.06	.11	-.01	-.10	.05	-.18*	-.51	-.03
a_2b_2	-.07	-.27	.11	.03	-.13	.19	-.06	-.43	.21
$a_1a_3b_2$.01	-.08	.09	-.01	-.10	.05	-.17*	-.43	-.04

n = 85; Initial Model $R^2 = .30^{***}$; Full Model $R^2 = .62^{****}$

† $p < .10$; * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$; **** $p \leq .0001$; ns = non-significant

See Figure 1 for graphic representation of pathways

Analyses adjusted for age, sex, ethnicity, and ALSFRS-R score.

Depression and Anxiety

Table 4 includes the results of the analyses conducted with the symptoms of depression and anxiety total score (i.e., combined together) as the dependent variable. Ritualistic spirituality was not statistically significantly related to depression and anxiety within the model, neither directly or indirectly. The total effect of theistic spirituality ($c = -.11$, ns) on depression and anxiety was non-significant. However, the direct effect of theistic spirituality ($c' = -.12$, $p \leq .05$) was significantly related to depression and anxiety, such that, after accounting for the mediators, higher levels of theistic spirituality were associated with fewer symptoms of depression and anxiety. Further, the association between theistic spirituality and depression and anxiety was not significantly mediated by trait hope or perceived stress, neither alone nor in serial. Although the total effect of existential spirituality ($c = .04$, ns) on depression and anxiety was non-significant, existential spirituality had a trending significant direct effect ($c' = .22$, $p \leq .10$), such that, after accounting for the mediators, higher levels of existential spirituality were associated with more symptoms of depression and anxiety. It may be that a suppression effect is being observed, such that the inclusion of hope and perceived stress as mediators within the model affect the direction and strengthen the association between existential spirituality and anxiety/depression (MacKinnon, Krull, & Lockwood, 2001). Rucker and colleagues (2011) state that “evidence of suppression is found when including an intervening variable produces a value of c' that is greater in magnitude than c ” (p. 366). Furthermore, when the suppressor variables are omitted from the equation, both total and direct effects may be non-significant (Rucker et al., 2001).

A significant indirect effect in the context of existential spirituality was also observed. The association of existential spirituality with symptoms of depression and anxiety also operated through trait hope and perceived stress ($a_1a_3b_2 = -.14$, 95CI: $-.35$ to $-.03$), in serial fashion. That

is, higher levels of existential spirituality were associated with higher levels of hope which, in turn, were associated with lower levels of perceived stress and fewer subsequent symptoms of depression and anxiety.

Somatic symptoms

Ritualistic spirituality was not significantly related directly or indirectly to somatic symptoms (see Table 5). Theistic spirituality had a significant total effect ($c = -.26, p \leq .05$) and direct effect ($c' = -.26, p \leq .05$) on somatic symptoms; however, there were no significant indirect effects. That is, higher levels of theistic spirituality were related to fewer somatic symptoms, and this relationship was not mediated by hope or perceived stress, neither alone nor in serial. Additionally, existential spirituality ($c' = .54, p \leq .05$) was significantly directly associated with somatic symptoms, such that higher levels of existential spirituality were associated with more somatic symptoms. However, indirect effects in the context of existential spirituality were also observed. That is, higher levels of existential spirituality were associated with higher levels of trait hope which, in turn, were associated with lower levels of perceived stress and fewer somatic symptoms ($a_1a_3b_2 = -.17, 95\text{CI}: -.43 \text{ to } -.04$). Also, higher levels of existential spirituality were associated with higher levels of hope which, in turn, were singularly associated with fewer somatic symptoms ($a_1b_1 = -.18, 95\text{CI}: -.51 \text{ to } -.03$). As noted in the previous section, again there is evidence of a suppression effect, such that the inclusion of hope and perceived stress as mediators within the model affect the direction and strengthen the direct association (c') between existential spirituality and somatic symptoms (MacKinnon et al., 2001).

CHAPTER 4

DISCUSSION

Generally, a salutary empirical relationship between spirituality and psychological well-being has been supported in the literature (e.g., Hill & Pargament, 2008; Koenig & Larson, 2001; Toussaint et al., 2012); however, distinct mechanisms through which these constructs are related have received much less attention. In this study, overall, models assessing the relation between spirituality and psychological well-being were significant. Furthermore, hope and perceived stress played important mediating roles with respect to existential spirituality, but not ritualistic or theistic spirituality. This section will evaluate the four distinct hypotheses in light of the results, discuss the results in relationship to previous findings, discuss limitations of the study, and implications, especially in regards to areas of future research.

Evaluation of Hypotheses

Hypothesis 1

The first hypothesis stated that after controlling for demographic variables, among caregivers of people with ALS, spirituality (i.e., ritualistic, theistic, and/or existential) would be directly associated with psychological well-being (i.e., fewer symptoms of depression and anxiety, and/or somatic symptoms) and that this association would also operate indirectly through hope. The first hypothesis was partially supported in that theistic spirituality was salutarily related to both psychological well-being outcomes, but only in a direct fashion. Also, hope, considered singularly, was observed to be a mediator only in the context of existential spirituality and somatic symptoms, again in a salutary fashion.

Hypothesis 2

The second hypothesis stated that after controlling for demographic variables, among caregivers of people with ALS, spirituality would be directly associated with psychological well-being (see Hypothesis 1) and indirectly associated therewith through perceived stress. Regarding the indirect association, perceived stress was not observed to play a role as a singular mediator in the association of multidimensional spirituality with psychological well-being.

Hypothesis 3

The third hypothesis stated that, among caregivers of people with ALS, spirituality would be indirectly associated with psychological well-being, sequentially, through hope and perceived stress. Only existential spirituality was associated with psychological well-being through hope and perceived stress, in serial fashion. That is, higher levels of existential spirituality were associated with higher levels of hope which, in turn, were associated with lower levels of perceived stress and consequent psychological well-being.

Hypothesis 4

The fourth hypothesis stated that, among caregivers of people with ALS, the association between spirituality and psychological well-being and the indirect role(s) of hope and perceived stress, individually and in serial, would vary according to the multidimensional nature of spirituality (i.e., ritualistic, theistic, existential) and the particular aspect of psychological well-being under consideration (i.e., symptoms of depression and anxiety, somatic symptoms). The fourth hypothesis was supported in that direct and indirect associations did vary based on the variables under consideration. Ritualistic spirituality was not significantly associated with either dependent variable, neither in a direct nor indirect fashion. Theistic spirituality was salutarily associated with both dependent variables, but only in a direct fashion. Existential spirituality

was directly associated with both dependent variables in a deleterious fashion. However, when the mediating variables were introduced into the models, existential spirituality was also salutarily associated with each dependent variable indirectly through hope and perceived stress in a serial fashion, as well as singularly with somatic symptoms through hope.

Implications of Findings

ALS Caregiving

The progressively debilitating and inevitably fatal nature of ALS, as previously described, contributes to increased physical and mental strain for the individual(s) caring for the ALS patient (Clarke & Levine, 2011; Anderson et al., 2012). There has been little sole investigation of *caregiver* psychological factors, but instead there has been more investigation of the caregiver-patient dyad, their interpersonal relationship, and related distress. One of the seminal investigations of the patient-caregiver unit found that the caregiver's perceived burden increases as the patient's disease symptomology increases (i.e., worsens) and, furthermore, may increase "in excess of the patients' clinical impairment" (Chio et al., 2005, p.1781). Other investigations found similar correlations between patient functionality, as measured by the ALSFRS, and caregivers' perceived burden, especially noting physical, mental, and social concerns (Hecht et al., 2003; Lillo et al., 2012; Pagnini et al., 2010). Our results are similar to these previous findings in that the patients' reported level of functionality was detrimentally related to caregivers' perceived stress and well-being.

These results suggest that the relation between the ALS patient's functionality, which has been shown to worsen over time (e.g., Chio et al., 2005; Rabkin et al., 2009), and the caregiver's perceived burden or stress, as well as psychological well-being, is a critical element of investigation. Clearly, more needs to be done to further clarify this relationship, including

directionality, defining predicting elements that may influence the relationship, and elucidating mechanisms that may act as catalysts within the relationship. In Pagnini's (2013, p. 196-200) review of the literature on well-being and quality of life in ALS patients, he concluded that four primary areas were of utmost concern including "pain," "hope and hopelessness," "spirituality and existential well-being," "depression and anxiety," "caregivers," and "psychological support." While Pagnini's review directly concerned patients with ALS, most of these areas were extended to include caregivers, as well, and he called for more investigation in each of these areas.

Our study has attended to Pagnini's (2013) call and has elucidated predictors of psychological distress, the antithesis of well-being, in ALS caregivers. Based on prior literature, we developed a model that not only includes psychological well-being (e.g. fewer symptoms of depression and anxiety; fewer somatic symptoms) in ALS caregivers, but multidimensional spirituality, trait hope, and perceived stress (Chang et al., 2013; Hebert et al., 2006; Koenig & Larson, 2001; Pagnini, 2013; Pearlin et al., 1991). We found that higher levels of theistic spirituality were directly related to better psychological well-being in ALS caregivers. Additionally, and in a more complex relationship, higher levels of existential spirituality were directly related to psychological well-being in a detrimental way. However, when hope and perceived stress were considered in the mediational model, existential spirituality was related to psychological well-being in a salutary way through hope and perceived stress, in serial. Nonetheless, our study not only serves to reiterate Pagnini's (2013) call for investigation of these particular constructs that may be key to understanding the challenges associated with being an ALS caregiver, but key to developing intervention strategies and means of support for the caregiver and patient.

Spirituality

Reviews of the literature have found consistent evidence of salutary relationships between spirituality/religiousness and individuals' health and well-being (Koenig, McCullough, & Larson, 2001; Toussaint et al., 2012). However, less is known about the specific mechanisms of these relationships and especially within special populations, such as ALS caregivers (George et al., 2002; Koenig & Larson, 2001; Rosmarin & Wachholtz, 2011).

Mechanisms of spirituality/religiousness. Three models of spirituality and general psychological well-being were identified through the initial review of the literature for this study (i.e. Baetz & Toews, 2009; George et al., 2002; Koenig & Larson, 2001). The Koenig and Larson (2001) model of spirituality and psychological well-being was the most comprehensive of the three models and emphasizes three components. The first component applies directly to the current study and suggests that spirituality and religiousness may foster positive worldviews, such as hope, optimism, purpose, and motivation, and especially in a period of significant stress. The two other components focus on spirituality/religion fostering pro-social values (e.g. humility, compassion, forgiveness) and increased social support. Besides acknowledging a direct relationship between spirituality/religiousness and psychological health and well-being, Koenig and Larson (2001) identified the fostering of positive worldviews, pro-social values, and social support as mechanisms by which spirituality/religiousness may be indirectly related to psychological well-being. These relationships may be especially pertinent for caregivers, and especially ALS caregivers, considering the mentally and physically strenuous nature of care they provide (Hebert et al., 2006; Hebert et al., 2007; Lopez et al., 2012).

Pearlin et al. (1990) investigated models of stress and coping in Alzheimer caregivers and suggested that there may be three different ways, or opportunities, in which an individual may

manage their caregiving stress. A caregiver may manage by attempting to make changes to the source of stress, by making sense of the meaning of the stressful event, or by altering the way in which they react to the stressful event (Hebert et al., 2006; Lopez et al., 2012, Pearlin et al., 1990).

Consistent with Koenig and Larson (2001) and Pearlin et al. (1990), results from our study show that existential spirituality was salutarly related to psychological well-being through both trait hope and perceived stress, in sequence. For ALS caregivers who endorse characteristics of existential spirituality, it may be that hope plays a role in aiding them in manipulating, making sense of, and reacting to the primary and secondary stressors associated with ALS caregiving. That is, the goal oriented nature of hope may allow those ALS caregivers who are engaged in a transcendent search for meaning and/or purpose in life to better cope with distress, resulting in better psychological well-being (Chang et al., 2013; Laubmeier, Zakowski, & Bair, 2004; Lopez et al., 2012).

Hope was also found to mediate the relation between existential spirituality and somatic symptoms singularly. It may be that the “seeking” nature of existential spirituality supports ALS caregivers in their goal oriented endeavors, such as those focused on their relationship with the patient, their own health, or finding meaning and purpose in the midst of adversity, thereby resulting in fewer somatic complaints. Trait hope draws from an individual’s belief that they have the ability to reach a desired goal, as well as the belief that there may be a variety of ways or paths to successfully complete the goal (Snyder et al., 1991). In prior research, Baumeister and Vohs (2005) describe the need for meaning as being comprised of four primary components: “the need for purpose,” “the need for values,” “the need for a sense of efficacy,” and “the need for self-worth” (p. 610-611). Additionally, when these needs have been met or meaning has been

made the individual may derive physical and psychological benefit (Baumeister & Voh, 2005). For individuals who endorse an existential dimension of spirituality, the active search for meaning and purpose may lead to an acknowledgement, and perhaps, cultivation of hope. Hopefulness is values-oriented and self-efficacious by definition, and appears to lend to less somatic complaints for ALS caregivers in our study.

Furthermore, it is worth noting that perceived stress did not mediate the relation between dimensions of spirituality and psychological well-being in a singular fashion, failing to support our hypothesis. It was only found to be related when in conjunction with hope, together serially mediating the association of existential spirituality with psychological well-being (i.e., fewer symptoms of depression and anxiety and fewer somatic symptoms). It may be that rather than one's spiritual orientation, so to speak, being directly related to perceived stress, it is through the values that an individual acquires, displays, or nurtures as a function or result of one's spiritual orientation that is what is potentially related to perceived stress. In this sense, trait hope may aid the ALS caregiver in reappraising the negative aspects of their caregiving role, as they are perceived, to taking into consideration their purpose, ability, and value in performing their tasks (Baumeister & Vohs, 2005); this may, ultimately, lead to increased psychological well-being.

Additionally, while there may be an association between hope and perceived stress, as Folkman (2010) has described in previous literature, values other than hope may also play a key role in a similar fashion (e.g., optimism, compassion, forgiveness), which is consistent with Koenig and Larson's (2001) model of spirituality and psychological well-being. When considering ALS caregivers, it may be that how an individual perceives their physical and intrapsychic stressors (Pearlin et al., 1990) is dependent on the values they most readily employ and turn to for strength, rather than simply the dimension of spirituality to which they ascribe.

That is not to say that the dimension of spirituality is not important in relation to one's personal values but, in the context of perceived stress, the values-oriented product of the dimension of spirituality is what may be important. More research is needed to elucidate our understanding of perceived stress within this model.

The multidimensional nature of spirituality. Our findings support previous literature (Webb et al., 2014) which suggests that spirituality/religiousness may be multidimensional in nature. Our findings also support the call from experts within the area of spirituality/religiousness and in the field of caregiving research who have suggested that more be done to clarify the definition, measurement, and validation of the potential multidimensionality of spirituality and its application to caregiving and health (Hebert et al., 2006; Koenig & Larson, 2009). Historically, spirituality and religiousness have been deemed by some as interchangeable constructs and only recently have researchers studied and acknowledged delineation between the two (see Webb et al., 2014). As such, Webb and colleagues (2014), in their article describing the RiTE model and measure of spirituality, suggested that religiousness is most closely aligned with the ritualistic dimension of spirituality, that spirituality is most closely aligned with the theistic dimension, and that a third, non-theistic, yet transcendent, dimension of spirituality is useful to conceptualize, namely existential spirituality. We found that the theistic and existential dimensions of spirituality are related to psychological well-being in meaningfully different ways, and that ritualistic spirituality was not related to psychological well-being neither directly nor indirectly.

Previous research on aspects of spirituality that would be most congruent with our ritualistic dimension of spirituality would focus on factors such as religious attendance, prayer, and the importance of rituals/religious practices. Hebert et al. (2007) investigated religious

beliefs and practices of caregivers of dementia patients and found that religious attendance, prayer, and the caregivers' perceived level of religiousness were each significantly related to lower levels of depression before and after controlling for social support. Our findings regarding ritualistic spirituality are inconsistent with the outcomes of this particular study (Hebert et al., 2007). We found that ritualistic spirituality was not related to psychological well-being in either a direct or indirect fashion, which suggests that involvement in structured religious activities may not be a feasible, or salient, contributor to psychological well-being among ALS caregivers.

However, in a study of stress, religiousness, and depression in dementia caregivers, LeBlanc, Driscoll, and Pearlin (2004) found that in relation to depression, there was a difference between subjective ratings of religiousness (i.e. how religious are you?) and objective ratings (i.e. religious services attendance and prayer frequency), in that subjective religiousness was related to greater depression in caregivers with poor physical health, but not caregivers with better physical health, and objective ratings of religiousness were not significantly related to depression at all (LeBlanc et al., 2004). These findings are consistent with our results and suggest that the impact of an individual's perception of religiousness on psychopathology, may be different than the impact of more-ritualistic behaviors such as religious attendance and prayer. Taken together, these investigations, along with our findings, support the need for further clarification of the mechanisms underlying the relation between religiousness/ritualistic spirituality and psychological well-being.

Previous research has also investigated religious belief, a concept closely aligned with our measure of the theistic dimension of spirituality. Ross (1990) found that strong religious belief, regardless of content, was inversely related to psychological distress in a sample of Illinois residents. In a recent study, Chang, Jilani, Fowler, and colleagues (2015) found that the

depression facet of the NEO-FFI was negatively related to theistic spirituality, as measured by the RiTE measure of spirituality (McCrae & Costa, 2005; Webb et al., 2014). However, the anxiety facet of the NEO-FFI was not significantly related to theistic spirituality and, within regression analyses, sociability, unconventionality, and prosocial orientation were each significant predictors of theistic spirituality (Chang, Jilani, Fowler et al., 2015). Consistent with these findings, our study revealed that theistic spirituality was directly related to psychological well-being (i.e. less depression and anxiety; fewer somatic symptoms). However, our study differed from Chang et al., in that anxiety was included along with depression and, together, they were related to theistic spirituality. In other words, ALS caregivers who engage in deity-focused belief, but non-structured spiritual activities, reported better psychological well-being. It may be that acknowledging one's belief in and/or connection to a deity, such as belief in a creator, or a transcendent being who may be omnipotent, omnipresent, and/or omniscient, rather than engaging in structured practices (e.g. going to church or synagogue; taking communion), leads to less depression and anxiety in ALS caregivers, as well as less complaint of somatic symptoms.

These findings suggest that endorsing religious beliefs, but not necessarily engaging in religious behaviors, per se, is generally healthy, and our study extends this pattern of effects to ALS caregivers. Although more investigation must be done to understand the relationship between theistic spirituality and psychological well-being, nuances of the theistic measurement (e.g., "I feel connected to a deity or deities; "I believe in a deity or deities who has/have a purpose/plan for my life;" "The world was created by a deity or deities") suggest what previous experts have operationalized as "spiritual surrender" (Cole & Pargament, 1999; Webb et al., 2014). Furthermore, Cole and Pargament (1999) state that spiritual surrender may be especially important during times when an individual is faced with an extreme uncontrollable situation.

ALS caregivers are continually faced with an illness that is beyond anyone's control, yet for those who espouse theistic spirituality, the inherent surrender of control to deity may be the most beneficial aspect of their spirituality (Cole & Pargament, 1999; Koenig, Pargament, & Nielsen, 1998).

In an investigation of existential spirituality, by Chang, Jilani, Fowler and colleagues (2015), existential spirituality was inversely related to the depression and self-reproach facets of the NEO-FFI, but not significantly related to the anxiety facet. However, in regression analyses, positive affect, intellectual interests, unconventionality, prosocial orientation, and goal-striving each served as predictors for existential spirituality. Not only does our current study serve to validate the differences between the three subscales of the RiTE measure, but also uncovers various characteristics of each scale. Pro-social orientation and goal-striving are the two predictors that are of greatest interest in relation to our study (Chang, Jilani, Fowler et al., 2015).

We found that existential spirituality, which is a non-theistic involvement in transcendent activities relating to a search for meaning and purpose, was deleteriously related to symptoms of depression and anxiety, as well as somatic problems. For the ALS caregiver, it may be that espousing existential spirituality (e.g., the notion that helping others is very important and that there may be a right or wrong way to treat individuals) overshadows one's own sense of importance of self-care. As such, Chang, Jilani, Fowler and colleague's (2015) findings suggest that pro-social orientation and goal striving may be especially salient for individuals endorsing existential spirituality. Furthermore, it may not be that ALS caregivers fail to see the need for self-care, but may ultimately place the needs of their patient (often a family member) above their own, as a patient's needs are extremely time sensitive.

However, when hope was considered as a mediator within the model, an indirect effect emerged, perhaps as a result of statistical suppression, such that existential spirituality contributed salutarily to psychological well-being when operating through hope alone and also in conjunction or sequence with perceived stress. Hope is typically thought of as a future-oriented construct (Lopez, 2013; Snyder, 2000; 2002), however there are motivational and goal-oriented elements of trait hope that may facilitate a present-moment awareness of one's current self-efficacy and ability to problem-solve. Therefore, it may be that trait hope offers the existentially-spiritual ALS caregiver the ability to more-effectively address stressors. Together, these findings bring additional support to the notion that spirituality/religiousness may operate multidimensionally (Hebert et al., 2006; Koenig & Larson, 2001; Webb et al., 2014).

Spirituality and ALS caregiving. Our results suggest that the dimension(s) of spirituality that an ALS Caregiver espouses may have a meaningful impact on aspects of their psychological well-being. The endorsement of theistic spirituality may serve as a protective factor, but only in a direct fashion. Paradoxically, existential spirituality may directly play a deleterious role, but indirectly contribute to the development of other protective factors, such as hope and consequent coping ability and, thereby, better psychological well-being. Of note, ritualistic spirituality was not associated with psychological well-being in our sample, neither at the bivariate level nor directly or indirectly at the multivariable level of analysis. Caregivers of ALS patients take on a task that, due to the nature of the disease, gradually becomes increasingly challenging, tiresome, and physically and mentally demanding. For caregivers who have an active belief in deity, the continued acknowledgement of belief in deity, and feelings of connectedness to one's deity/deities, there may be some resultant benefit to their psychological well-being. However, the endorsement of one dimension of spirituality does not suggest that the

caregiver is devoid of the other dimensions. Those caregivers who are actively spiritual but do not endorse belief in a particular deity also have better psychological well-being, but only if trait hope is present.

There are several points within our model that should be targeted for assessment and intervention. First, health care providers, social workers, and support group leaders who work with ALS patients and their caregivers may facilitate increased caregiver well-being by acknowledging that spirituality may be a prescient concern and assessing caregivers' levels and dimensions of endorsed spirituality (Hebert et al., 2006; Pagnini, 2013). Our findings support the notion that the dimension of spirituality endorsed by an individual ALS caregiver helps determine what intervention may be preferred.

Interventions that bolster the concept of "spiritual surrender" may be especially poignant for ALS caregivers who endorse the theistic dimension of spirituality. Cole and Pargament (1999) have suggested that "spiritual surrender" may be integrated within behavioral techniques with success (Martin & Carlson, 1988). Additionally, mindfulness meditation, the 12-Step Model of addiction and recovery, and forgiveness are all distinct methods of tapping into spiritual surrender which may ultimately bolster an individual's theistic spirituality and lead to better psychological well-being (Cole & Pargament, 1999; Marlatt & Kristeller, 1999; Sanderson & Linehan, 1999; Tonigan, Toscova, & Connors, 1999).

Mindfulness meditation is a practice that may be helpful in bolstering both theistic and existential spirituality, but for different reasons (Marlatt & Kristeller, 1999). Mindfulness meditation (a.k.a. mindfulness) is most commonly recognized as a relaxation technique and, while it is true that mindfulness practice facilitates physical and mental relaxation, there are numerous other benefits. The practice of mindfulness has been utilized in both behavioral and

acceptance-based interventions such as Dialectical Behavior Therapy and Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 2012; Sanderson & Linehan, 1999). For those who endorse higher levels of theistic spirituality, utilizing mindfulness exercises that bring about acceptance, forgiveness, and letting go of sticky or fused thoughts may be helpful. For those who endorse higher levels of existential spirituality, utilizing mindfulness exercises that facilitate foci on personal values, meaning, and purpose may be helpful in leading to increased well-being. Furthermore, aiding ALS caregivers with acceptance of the pain and stress associated with the numerous caregiving tasks, feelings of being trapped in the caregiving role, and the sheer pain in witnessing a loved one deteriorate may be beneficial to them.

For ALS caregivers who endorse existential spirituality, incorporating a focus specifically on trait hope may serve to aid the caregiver in reappraising their perceived stressors. Focusing on hope may also facilitate the caregiver in meeting the various and, often, spontaneous challenges that arise throughout the caregiving process. Hope interventions have been developed and utilized in a number of different settings and populations (Cheavens et al., 2006; Klausner et al., 1998). These interventions have been found to increase levels of hope, as well as decrease levels of depression (Cheavens et al., 2006). A recent study has found that a 90-minute hope workshop for college students may result in better academic performance and goal-oriented action (Feldman & Dreher, 2012). Howell, Jacobsen, and Larsen (2015) found that hope may be facilitated in a group counseling setting and provide a beneficial impact to overall well-being for patients with chronic pain. These results are positive and meaningful, especially for those whose time and availability is compromised.

Study Limitations and Future Directions

There are several limitations to the present study. Our cross-sectional and correlational study does not allow assumptions to be made regarding causation or direction of associations among the variables examined. The variables chosen and the ordering and direction of the variables entered in the mediation model were based on theoretical models described by Koenig and Larson (2001), Webb et al. (2014), Snyder (2001), and Pearlin (1990). Regarding directionality, it may be that participants with less depression and anxiety have more hope, for example. Additionally, there is a chance that there are critical mediating variables that are missing from the model (e.g., social support, compassion, forgiveness, gratitude, optimism, meaning making, purpose in life) (Koenig & Larson, 2001; Webb et al., 2010). More experimental, quasi-experimental, longitudinal, and/or intervention-based research is needed in order to support the causal directions of these relationships. Similarly, further investigation of bi-directionality and other mediating variables is warranted.

Likewise, there may be differences in perceived stress versus actual physical stress that one's body is experiencing, yet this study focuses on perceived stress as a function of Lazarus' (1984) model of stress and coping. Perceived stress is a measurement of the psychological appraisal of stress in one's life as a result of events, responsibilities, and their consequences (Pearlin et al., 1991). Physiological measurements of stress, such as studies of cortisol levels and cardiovascular indicators of physical stress, have been linked to perceived stress such that individuals' subjective measures of stress have been found to be related to physiological measures of stress during difficult events such as examinations or speech giving (O'Brien, Tronick, & Moore, 2013; Zanna & Johnston, 2011). The physiological components of stress were not measured in this study, which is a potential limitation. The absence of physiological

stress measurement does not suggest the lack of importance but, rather, is beyond the scope of this study and is an appropriate area for future investigation.

Furthermore, self-report data may affect the degree to which we may base conclusions about a particular set of responses. With self-report data, there is always a chance for responses to be polluted by social desirability factors, as well as dishonesty or inaccuracy (Dodou & de Winter, 2014). Future studies should consider controlling for social desirability. Social desirability factors were not included in the current analysis due to the small sample size and in the interest of preserving power. Additionally, due to the population sought for this study, the sample and data that was obtained may only be viewed in the context of those ALS caregivers who receive social support and resources through groups such as the ALS Association. There may be ALS caregivers who are not represented in this sample. As such, they may not be aware of support mechanisms offered by such organizations, or they may not wish to participate in such offerings. Further research can address this by making use of databases such as BUILD forum, www.patientslikeme.com, and the new CDC database, which offers researchers complete access to diverse patient data despite association or group affiliation (Locock & Brown, 2010; Centers for Disease Control and Prevention, 2014).

Finally, the number of participants who fully completed the ALS Caregiving survey materials was limited. Moreover, the sample size utilized for this analysis was lower than the number projected ($n = 125$) for appropriate statistical power. It may be that the sample size of 85 participants has a detrimental effect on statistical power and effect sizes, thereby increasing the likelihood of both Type I and Type II errors. However, despite the sample size, our sample represents a specialty population and several actions were taken specifically to aid in preserving power (e.g., limited analytical operations and bootstrapping) (Field, 2009). It is likely that the

bivariate analyses that were trending significant (i.e., $p < .10$) would reach significance with an increased sample size. Nonetheless, multivariable effect sizes were found to be large.

Further research is warranted on several fronts. Some research regarding ALS patients and caregivers has suggested that there may be a symbiotic relationship between the patient and their caregiver in the sense that one's psychological well-being may affect the other (Hecht et al., 2003; Rabkin et al., 2000). However, the nuances of that relationship have not been uncovered. Yet, the mere suggestion of the possibility that the caregiver's psychological health may be detrimental to the psychological health of the patient or vice versa has significant implications, including for intervention. As the nature of health care gradually shifts to a more integrated approach offering care for the whole person, and especially for those with chronic illnesses, the intervention focus must shift to include the caregiver (Anderson et al., 2012; Austrom et al., 2006). Not only is the patient's health of concern, but also that of the caregiver (Anderson et al., 2012). More must be done to investigate psychological well-being in ALS caregivers, as well as other caregivers, as the numbers of individuals who are caring for those with chronic illnesses are steadily increasing (Pew Research Center, 2013).

Additionally, it may be that investigating the various dimensions of spirituality in other chronic illness caregivers may give further insight into concerns of their psychological well-being. There has been little investigation comparing aspects and impact of caregiving among various types of chronic illness caregivers, especially including ALS caregivers (Kim & Schulz, 2008). While there may be differences in outcomes between various types of caregivers (Kim & Schulz, 2008), spirituality is a common thread among many individuals (Webb, Toussaint, & Conway-Williams, 2012) and may be a focal point for other and various caregiving research.

Future investigations should also examine possible interventions that might help alleviate the stress and strain faced by ALS caregivers, as well as facilitate aspects of spirituality that promote hope and other values-oriented behavior, meaning, and purpose. Focused interventions such as Focused Acceptance and Commitment Therapy (FACT) (Linde & Strohsal, 2014) should be investigated for utility and outcomes with caregiving populations such as ALS caregivers, as time is a commodity for these individuals and their patients. FACT, likewise, promotes values-oriented behavior which our study found may be of critical importance for ALS caregivers.

Conclusions

Over recent years, empirical study of the salutary relationship between spirituality/religiousness and psychological well-being has increased. Although some studies have shown deleterious associations (e.g., negative religious coping; see Pargament, 1997), a vast majority of research suggests a salubrious association (e.g., 70% in the context of mental health; see Toussaint et al., 2012; see also Koenig et al., 2012). Nevertheless, mechanisms of this association have received less empirical attention. Theory suggests that spirituality/religiousness may lead to positive psychological characteristics such as hope (i.e. through the facilitation of meaningful world views, values, and pro-social qualities), which may function as a means of coping in the context of a significant stressor or stressful situation, thereby leading to better psychological well-being (see Koenig & Larson, 2001). The perceived burden and stress associated with caring for individuals with chronic illnesses such as ALS is significant, and caregivers may be at risk for increased symptoms of depression, symptoms of anxiety, somatic symptoms, and other deleterious psychological and physical health outcomes. Within the context of ALS caregiving, we found that caregiver psychological well-being is dependent upon the dimension of spirituality that the caregiver endorses. Caregivers endorsing

increased levels of theistic spirituality also reported increased psychological well-being in a direct fashion and those endorsing increased levels of existential spirituality reported increased levels of psychological well-being, when hope and perceived stress were considered. Of note, ritualistic spirituality was not related to psychological well-being. The literature is clear that more needs to be accomplished in the area of the differential effects of multiple dimensions of spirituality on health and with regard to the psychological well-being of ALS caregivers; however, our study offers preliminary insight into ALS caregivers' psychological well-being, and offers a potential mechanistic explanation for the relation of spirituality and health in a vulnerable, caregiving sample.

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APPENDICES

Appendix A

Amyotrophic Lateral Sclerosis Functional Rating Scale – Revised (ALSFRS-R) (Brooks et al., 1996)

1. Speech

0) Loss of useful speech 1) Speech combined with non-vocal communication 2) Intelligible with repeating 3) Detectable speech with disturbances 4) Normal speech processes

2. Salivation

0) Marked drooling; requires constant tissue or handkerchief 1) Marked excess of saliva with some drooling 2) Moderately excessive saliva; may have minimal drooling 3) Slight but definite excess of saliva in mouth; may have nighttime drooling 4) Normal

3. Swallowing

0) NPO (exclusively parenteral or enteral feeding) 1) Needs supplemental tube feeding 2) Dietary consistency changes 3) Early eating problems – occasional choking 4) Normal eating habits

4. Handwriting

0) Unable to grip pen 1) Able to grip pen but unable to write 2) Not all words are legible 3) Slow or sloppy; all words are legible 4) Normal

5. Does subject have gastrostomy?

No: Answer 5a Yes: Answer 5b

5a. Cutting food and handling utensils

0) Needs to be fed 1) Food must be cut by someone, but can still feed slowly 2) Can cut most foods, although clumsy and slow; some help needed 3) Somewhat slow and clumsy, but no help needed 4) Normal

5b. Cutting food and handling utensils (alternate scale for patients with gastrostomy)

0) Unable to perform any aspect of task 1) Provides minimal assistance to caregivers 2) Some help needed with closures and fasteners 3) Clumsy but able to perform all manipulations independently 4) Normal

6. Dressing and hygiene

0) Total dependence 1) Needs attendant for self-care 2) Intermittent assistance or substitute methods 3) Independent and complete self-care with effort or decreased efficiency 4) Normal function

7. Turning in bed and adjusting bed clothes

0) Helpless 1) Can initiate, but not turn or adjust sheets alone 2) Can turn alone or adjust sheets, but with great difficulty 3) Somewhat slow and clumsy, but no help needed 4) Normal

8) Walking

0) No purposeful leg movement 1) Nonambulatory functional movement only 2) Walks with assistance 3) Early ambulation difficulties 4) Normal

9. Climbing Stairs

0) Cannot do 1) Needs assistance 2) Mild unsteadiness or fatigue 3) Slow 4) Normal

R-1. Dyspnea

0) Significant difficulty, considering using mechanical respiratory support 1) Occurs at rest, difficulty breathing when either sitting or lying 2) Occurs with one or more of the following: eating, bathing, dressing 3) Occurs when walking 4) None

R-2. Orthopnea

0) Unable to sleep 1) Can only sleep sitting up 2) Needs extra pillow in order to sleep (more than two) 3) Some difficulty sleeping at night due to shortness of breath, does not routinely use more than two pillows 4) None

R-3. Respiratory Insufficiency

0) Invasive mechanical ventilation by intubation or tracheostomy 1) Continuous use of NIPPV during the night and day 2) Continuous use of NIPPV during the night 3) Intermittent use of NIPPV 4) None

Appendix B

The RiTE Spirituality Measure (Webb, Toussaint, & Dula, 2014)

PLEASE READ THE FOLLOWING DEFINITIONS:

This survey is for use with different cultures, so keep in mind that deity/deities can have several meanings, including supremeness of one God or Goddess, multiple gods/goddesses, a higher power, a divine quality in nature and/or the universe, etc. As such, please think of the term deity/deities as it applies to you.

For example, if you are a:

- Buddhist, read deity or deities as “Buddha”**
- Christian or Jew, read deity or deities as “God”, “Jehovah,” or “Yahweh”**
- Hindu, read deity or deities as “Brahma” “Shiva”, “Vishnu,” “Ram,” etc.**
- Muslim, read deity or deities as “Allah”**
- Spiritual, non-specific, read deity or deities as “Nature,” “Higher Power,” etc.**
- Wiccan, read deity or deities as “The Goddess,” “Horned God,” etc.**

READ EACH ITEM AND MARK THE LEVEL OF AGREEMENT THAT COMES CLOSEST TO HOW YOU THINK, FEEL, OR BELIEVE.

1. A deity or deities was/were responsible for the creation of the universe.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
2. The world was created by a deity or deities.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
3. I believe in a deity or deities.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
4. I believe in a deity or deities who know/s me.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
5. A deity or deities is/are at some time going to judge the rightness or wrongness of the actions of individuals.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
6. I feel connected to a deity or deities.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
7. I feel belief in a deity or deities is very important.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree

8. I believe in a deity or deities who has/have a purpose/plan for my life.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
9. I believe in a deity or deities who has/have power to control world events.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
10. It is important to acknowledge the existence or reality of a deity or deities.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
11. I regularly perform traditional spiritual practices.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
12. I observe or follow the rules of a formal belief system.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
13. I regularly attend organized worship services.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
14. I feel faith-related rituals and/or practices are very important.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
15. I set aside time to contemplate issues related to religious or spiritual teachings.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
16. I regularly meditate as I have been taught in my faith.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
17. I feel good after I attend organized worship services.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
18. Observing or following traditions is a very important part of spirituality or faith.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
19. It is important to tell others about one's own spiritual path in order to try and convince them of the correct path.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
20. I would not be good in the judgment of a deity or deities if I did not practice my faith as prescribed.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
21. I feel that helping others is very important.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
22. Helping other people is very important.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
23. I feel that understanding oneself is very important.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
24. I believe that finding meaning and purpose in life is very important.
 A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree

25. I feel that taking care of nature is very important.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
26. Human life is a beautiful thing.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
27. There is a right way to treat other people.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
28. There is a wrong way to treat other people.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
29. It is the responsibility of each person to find their purpose in life.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree
30. I see life as a journey toward fulfillment.
A. Strongly Disagree B. Disagree C. Neutral/No Opinion D. Agree E. Strongly Agree

Appendix C

The Hope Scale (Snyder et al., 1991)

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1=Definitely False 2=Mostly False 3=Mostly True 4=Definitely True

- _____ 1. I can think of many ways to get out of a jam.
- _____ 2. I energetically pursue my goals.
- _____ 3. I feel tired most of the time.
- _____ 4. There are lots of ways around any problem.
- _____ 5. I am easily downed in an argument.
- _____ 6. I can think of many ways to get the things in life that are most important to me.
- _____ 7. I worry about my health.
- _____ 8. Even when others get discouraged, I know I can find a way to solve the problem.
- _____ 9. My past experiences have prepared me well for my future.
- _____ 10. I've been pretty successful in life.
- _____ 11. I usually find myself worrying about something.
- _____ 12. I meet the goals that I set for myself.

Appendix D

Perceived Stress Scale- 10 Item (Cohen, Kamarck, & Mermelstein, 1983)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

3. In the last month, how often have you felt nervous and "stressed"?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

5. In the last month, how often have you felt that things were going your way?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

7. In the last month, how often have you been able to control irritations in your life?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

8. In the last month, how often have you felt that you were on top of things?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

9. In the last month, how often have you been angered because of things that were outside of your control?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

Appendix E

Physical Health Questionnaire (Schat, Kelloway, & Desmarais, 2005)

1 – 14: The following items focus on how you have been feeling *physically* during the *past 6 months*. Please respond by circling [choosing] the appropriate number.

Over the past 6 months . . .	Not at all 1	Rarely 2	Once in a while 3	Some of the time 4	Fairly often 5	Often 6	All of the time 7
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1. How often have you had difficulty getting to sleep at night?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
2. How often have you woken up during the night?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
3. How often have you had nightmares or disturbing dreams?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
4. How often has your sleep been peaceful and undisturbed?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
5. How often have you experienced headaches?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
6. How often did you get a headache when there was a lot of pressure on you to get things done?

1	2	3	4	5	6	7
---	---	---	---	---	---	---
7. How often did you get a headache when you were frustrated because things were not going the way they should have or when you were annoyed at someone?

1	2	3	4	5	6	7
---	---	---	---	---	---	---

8. How often have you suffered from an upset stomach (indigestion)?
- 1 2 3 4 5 6 7
9. How often did you have to watch that you ate carefully to avoid stomach upsets?
- 1 2 3 4 5 6 7
10. How often did you feel nauseated (“sick to your stomach”)?
- 1 2 3 4 5 6 7
11. How often were you constipated or did you suffer from diarrhea?
- 1 2 3 4 5 6 7
12. How often have you had minor colds (that made you feel uncomfortable but didn’t keep you sick in bed or made you miss work/school)?
- 1 2 3 4 5 6 7
13. How often have you had respiratory infections more severe than minor colds (such as bronchitis, sinusitis, etc.) that “laid you low”?
- 1 2 3 4 5 6 7
14. When you have a bad cold or flu, how often does it last longer than it should?
- 1 2 3 4 5 6 7

Appendix F

Depression Anxiety Stress Scale – 21 (DASS-21) (Lovibond & Lovibond, 1995)

Please read each statement and circle a number 0, 1, 2 or 3 that indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (e.g., in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

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