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Neurologists' Emotional Experiences in Caring for Individuals With Amyotrophic Lateral Sclerosis: An Exploratory Study

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NEUROLOGISTS' EMOTIONAL EXPERIENCES IN CARING FOR INDIVIDUALS WITH AMYOTROPHIC LATERAL SCLEROSIS: AN EXPLORATORY STUDY

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Dissertation Approval

This is to certify that the thesis presented to us by Ashley E.P. Hennessey on the *10th* day of *May, 2016*, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Dedication

This dissertation is dedicated to the neurologists who volunteered to participate in this study. Thank you for your time, your voice, and your selflessness. Your self-disclosure in this study and dedication to your patients is a true example of altruism. I hope that the data presented in these pages will shine a light on the wonderful care that you provide for your patients and their loved ones and will have a positive impact on your professional lives. Thank you, thank you, thank you!

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Abstract

Amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, is a progressive neurodegenerative disease, with a reported incidence of 2 in 100,000 people in Western countries, that has no known cure and results in death. The life expectancy for patients with ALS is approximately 3 years. This study utilized a qualitative research design to explore neurologists' experiences in caring for patients with ALS and their families. A semistructured interview was conducted with 11 neuromuscular neurologists who treat patients with ALS. This study explored their perceived challenges of caring for patients with ALS and their caregivers, coping strategies for work-related stress, training experiences regarding communication skills and end-of-life discussions, perceived rewards from their work, emotional reactions, and perceptions of burnout. Twelve themes were identified: diagnosis versus end of life, diagnosis and demographics, physicians as healers, the challenges of frontotemporal dementia, professional pride, burnout, patient and caregiver gratitude, balancing hope versus reality, the challenges of caregivers and families, coping, communication training, and perceived resources to cope. Two theories were developed from this data. The ALS provider two-factor existential reward theory states that neurologists who personally identifies with patients struggle to communicate the diagnosis and treat the patients, but also experience a sense of appreciation and gratitude for their own and their families' health. The second theory, the ALS provider grief and resource theory, posits that a neurologist's history of losing a family member, coupled with limited clinic resources, appears to foster burnout.

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Chapter 1

Introduction

Statement of the problem.

Amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, is a devastating disease for both the patient and his or her family. Approximately 20,000 to 30,000 people ALS in the United States, and 5,000 individuals are newly diagnosed with ALS per year (Centers for Disease Control and Prevention, 2012). ALS is unique in its pathophysiology; it is a progressive neurodegenerative disease that has no known etiology or cure. The life expectancy for an individual diagnosed with ALS is typically 3 years from onset.

In most individuals with ALS (65%), the disease begins as lower extremity weakness and progresses until the patient no longer has use of all limbs and must rely on a caregiver. This dysfunction later impacts the bulbar region, a group of muscles responsible for swallowing and speaking. Eventually, the muscles associated with respiration are weakened and the individual is unable to breathe without assistance; complications related to this typically lead to the patient's death. These symptoms, the terminal nature of the disease, and the general lack of disturbance in mental functioning bring unique challenges and experiences for the neurologists who treat individuals with ALS (Gordon, 2011). Some of these challenges may include relaying the diagnosis and grim prognosis to patients and their families, observing patients' health decline while being unable to treat the disease, and issues related to implementing palliative care and planning for death.

Much research has been conducted regarding the coping strategies, challenges, grief, burnout, and other issues related to end-of-life care for other diseases among physicians from a variety of specialties. These specialties include oncology (Dougherty et al., 2009; Shanafelt, Adjei, & Meyskens, 2003; Shanafelt & Dyrbye, 2012), palliative care (Moon, 2011), primary care (Johansen, Holtedahl, Davidsen, & Rudebeck, 2012; Zambrano & Barton, 2011), nursing (Gerow et al., 2010), and samples from across multiple specialties (Giddings, 2010; Kutner & Kilbourn, 2009). Studying the coping strategies, challenges, emotional reactions, rewards, and burnout among physicians who treat patients at the end of life may reveal ways in which we can help to continue to improve training and support for physicians, thus leading to better patient care. Unfortunately, little is known about these factors as they pertain to neurologists, who are ultimately responsible for the diagnosis, prognosis, and care of patients with ALS. Because there is no cure for ALS, the neurologist is only able to treat the symptoms and delay disease progression. It is conceivable that physicians who are unable to heal their patients may experience grief, feelings of helplessness or futility, or similar emotions, which has been linked to physician burnout. For this reason and others, it is important to study physician burnout.

Patient care and physician burnout are closely interrelated. There are many sources of physician burnout, such as insufficient time to grieve patients' deaths (Dougherty et al., 2009), excessive work hours (Keeton, Fenner, Johnson, & Hayward, 2007), and involvement in the emotional stress of patients (Grunfeld et al., 2004). It appears that the repercussions of burnout impact the physician and his or her ability to provide the best care for his or her patients and caregivers. For example, burnout has

been found to be associated with a poorer immune system (Bargellini et al., 2000), substance abuse, and suicide (Gundersen, 2001). Some consequences of burnout directly affect patient care, such as an increase in medical errors (Shanafelt & Dyrbye, 2012) and compassion fatigue. Compassion fatigue is the experience of hyperarousal, avoidance, and reexperiencing of a patient's pain and suffering, and it decreases the physician's ability to care for and treat a patient (Kearney, Weininger, Vachon, Harrison, & Mount, 2009).

The repercussions of physician burnout, and the lack of literature regarding neurologists who treat patients with ALS in particular, reinforce the need for exploratory research to help identify challenges, coping strategies, emotional reactions, rewards, perceived resources, and training experiences related to end-of-life issues for individuals with ALS. Exploring these factors can improve our knowledge of the experiences of neurologists, thus helping to improve their quality of life and the care they provide.

Purpose of the study.

Amyotrophic lateral sclerosis (ALS) is a progressive disease that is irreversible, and therefore physicians' options for patient care are limited. Given the challenges of treating patients with ALS and the literature concerning other medical specialties, it is suggested that neurologists are at risk for burnout. The purpose of this study was to explore neurologists' perceived challenges of caring for patients with ALS and their caregivers, coping strategies for work-related stress, training experiences regarding end-of-life treatment and communication skills, and the perceived rewards that neurologists receive from their work. Additionally, neurologists' emotional reactions were explored in terms of their experiences with patients and work-related stressors, such as work-

related grief (grief that is due to the suffering and death of their patients), and their perceptions of burnout. The information acquired in this qualitative study provides insight into how psychologists might improve trainings, provide support, and acquire or implement resources for neurologists to decrease possible burnout or negative reactions and maximize the quality of patient care.

Literature Review

Overview of ALS.

The life expectancy for a patient with ALS is approximately 3 years, though it can range from 2 months to a decade after the initial diagnosis (Gordon, 2011). ALS is a rare disease, with a reported incidence of 2 in 100,000 in Western countries (Logroscino et al., 2010). Research on sporadic ALS (sALS) has shown that there are multiple genetic and environmental factors that contribute to ALS, but each factor is only a small contributor; there is no definitive cause for the disease. Some environmental risk factors cited in Gordon (2011) that appear to be correlated with sALS include age (55 to 65 years), male gender, smoking, and to a lesser extent, athleticism, physical stress, and exposure to pesticides (Rowland & Schneider, 2001; Nelson, McGuire, Longstreth, & Matkin, 2000; Horner et al., 2003; Gallo et al., 2009; Weisskopf & Ascherio, 2009; McGuire et al., 1997; Scarmeas, Shih, Stern, Ottman, & Rowland 2002). Unfortunately, no clear causal connections between these environmental factors and ALS have been found.

Approximately 5% to 10% of ALS cases are genetic and inherited; these cases are referred to as familial ALS. Familial ALS is caused by 1 of more than 100 mutations in a gene, though the connection between these mutations and the disease progression of ALS is not completely understood at this time (Gordon, 2011).

Manifestations of ALS.

One of the first signs of ALS is limb weakness. In approximately 65% of ALS cases, difficulty walking, foot drop, loss of dexterity in hands, shoulder weakness, cramps, muscle atrophy, and muscle spasms are early indicators of the disease. These result in the inability to stand or walk and lead to increased dependence on caretakers. For the rest of the population with ALS, early signs occur in the bulbar region. Difficulty with swallowing, speaking, and articulation are typical bulbar region symptoms of ALS (Gordon, 2011).

As previously stated, ALS typically progresses from muscle weakness to bulbar dysfunction. As the disease develops, individuals with ALS have difficulty with speech articulation. The dysfunction of the bulbar region brings difficulty in swallowing, drooling, dehydration, malnutrition, and possible aspiration. Near the end of disease progression, respiratory symptoms include an inability to breath while reclined or lying down, headaches, and a weakened cough. Later symptoms include difficulty breathing during exertion and progress to increased effort for the patient to breathe while inactive. The complications of bulbar symptoms and respiration often lead to death; patients with ALS frequently die due to aspiration pneumonia (Gordon, 2011).

Cognitive decline was observed in approximately 25% to 50% of patients who received neuropsychological testing. Approximately 15% of individuals with ALS develop frontotemporal dementia (FTD, Gordon, 2011). Neary et al. (1990) reported that frontotemporal dementia differs from other forms of dementia (e.g., Alzheimer's disease in that personality, social skills, and conduct are significantly altered. These areas typically remain intact until late in the progression of other forms of dementia (Neary et

al., 1990). Patients with dementia may also be less compliant with treatment recommendations and could therefore have a shorter life expectancy (Gordon, 2011). Changes in personality and cognition may make it difficult for an individual with ALS to make appropriate choices for his or her care. He or she may require a caretaker or person with power of attorney to make decisions related to treatment options.

Emotional lability is another symptom typically associated with ALS. This is referred to as a *pseudobulbar affect,* and is reported to occur in approximately 19% to 50% of patients with ALS (McCullagh, Moore, Gawel, & Feinstein, 1999). Pseudobulbar affect is a display of emotion that is either out of proportion to or disconnected from the triggering stimulus. Pseudobulbar affect can include uncontrollable laughter or crying, though crying is more common, and can include inappropriate affect in situations that would not have previously elicited a strong emotional response, such as a sad television show or affection from a grandchild. The display of emotion could be exaggerated in these instances or could be unrelated to any triggering stimulus (Ahmed & Simmons, 2013).

The diagnosis of ALS usually takes approximately 1 year from symptom onset to confirmation of diagnosis. Similar periods for the confirmation of a diagnosis have been found across Eastern and Western countries (Gordon, 2011; Iwasaki, Ikeda, & Kinoshita, 2001). It can often be difficult to accurately diagnose ALS due to the slow progression of early symptoms that can be misinterpreted as another disease. Patients with ALS often do not seek consultation with a physician for several months, especially if the disease first manifests as bulbar symptoms. However, patients with symptoms that begin in the

bulbar region are typically diagnosed more quickly with ALS than patients with symptoms that begin in the extremities (Iwasaki et al., 2001).

Though there is no cure for ALS, there are various resources and some medications that can be utilized to increase the patient's quality of life.

Treatment of ALS.

Treatments for patients with ALS are focused on controlling symptoms and improving quality of life. At this time, riluzole is the only medication approved by the U.S. Food and Drug Administration (FDA) to prolong the survival of patients with ALS. Researchers believe that excess glutamate may be associated with neurodegeneration in patients with ALS. Riluzole was first developed as an antiepileptic drug. It inhibits the presynaptic release of glutamate, though the exact mechanism of action for riluzole in ALS is not known. Riluzole does not reverse the disease progression, but slows the course of ALS; it appears to prolong the life of ALS patients by 2 months (Gordon, 2011; Miller, Mitchell, Lyon, & Moore, 2003).

Multidisciplinary care.

The goal of treatment for patients with ALS is to achieve the highest quality of life for the patient. Large centers for the treatment of ALS use a multidisciplinary approach, which consists of professionals from various disciplines at the same location caring for the patient. Some research suggests that using this approach results in longer life expectancies for patients with ALS. One study found that the median survival rate for patients receiving care at a multidisciplinary clinic was 7.5 months longer than for patients in a general neurology setting (Traynor, Alexander, Corr, Frost, & Hardiman, 2003). Additionally, multidisciplinary care is correlated with better mental quality of life

for patients with ALS (Van den Berg et al., 2005). One reason for longer survival rates and improved quality of life may be the early detection of symptoms through frequent evaluations of patients at ALS clinics. Patients and neurologists are able to make informed decisions about care and are able to plan ahead and construct advance directives. Patients at ALS clinics receive treatment from a host of clinicians, including neurologists, nurses, physical therapists, occupational therapists, dietitians, speech pathologists, respiratory therapists, social workers, and possibly pulmonologists, gastroenterologists, and psychiatrists or psychologists.

In each multidisciplinary clinic and in nonclinic settings, the patient's neurologist is ultimately responsible for his or her care (Gordon, 2011). The great responsibility of neurologists for the treatment of patients with ALS warrants a closer look at the experiences and stressors of these physicians.

Physicians as healers.

Physicians are trained to heal patients, and they enter the healthcare field with the hope of saving lives. As a result, it could be difficult to accept or cope with the inability to heal a patient with an illness that has no cure. During their medical training, new physicians take the Hippocratic Oath, an ancient Greek oath in which one swears to the gods that he or she will uphold highly professional and responsible behavior as a physician (North, 2002). The Hippocratic Oath includes the following: ". . . I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice. I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect" (Markel, 2014, p. 2028).

Veatch states that physicians often consider the Hippocratic Oath a promise to not allow patients to die (Veatch, 1981). Similarly, Lee (2008) mentions that physicians consider patient death to be a failure on the part of the medical provider (SUPPORT, 1995). Unfortunately, the reality for neurologists treating patients with ALS is that there is no medical intervention to cure their patients.

ALS care providers.

At this time, very little is known about the experiences of neurologists who care for patients with ALS. Only one study explored the experiences of ALS care providers. Bromberg, Schenkenberg, and Brownell (2011) examined stress and coping among neurologists and clinic managers at multidisciplinary ALS clinics across the country.

Bromberg et al. received 32 responses from neurologists and 31 responses from clinic managers (47% and 46% response rates, respectively) they surveyed at multidisciplinary ALS clinics certified by the Muscular Dystrophy Association or the ALS Association. The authors believed that the neurologists and clinic managers at these clinics diagnose approximately 40% of the nation's new ALS cases per year. When the ALS diagnosis was revealed, 100% of the neurologists and 71% of the clinic managers were present with the patient for an average of 60 and 45 minutes, respectively. This is especially encouraging, as it is part of the good care guidelines for ALS providers to communicate the diagnosis in person (Miller et al., 1999). At the time of the patient's death, Bromberg et al. reported that most of the neurologists and clinic managers (66% and 94%, respectively) contacted the family using letters or phone calls and that about 25% of neurologists and 55% of clinic managers attended the patient's funeral. They reported that this was to provide closure for both themselves and the family.

Interestingly, 100% of the neurologists and clinic managers reported feeling satisfaction in providing care for patients with ALS and believed that they provided good care. However, 29% of neurologists and 43% of clinic managers reported that they considered leaving their position at the ALS clinic at some point in time. Some of the reasons for this include stress and financial issues.

Burnout was not reported as a factor in the ALS healthcare providers' consideration of leaving. This lack of burnout is in conflict with the literature on oncologists, who describe higher levels of burnout and emotional exhaustion. The authors surmised that these findings may be due to the fact that most neurologists work approximately 1 day per week at these clinics, whereas oncologists spend more time in their clinics (Bromberg et al., 2011).

Bromberg et al. found that overall levels of stress for neurologists and clinic managers varied across time points (time of diagnosis, continuing care, and patient death) and providers (neurologists versus clinic managers). Providers reported a wide range of stress, though patient and family acceptance of diagnosis was the only factor established in this study that correlated with provider stress. Perhaps most important for the present study is the conclusion that providers experience mild to extremely severe stress due to the lack of effective treatments for ALS (Bromberg et al., 2011). For neurologists, it appears that greater levels of stress are experienced at the time of diagnosis and death. The results of the Bromberg et al. study suggest that the incurable nature of ALS may produce stress in at least some neurologists. It is unclear what aspects of diagnosis and death are most stressful for neurologists, and revealing this was an aim of the present study.

The authors also addressed stress reduction techniques in their study. They report that 47% of neurologists and 16% of clinic managers did not use any stress reduction techniques. Of those who did use stress reduction techniques, the most common was exercise, but also included spirituality, speaking with others and, for a small group, alcohol. Clinic managers were more likely to use spirituality and group discussion (e.g., support groups and grieving meetings) than neurologists. About half as many neurologists (48%) as clinic managers (91%) identified themselves as spiritual. Clinic managers also reported greater efficacy of their relaxation techniques than neurologists.

The study by Bromberg et al. provides an excellent starting point for studying the experiences of neurologists caring for patients with ALS. It offers information about neurologists' stress levels and some coping strategies that they utilize, but it also leaves many questions unanswered, such as why the diagnostic process may lead to increased stress, why neurologists may not use relaxation techniques, and how spirituality may or may not be affected by their training and experiences as physicians.

Although there is very little information regarding neurologists in the literature, there is a vast array of research conducted on the experiences of healthcare professionals from other disciplines, especially oncology. Physicians' grief and emotional experiences, coping strategies, physician communication skills, and burnout are important areas to explore because they can affect the quality of patient treatment. Much of the review of the following areas is focused on oncologists because their clinical experiences are perhaps most closely related to those of neurologists treating patients with ALS. The knowledge gathered in oncology research can be used to direct research efforts with neurologists who care for patients with ALS. However, the conclusions reached in the

study of oncologists cannot be directly translated to neurologists. Neurologists who treat patients with ALS use lengthy diagnostic processes with their patients, whereas oncologists typically have definitive tests (e.g., biopsies) that directly diagnose the presence of cancer. Chemotherapy or surgery may help to eradicate cancerous cells, but there is no treatment to reverse the process of ALS once the diagnosis is made. ALS is a terminal illness and its course is unchanging, unlike cancer, in which there may be hope for remission.

The Bromberg article (2011) noted that neurologists and clinic managers attempt to attend their patients' funerals to provide closure for not only the families of the patients, but also for themselves. Much research has been conducted on the construct of grief for oncologists, and it is reasonable to expect that neurologists who treat terminally ill patients may also struggle with grief reactions at some point in their careers.

Grief.

Grief can be described as "the psychological distress associated with loss" (Redinbaugh, Schuerger, Weiss, Brufsky, & Arnold, 2001, p. 187). According to Redinbaugh et al., grief can arise as a result of the lack of hope for a cure, the death of a patient, and death that lacks dignity. Wooley, Stein, Forrest, and Baum (1989) state that recent personal bereavement and unresolved grief may accentuate the grief experience of a healthcare provider.

Experiences with grief can be mediated by various factors. For example, one study found that, despite having satisfying experiences caring for dying patients, physicians experienced moderate levels of grief. Stronger emotional reactions were impacted by the length of time a patient was in treatment. For neurologists treating

patients with ALS, particularly patients who have lengthier periods of survival, this may be a factor in the neurologist's experience with grief. Additionally, less work experience (e.g., interns versus attending physicians) was also correlated with more intense emotional reactions (Redinbaugh et al., 2003). In a survey of 598 oncologists by Whippen and Canellos (1991), burnout was reported by 56% of respondents. Of these respondents, 53% attributed their burnout to excessive exposure to terminal illness. The physicians reported that low treatment success rates lead to feelings of burnout.

Sanders's integrative theory of bereavement was used to conceptualize grief in this study. Sanders believes that there are five phases of grief that an individual progresses through after a loss. These are Phase 1: shock, Phase 2: awareness of loss, Phase 3: conservation−withdrawal, Phase 4: healing, and Phase 5: renewal. Additionally, Sanders believes that there is a biological basis for each stage. She ties her stages to Cannon's fight-flight theory and the notion that the sympathetic nervous system is activated, and the individual is at a state of readiness (Sanders, 1999). Sanders's model may apply to physicians who experience multiple losses at work and do not have time to grieve or process each loss. As a result, these physicians may remain in Phase 1, or shock, in which their bodies are in a state of arousal, which leads to exhaustion or burnout. Additional personal losses may compound their grief and make it more difficult to progress past the initial stages into renewal.

It is reasonable to consider that neurologists who treat patients with ALS may also experience burnout as a result of the incurable nature of ALS. Unfortunately, burnout is a common phenomenon in physicians and its effects can be detrimental to the care of their patients.

Burnout.

While there is no universal definition of burnout, Maslach's Burnout Inventory (MBI; Maslach, Leiter, & Schaufeli, 2009) is generally used as a primary source in the literature to describe this phenomenon. Maslach's three-factor structure of burnout is characterized by a "loss of enthusiasm for work (emotional exhaustion), feelings of cynicism (depersonalization), and a loss of perspective that work is meaningful (low sense of personal accomplishment)" (Shanafelt & Dyrbye, 2012, p. 1235). This definition and characterization of burnout will be utilized in this study, based on the widely accepted use of the MBI as a measure and conceptualization of burnout.

Though burnout is commonly associated with an individual who has worked for a lengthy period, studies have shown that burnout can occur at any stage in a physician's career. For example, researchers have indicated that burnout can occur in medical students (Dyrbye et al., 2009) and clinicians early in their careers (Peisah, Latif, Wilhelm, & Williams, 2009; Ramirez et al., 1995).

There are extensive studies of burnout across most disciplines of medicine, such as emergency medicine (Keller & Koenig, 1989), primary care (Bakker, Schaufeli, Sixma, Bosveld, & Van Dierendonck, 2000), palliative care (Pereira, Fonesca, & Carvalho, 2011), and surgery across specialties (Shanafelt et al., 2009). It appears that burnout is common in all medical disciplines. Not surprisingly, burnout is often correlated with higher levels of exposure to patient death (Granek, Tozer, Mazzotta, Ramjaun, & Krzyzanowska, 2012). However, a systematic review of articles from 1999 to 2009 showed that palliative care physicians and nurses do not experience higher levels of burnout than their counterparts in other disciplines, despite higher levels of exposure to

patient death (Pereira et al., 2011). The following study illuminates some of the sources of work-related stress for both palliative care physicians and oncologists.

In one study of palliative care and oncology staff, 63% of staff reported that they experienced a great deal of work-related stress (Dougherty et al., 2009). The authors reported that the issues that most likely predicted work-related stress were the perceptions that their workload negatively impacted patient care, a lack of time to grieve the death of their patients, and not enough resources available for them to cope with work-related stress. In this study, 55% of the staff felt that they had an insufficient amount of time to grieve the death of their patients. Oncology staff were more likely to endorse the lack of time (64%) than palliative care staff (48%). Interestingly, the death rate on the oncology inpatient unit at that time was 6%, and it was 48% on the palliative care unit (Dougherty et al., 2009). Additionally, feeling supported by the hospital was negatively correlated with work-related stress. This could indicate that work-related stress may be alleviated by support from others in the work setting.

Other stressors that are correlated with burnout for oncologists are personal stressors, malpractice litigation, excess workload, loss of autonomy, lack of meaning in work, and, again, too little time spent with patients (Shanafelt & Dyrbye, 2012). Additionally, difficult professional tasks such as telling bad news may increase the likelihood of burnout (Pereira et al., 2011). Communicating bad news to patients is certainly an experience that neurologists who treat patients with ALS have on a regular basis. Neurologists must also face additional challenges in telling bad news that physicians from other disciplines may not, such as the emotional or cognitive states of the patients (e.g., if the patient has pseudobulbar affect or cognitively impairment).

The personal consequences for a physician with burnout may include an increased likelihood of mental illness, substance abuse, and increased rates of suicide. Substance abuse is a common consequence of burnout for the healthcare professional. According to Shanafelt and Dyrbye (2012), substance abuse disorders are more prevalent among physicians (10% to 15%) than the general population (8%).

Although physicians have healthier lifestyles than the general population, they are at a higher risk for completing suicide (Frank, Biola, & Burnett, 2000; Schernhammer, 2005). According to a meta-analysis by Schernhammer and Colditz (2004), male physicians have a modestly higher rate for suicide completion. Furthermore, female physicians have a much higher suicide completion rate than the general population in Northern European and North American countries. Silverman (2000) notes that the higher rate of suicide completions than suicide attempts may be because physicians have access to lethal medication and knowledge of toxicology (Simon, 1986).

There are clear repercussions for physicians as a result of burnout. However, the symptoms of physician burnout have dangerous repercussions for patients, as well. For example, Shanafelt, Bradley, Wipf, and Back (2002) found that residents who met the criteria for burnout on the Maslach Burnout Inventory reported that they were responsible for at least one incident of suboptimal patient care practices and attitudes on a monthly basis. Some examples of suboptimal patient care in the survey included “I did not fully discuss treatment options or answer a patient’s questions” and “I felt guilty about how I treated a patient from a humanitarian standpoint” (Shanafelt et al., 2002, p. 360). Gender, depression, and substance abuse were not associated with reports of suboptimal care.

The emotional exhaustion that accompanies burnout can often be a result of physicians putting more effort into their relationships with their patients. Emotional exhaustion also arises from poor behavior on the part of the patient (e.g., lying or manipulating, not following through with medical advice, making impossible demands; Bakker et al., 2000). In one study, the authors found that physicians who reported emotional exhaustion exhibited negative attitudes towards patients and their jobs (depersonalization and reduction in feelings of competence) and in turn evoked demanding and threatening patient behaviors (Bakker et al., 2000). Additionally, Shanafelt and Dyrbye (2012) reported that patients' resistance to follow up with physicians' recommendations is associated with physician burnout.

Burnout can also affect physicians' conduct and attitudes about their professional practice. For example, Dyrbye et al. (2010) found that medical students who endorsed burnout on the Maslach Burnout Inventory reported unprofessional behavior related to patient care and were less likely to be altruistic in their professional lives (e.g., working in underserved areas). These findings support other literature that states that empathy often declines and negative emotions often increase in medical school and residency as a result of burnout (Bellini, Baime, & Shea, 2002; Brazeau, Schroeder, Rovi, & Boyd, 2010).

Perhaps most alarming is the finding that medical errors increase as a result of burnout. For example, one study found that internal medicine residents' self-perceived errors in medical practice were highly correlated with later increases in reports of burnout, poorer quality of life, and increases in reports of depression (Shanafelt et al., 2002). Additionally, this increase in burnout preceded reports of decreased empathy and

more self-perceived medical errors, which suggests that medical errors and burnout are cyclical in nature. Similar studies have found that perceived medical errors are correlated with burnout, symptoms of depression, and mental quality of life (Shanafelt et al., 2010) and that burnout is related to perceived suboptimal patient care and an increase in the likelihood of making medical errors (Williams, Manwell, Konrad, & Linzer, 2007).

It is clear that the consequences of burnout are varied and serious. Fortunately, there are adaptive coping strategies to help physicians manage the daily stressors that are associated with working in the difficult field of healthcare.

Coping strategies.

Coping strategies are important for any individual in a high-stress job, but are imperative for physicians because of their responsibilities to patients. Coping strategies typically refer to behavior and psychological interventions that help alleviate stress (Lemaire & Wallace, 2010). Lemaire and Wallace sampled physicians across specialties to study their coping strategies at work and home for work-related stress. The authors found that physicians most often reported "working through or simply dealing with the stress at work" or "concentrate on what to do next" as their coping strategy at work. This was followed by "talking with coworkers, taking a time-out, using humor, and ignoring or denying stress" (Lemaire & Wallace, 2010, p. 212). The major coping strategy themes for home were "exercising, having quiet time, talking to spouse, spending time with family and leaving work at work" (Lemaire & Wallace, 2010, p. 213). Unfortunately, some less popular themes included completing additional work at home and the use of alcohol. Perhaps most important is the relationship of these coping strategies to emotional exhaustion. The authors found that physicians who kept their stress to

themselves, concentrated on what to do next, and continued as if nothing happened were most likely have emotional exhaustion (a subscale on the Maslach Burnout Inventory). Additionally, the authors stated that these coping strategies indicate denial. Although these coping approaches may be successful while the physician is at work and is in the stressful situation, it appears that they are the most likely to lead to emotional exhaustion at a later time. Conversely, talking with colleagues was another commonly used coping strategy that lead to emotional and informational support for the physicians.

The secrets to coping with work-related stressors seem to come with age. A study that focused on age and experience and burnout found that physicians with more experience in their fields (i.e., older physicians) have lower levels of emotional exhaustion and depersonalization on the Maslach Burnout Inventory than less-experienced physicians (Peisah et al., 2009). Clearly, burnout is not simply due to a long time in the field; rather, time in the field can foster coping strategies that can be used to manage the daily stressors that promote emotional well-being.

In addition to using coping strategies at home and work to deal with work-related stress, it appears that using a combination of coping methods is also helpful. For example, a study by Keller and Koenig (1989) found that emergency physicians who reported high levels of satisfaction with their jobs and high personal accomplishment used a balance of short- and long-term coping strategies. Some of the long-term coping strategies included “I talk it out with others,” “I believe in a supernatural power who takes care of me,” and “I work it off by exercise.” The short-term strategies included “I curse,” “I try to see humor in the situation,” and “I cry” (Keller & Koenig, 1989).

Work-related stressors can have a major impact on a physician's personal health and ability to cope with the demands and stress of his or her employment. Physician communications skills are also associated with stress and coping and can contribute to burnout.

Physician communication skills.

A physician's communication skills impact patients in many different ways. For example, physician communication skills can affect the patient's satisfaction with treatment (Bertakis, Roter, & Putnam, 1991), and good communication and thus a good physician-patient relationship can improve their health (Kaplan, Greenfield, & Ware, 1989). Similarly, patients believe that a physician's ability to listen to them is important for many reasons, including that listening was part of the healing process (Jagosh, Boudreau, Steinert, MacDonald, & Ingram, 2011).

Physicians' communication skills can not only impact patient care, but also their own physical and mental health. For example, inexperienced physicians have considerable cardiovascular stress when taking a history and breaking bad news (Hulsman et al., 2010). Insufficient training in communication skills may also contribute to burnout. Ramirez et al. (1995) examined burnout and psychiatric disorders in oncologists. The authors found that physicians who believed that they did not receive sufficient training in communication and management reported higher levels of distress than those who felt that they received enough training in these areas. More specifically, only 56% of clinicians in this study believed that they received sufficient training in communication skills. The individuals who believed that their communication training was not sufficient had a higher level of depersonalization and a lower level of personal

accomplishment (Ramirez et al., 1995). Yet another study found that primary care physicians who had better communication skills had a decreased likelihood of having malpractice claims filed against them. The authors analyzed audiotapes of office visits and found that many of the skills that these physicians utilized are specific and teachable (Levinson, Roter, Mullooly, Dull, & Frankl, 1997).

Summary.

ALS is a rare neurodegenerative disease that strikes about 2 in 100,000 people in Western countries. Its symptoms include limb weakness, difficulty swallowing and speaking, and later, respiratory difficulties and eventual death. It has no known etiology and no cure. Physicians' grief, coping strategies, and training and communication skills are explored in this study because of the established connections with burnout. As discussed, burnout has serious consequences for both the physician and the patient and his or her caregivers. The purpose of this study was to explore neurologists' emotional reactions, challenges, coping strategies, perceived resources, rewards, and communication training experiences related to caring for patients with ALS at the end of life. The goal was to uncover information about these physicians to help build theories about their experiences in treating patients with ALS and to identify ways to better support neurologists.

Chapter 2

Research Question

What are the rewards, challenges, emotional reactions, coping strategies, perceived resources, communication training experiences, and perceptions of burnout for neurologists caring for patients with amyotrophic lateral sclerosis and their caregivers?

Chapter 3

Method

Design.

The aforementioned lack of research on neurologists' experiences with patients with ALS, coupled with the nature of the research question, warrants a qualitative design for this study. Grounded theory, developed by Glaser and Strauss in 1967 and outlined in *The Discovery of Grounded Theory* (Denzin & Lincoln 2000), is defined as "the purpose of building theory from data" (Corbin & Strauss, 2008, p. 1). Grounded theory was utilized as the basic approach for this study to analyze the data and identify common themes. These themes were analyzed to develop general theories and hypotheses about the experiences of neurologists caring for patients with ALS and their caregivers. Grounded theory is appropriate for this study because it is inductive and will help focus further research efforts with this population (Charmaz, 2000).

Participants.

Participants were recruited via e-mails sent to physician members of the Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS). This group of individuals performs clinical research trials in ALS. The sample consisted of 11 neuromuscular neurologists, that is, neurologists who specialize in the treatment of neuromuscular diseases. Inclusion criteria were:

1. Doctor of Osteopathic Medicine (DO) or Doctor of Medicine (MD) degree
2. treats motor neuron diseases
3. has treated patients with ALS in his or her career and has followed at least one patient with ALS from diagnosis to death

4. at least 2 years as an attending physician
5. dedicates at least 20% of his or her professional activities to direct or indirect care for patients with ALS

Prospective participants were informed of the inclusion criteria in a recruitment letter (Appendix A). Their demographics and career and educational history were confirmed using the demographics questionnaire following the interview (Appendix B).

Measures.

A semistructured interview was used to elicit information from participants concerning their experiences treating patients with ALS. The questions used in the semistructured interview were:

1. What is it like to care for patients with ALS and their caregivers? What is this experience like for you? Please tell me your thoughts and feelings related to it.
2. What rewards do you perceive are associated with treating patients with ALS and their caregivers?
3. Tell me about the emotional reactions you experience when working with your patients with ALS and their caregivers.
4. What are the greatest challenges that you encounter when working with patients with ALS and their caregivers?
5. How do you cope with the emotional challenges of working with patients with ALS and their caregivers? How do you cope with or address your emotional reactions to working with patients with ALS and their caregivers?

6. What resources do you believe are available to you to help you cope with the emotional challenges of treating patients with ALS and their caregivers? What do you wish was available to you?
7. What communication training or other training experiences related to relaying bad news and coping with the emotional challenges of caring for patients have you had that especially prepared you for treating patients with ALS at their end-of-life and their caregivers? What do you wish you had? How have you learned to communicate the diagnosis, prognosis, and need for end-of-life decisions with your patients? Tell me what these conversations are like for you.
8. Do you think professionals in this field are likely to experience burnout? What does burnout mean to you? Have you ever experienced burnout? If not, how would you know if you had it? How did you/would you deal with it?

Closed and opened-ended follow-up questions were utilized sparingly in the interview process if the participant gave minimal information. Additionally, questioning to clarify participants' answers was used as necessary. The investigator maintained methodological memos while recording the interview process to help recall all procedural details. Field notes were taken during the interviews to record the interviewee's tone or attitude and the general feelings of the investigator while interviewing the participant.

A demographics questionnaire was utilized to obtain further information about the physicians that was not directly covered in the semistructured interview. The questions in this demographic questionnaire were:

1. Age
2. Year of graduation from medical school
3. Type of degree (MD/DO)
4. Year of completion of residency
    a. Additional specialized training beyond neurology in motor neuron diseases (fellowships)
        i. Type and year of completion
5. Number of years spent caring for patients as a significant part of your practice
6. Percentage of time spent in direct care to patients with ALS
7. Approximate number of treated patients with ALS in your current practice
8. Work in a group or independent practice
9. Affiliated with a university-based hospital (yes/no)
10. Participation in research related to ALS
    a. Clinical trial/research
    b. Basic science research

Procedure.

After initial contact was made via e-mail, participants and the researcher planned an interview date and time. Participants were asked to complete and sign an informed consent document, then faxed or scanned it to the investigator.

All interviews were conducted via telephone because of the geographic distribution of the participants. On the day of the interview session, informed consent was reviewed and subjects were given the opportunity to ask the researcher questions. The researcher briefly reviewed the interview agenda and reminded the participants that it

included a semistructured interview and demographics questionnaire. Additionally, subjects were reminded that their interview and demographics questionnaire would be recorded and that all information would be de-identified.

The rationale for the order of the interview and demographics questionnaire was to decrease the likelihood of defensiveness based on the information sought in the demographics questionnaire. Participants were thanked and debriefed after the interview and questionnaire, given the opportunity to ask any remaining questions, and were encouraged to contact the researcher in the future if they had any questions or concerns. The entire interview process lasted approximately 40 to 70 minutes, depending upon the amount of information provided. Most interviews lasted 45 to 50 minutes. Generally, 40 minutes were devoted to the semistructured interview and 5 minutes to the demographics questionnaire.

Qualitative analysis.

As stated previously, this study utilized a grounded theory qualitative approach due to the exploratory nature of the research question. There is currently a lack of literature on the experiences of neurologists who treat patients with ALS. The information obtained from the qualitative analysis was used to construct themes and theories about neurologists' experiences treating patients with ALS and their caregivers.

The investigator transcribed the audio-recorded telephone interviews. After transcription, the data were de-identified to provide confidentiality for the participants. Additionally, any information that the subjects mentioned, for example, the name of their institution or a facility in which they trained, was redacted from the transcripts. Two additional doctoral level students with training in qualitative methods were recruited to

code the data. The use of three coders is referred to as *triangulation*. This allowed for consensual validation of the data. A licensed clinical psychologist with expertise in qualitative analysis supervised the research.

The coders in this study were three female students from the same clinical psychology PsyD program. The doctoral program has a cognitive behavioral orientation; thus, the students have background and training in this orientation. Additionally, all coders had a particular interest in ALS and opted to complete their dissertations on this topic. Thus, they utilized previous knowledge of ALS in their coding. All coders attended a meeting to discuss the process of open coding.

All coders read the transcripts a minimum of twice; first, the transcript was read in its entirety to gain a general understanding of the interview, then the transcript was reread to begin open coding. During the process of open coding, each coder read the transcripts to identify themes or repeating ideas. Repeating ideas are "an idea expressed in relevant text by two or more research participants" (Auerbach & Silverstein, 2003, p. 54). Each coder recorded the themes and repeating ideas that she identified in the transcript. During open coding, the coders were blind to previous information or literature related to the topics covered in the interviews. All coders reached 100% agreement regarding the data presented in this study; thus, it is considered valid.

As the coders reviewed the transcripts, they wrote memos about the data. Some of the memos were thematic or theoretical, in that they recorded their impressions of emerging themes or theories (Marshall & Rossman, 2011). Other memos were more personal or process-oriented and were based on the emotions, thoughts, or general impressions that were elicited in the interviews.

The coders and investigator met to discuss the themes and repeating ideas that were captured in the transcripts. The coders and investigator came to a consensus about the salience of each identified theme or idea found in each interview. The investigator maintained notes on the identified themes and ideas.

After open coding, the investigator used constant comparative analysis, a technique in which she compared themes and ideas found in each transcript to themes found in other transcripts. After using constant comparative analysis to compare the themes identified in each transcript, the investigator devised axial codes. Axial coding is a method in which the themes or concepts are related to each other (Corbin and Strauss, 2008). These axial codes reflect commonalities among the data (Marshall & Rossman, 2011). The axial codes were then integrated to develop theories to explain the data.

Theoretical saturation was reached when the data collected no longer presented any new themes or repeating ideas. This study achieved credibility through saturation, triangulation, audit codes (the methodological memos that detail the procedure for transparency and easy replication), and peer debriefing (contacting a knowledgeable source of neurology and ALS to get feedback on the data obtained) (Marshall & Rossman, 2011).

Chapter 4

Results

Interviews.

The identifying information about the study subjects has been changed to protect their identities and to maintain confidentiality. The first portion of this study included a semistructured interview with eight questions and follow-up questions to clarify the participants' responses (Appendix A). The second portion of the study included a brief demographics questionnaire (Appendix B). All interviews were completed via telephone due to geographic constraints. All participants lived in the continental United States, but most lived in different states and time zones than the interviewer.

Demographics.

The table presents the sample size and general demographic information for the study subjects. There were 10 males and 1 female. The mean age was 49.09 years, with a standard deviation of 9.59 years (M = 49.09, SD = 9.59). Eight physicians (73%) had doctor of medicine (MD) degrees, one of whom also earned a PhD in Neuroscience, and three physicians (27%) had doctor of osteopathic medicine (DO) degrees. The mean number of years that the participants cared for patients with ALS as a significant part of their practice was 13.5 years, with a standard deviation of 6.89 years (M = 49.09, SD = 9.59).

Table

Demographic Information

Subject Number	Age	Gender	MD or DO	Years treating ALS pts	Burned out?
1	42	Male	MD	12.0	No
2	41	Male	MD	5.5	No
3	49	Male	MD	17.0	No
4	66	Male	MD	20.0	No
5	39	Female	MD	7.0	Yes
6	53	Male	MD	20.0	No
7	57	Male	MD	18.0	No
8	64	Male	DO	25.0	Yes
9	44	Male	MD, PhD	7.0	No
10	44	Male	DO	12.0	No
11	41	Male	DO	5.0	Yes

Chapter 5

Discussion

Initial impressions.

Overall, the findings of this study indicate that neurologists who treat patients with ALS and their caregivers believe that it is a rewarding experience. The physicians described their experiences with this patient population as "something which I really treasure" and very rewarding. Additionally, participants said "it's something I have a passion for," "I really feel that caring for them and being a part of their lives has really had a huge positive impact for me," and that they "really enjoy taking care of ALS patients and their caretakers." They have said that this work is gratifying and motivating. Neurologists who treat patients with ALS have self-selected this specialty. Despite mixed reports of burnout and challenges and frustrations, the subjects overall had a positive view of their work. The following discussion further explores the themes that were revealed in the data.

Themes and theories.

Several themes that were observed across participating physicians who care for patients with ALS and their caregivers emerged from the data. These themes were: diagnosis versus end of life, diagnosis and demographics, physicians as healers, the challenges of frontotemporal dementia, professional pride, patient and caregiver gratitude, balancing hope versus reality, the challenges of caregivers and families, coping, communication training, resources to cope, and burnout. Additionally, two theories were developed from the data: the ALS provider two-factor existential reward theory and the ALS provider grief and resource theory.

This study revealed that the experience of caring for patients with ALS and their caregivers is highly dependent on the stage of disease. Some participants described ALS as dynamic or a moving target.

Diagnosis versus end of life.

Most study subjects noted that revealing the diagnosis was the most challenging or emotionally difficult aspect of their job. Many patients come from other care providers and are aware that they may have ALS. Subjects reported that communicating the diagnosis was more difficult for them when a patient did not have an inkling about their potential ALS diagnosis. End-of-life issues and related discussions were also noted as a challenge, but with less frequency. Additionally, if physicians noted the challenges of patient death and conversations about end of life, they noted that it was not as difficult as revealing the diagnosis. This finding is consistent with a previous study of ALS care providers (Bromberg et al., 2011). All but one participant explicitly mentioned the difficulty of the diagnostic sessions. According to the data, there are multiple factors that contribute to the difficulty of diagnostic sessions.

Some mentioned their concern regarding the patient and family's reactions to the diagnosis. Participants discussed the anxiety that they experienced when revealing the diagnosis. In particular, they feared that the patient and their family would react in an overly emotional or angry fashion and would become angry with the physician. This finding is similar to the results of Bromberg et al. (2011), though they also found that patient and caregiver acceptance of the diagnosis was the only factor they found that correlated with provider stress.

Some subjects noted the importance of being mindful of the fact that they did not actually give the disease to the patient. It was important to differentiate between communicating the diagnosis and believing, on some level, that they actually gave the disease to the patient. For example, one stated "So probably the most difficult time, I think, is when you have to tell the patient. And so again, it's hard and many people don't learn the fact that just because many patients have the disease doesn't mean I gave them the disease."

Multiple participants mentioned that their experience of stress and exhaustion on a day-to-day basis was positively correlated with the number of diagnoses they revealed in a day. In particular, subjects reported that communicating three diagnoses in 1 day was especially difficult for them. Three physicians (27%) reported that three was the maximum number of diagnostic sessions they had in a day, and when it reached three, they became both emotionally and physically exhausted.

Diagnosis and demographics.

The results also revealed that patient demographics affected the participants' emotional reactions when communicating the diagnosis. In particular, the age of the patient was a factor in the difficulty of revealing. Approximately half of subjects (45%) reported that older the patient was, the easier it was to communicate the diagnosis. For example, one physician stated "Sometimes I tell myself 'they've lived a full life' or sometimes the patients tell me that, you know, 'I've lived my full time, so even though this is a terrible disease, I feel like I've lived my life already, so if not from ALS, I will die from something else.'" Conversely, if a patient was younger, it was more difficult to reveal the diagnosis. One physician stated that he had to communicate the diagnosis to a

patient who was 19 years old, and that this was a particularly emotionally difficult diagnostic session for the participant.

Additionally, the more similar a patient was to a participant, the more emotionally difficult was to reveal the diagnosis. However, there were also rewards from caring for patients with whom they could personally identify. The symbiotic relationship between the challenges and rewards of caring for patients similar to the physicians is outlined below in the ALS provider two-factor existential reward theory.

ALS provider two-factor existential reward theory.

At several points throughout the interview process participants noted that they were likely to identify with their patients due to a common factor. These common factors were generally a demographic similarity, such as age, gender, family composition, and career. For example, a subject who was male, 45 years old, and had three young children reported that he was highly likely to personally identify with another male patient the same age with young children. Individuals who discussed their experiences identifying with their patients reported that the initial communication of the diagnosis was especially difficult in these circumstances. In this study, 73% of participants noted that they struggled when revealing the diagnosis to a patient with whom they personally identified in some way. This is referred to as the *personal identification factor* and is the first factor of the ALS provider two-factor existential reward theory. Subjects experiencing this factor identified a feeling of sadness for the patients and their families. They see themselves in their patients and their families, and this personal identification made it difficult for them to reveal the diagnosis.

However, the physicians also noted a reward that arises from personally identifying with their patients. This reward, referred to as the *carpe diem perspective* by one participant, is a phenomenon that was mentioned explicitly by a subset of the participants (50%) when they were asked about the rewards and emotional reactions that they experienced when caring for patients with ALS and their caregivers. The carpe diem perspective is the second factor in the ALS provider two-factor existential reward theory. Carpe diem, translated as "seize the day," is a Latin aphorism from Horace's Odes. Physicians reported that caring for patients who are similar to them fostered an attitude of appreciation and gratitude for their lives. For example, one physician stated that it "makes me confront my own humanity and makes me more appreciative of life in a personal way and in a professional way." Another stated "One benefit of what I do, is that, um, it really promotes a carpe diem perspective in myself, which is a benefit. Um, most people go through the day-by-day being sort of expecting and entitled that every day is gonna be just fine and dandy, and have that expectation, uh, and maybe take every day for granted. I don't. You can't live in this world and not recognize . . . it all can come to a grinding halt tomorrow because every time you see an ALS patient, they're almost — literally, one week they're fine and the next week they can't open a jar top, and their life has changed and it's gonna change rapidly. And that can happen to me tomorrow. Or maybe not ALS. Maybe my wife finds a lump in her breast. Or maybe my kid runs his car into a telephone pole or something. Um, and it really, in some perverse way, it's helpful because it really makes you appreciate every day that you have that's a good day."

The carpe diem perspective of the ALS provider two-factor theory appears to be a reward for the participants due to its apparent ability to cultivate gratitude. Gratitude is related to psychological well-being across diverse populations (Bhullar, Surman, & Schutte, 2015; Lee, Tong, & Sim, 2015), including health care practitioners (Cheng, Tsui, & Lam, 2015). It appears that one of the rewards of treating patients with ALS is the gratitude and appreciation for life that arises from the reminder that individuals who are similar to you may not be as fortunate.

Physicians as healers.

Though not expressed explicitly, multiple participants noted the concept of physicians as healers. Some stated that it was important to be cognizant of the difference between communicating a fatal diagnosis and remembering that they are not a failure as a physician. The results revealed that many physicians struggled with the lack of a cure for ALS. Over half of participants (55%) used the term *frustrating* when discussing their experiences treating this disease. For example, one stated "It's frustrating in a sense because we don't have a defined — a definitive treatment for them." The healthcare system can also serve as an obstacle to treating patients with ALS. Another stated, "Sometimes it's frustrating when you're trying to get stuff done for patients, and for reasons due to the healthcare delivery system, things don't get done, or get done in a timely manner, particularly with ALS moving fast. That's frustrating." Similarly, a third stated, "There's a frustration in a deficiency of services, lack of time, there's frustration in patients, sometimes, who have a FTD picture and they're declining and you want them to have other services and they are refusing everything. That's kind of frustrating . . . There is frustration at the end that we can't do more." Although the

frustration experienced when treating patients with ALS can be due to the incurable nature of the disease, the lack of real-world resources and financial obstacles also contribute to physicians' frustration and sense of futility. However, frontotemporal dementia creates a unique set of challenges for physicians who care for patients with ALS and their caregivers.

Challenges of frontotemporal dementia.

Several participants (45%) noted the challenges of treating patients with ALS who also have frontotemporal dementia (FTD) and their caregivers. Subjects reported that the challenges of FTD are especially associated with a patient's difficulty in understanding the diagnosis and making informed and medically sound decisions. One physician described the difficulty in having a patient commit to a plan: "I think that the frontotemporal dementia that we see in a substantial portion of patients does make decision making very difficult. And a lot of waffling and sort of difficulty with maintaining a choice that's made. If I have a person who is sort of drifting into dementia and at some point they're, they're kind of — earlier said they're not one to be sustained on a ventilator, but then as death goes near, they kind of end up on a ventilator. Either maybe not really planned, but sort of more or less happens because it's not in my control. And then they're not quite competent to be taken off the ventilator, so then they're just maintained on a mechanical ventilator until something happens." Multiple participants noted that FTD often results in patients having to indefinitely use life-sustaining interventions against their wishes. Additionally, this illustrates the importance of developing advance directives.

Other patients have difficulty understanding the diagnosis and prognosis of ALS when they already have FTD. For example, one physician recounted an interaction in which the patient believed that if he did more push-ups, he would become stronger and cure his ALS. The subjects reported that it was difficult for them because the patients made medical decisions that the physicians deemed to not be in the patients' best interest. Therefore, a challenge in treating patients with ALS is balancing patient autonomy and deciding when to step in and guide the patients and their families.

Professional pride.

Many physicians described the concept of *professional pride* as a reward of caring for patients with ALS and their caregivers. Professional pride refers to the knowledge that they provided helpful treatments to their patients and that they did it well. As one participant stated, "There's sort of, there's some professional pride, I suppose. There's sort of a work well done. There's some satisfaction in that." Similarly, another reported, "So I guess really, probably the biggest reward, truthfully, is that I feel I do it well. I know that may be selfish, but I think that they encounter so many situations where people just don't know how to deal with them. So I think it's something that I worked 25 years for, and the staff worked a long time for, so I think we are able to take care of the patients well." In this way, subjects reported that professional pride was a function of both the knowledge that they were providing their patients with quality treatment and the knowledge that they were treating patients who other physicians may be reluctant or unable to treat.

Patient and caregiver gratitude.

The concept of gratitude was mentioned repeatedly. Several participants (45%) believed that expressions of gratitude and appreciation from the patient and their family were another positive experience that they encountered in their work. Much of this gratitude appears to result from the patient's and family's perception that their physician and the multidisciplinary clinic were with them for the journey, spoke to them in honest terms, and educated them about the disease, prognosis, and end-of-life expectations. Some physicians also mentioned that their patients appreciated receiving a definitive diagnosis, which is an unexpected reaction, given the prognosis. Research has found that it takes approximately 1 year from the onset of symptoms to diagnose a patient with ALS (Gordon, 2011; Iwasaki et al., 2001). This time frame was also reported by participants in the current study. They reported that some patients expressed gratitude for receiving a final diagnosis and developing a plan for care.

Additionally, some subjects stated that other physicians who referred their patients to multidisciplinary clinics were hesitant to reveal the diagnosis to the patient. Some participants surmised that this was due to reluctance to break the news because of the difficulty of the conversation and concerns about the patient's reaction. It appears that the referring physicians' personal discomfort impeded their ability to provide effective care. One participant stated, "And I've had examples of patients who have literally thanked me for telling them they have ALS because they have been in limbo so long, because people are either incapable or unwilling to confront the patient with the diagnosis." This particular physician went on to discuss his perception of the reasons for the long time it takes to reveal the diagnosis: "I'm sure you're aware of this, but the

average duration between symptoms onset and diagnosis is a year. There's no doubt that at least part of that is due to other physicians beating around the bush. I mean, it's very common for me to see a second opinion where it's clear from the doctor's note that the patient has ALS, yet they never told the patient."

Balancing hope versus reality.

The concept of hope was discussed by many subjects (64%) and was regarded as both a reward and a challenge. They reported that fostering hope in their patients and their caregivers was a reward for the physician. The concept of hope as a reward can be divided into two subgroups. First, participants noted the importance of discussing interventions and reiterating their support for the patient, and that their intention was for the patients to leave with a sense of hope for their future. In this context, hope was generally regarded as the patients' anticipation of their ability to enjoy the rest of their lives and live as fully and with as high a quality of life as possible. The second subgroup of hope is for a cure for ALS. In this group, clinical trials were considered a vehicle for hope, in that they help patients to believe that there is a possibility for a cure for themselves or others in the future.

Similarly, participants also noted that hope was a challenge in caring for patients with ALS and their caregivers. In particular, the concept of balancing hope versus reality in terms of clinical trials and the prognosis of the disease was a challenge. They believed that clinical trials can both cultivate and discourage hope; it was difficult to balance encouraging patients to maintain hope for themselves and for the future, but to also plan for the end of life. One physician stated, "I've seen so many clinical trials come and go and not fulfill their promise, and you want — clinical trials provide hope for patients, but

also false hope, and um, how you counsel them — you don't want to diminish that hope, and you do want them to be involved with clinical trials because how else are we ever gonna learn and find out? But you realize that you're — they're committing a whole lot of time and energy to participate in something that's highly unlikely ever to help them, other than from the satisfaction that they've gained that they at least tried . . . That's a difficult subject to be truthful about without, um, being too negative with a group of people that you need to stay as positive as you possibly can."

Like the concept of hope, there are also both challenges and rewards in caring for patients' caregivers and families.

Challenges of caregivers and families.

Participants discussed the challenges related to including caregivers and families in the care of the patient. Caregivers and families, referred to simply as *caregivers* for the purpose of this discussion, can provide support for the patient and contribute to the patient's well-being or can create barriers to optimal patient care. As one physician stated, "So when you have a dysfunctional family and you throw them into this? Everything just gets amplified, and you're trying to help them out, but you realize that if they had come in before the disease, they needed help then too . . . At the end of the day, often times they'll come back in 3 months and it's the same story again. Just nothing seems to have happened or, you know, that's very frustrating . . . ." The results revealed that inadequate care is a function of multiple causes, such as a lack of understanding by the family or dysfunction among caregivers, lack of time, and lack of resources, such as money, insurance, or appropriate housing or facilities.

A second challenge of caring for caregivers was balancing the needs of the patients and their caregivers. Several physicians noted that caregivers typically would like more information in the diagnostic sessions than the patient and that it was difficult to balance these sessions with providing a level of information that is best for the patient. Participants repeatedly noted that patients reach a point in the diagnostic sessions at which they are no longer able to retain information because they are overwhelmed by the shock of the diagnosis. Subjects noted that it was important to use both verbal communication and observation of the patients' nonverbal communication to determine the pace of the sessions and the amount of information to share with the patients and their caregivers, especially in the diagnostic session.

Coping.

There were multiple ways in which physicians coped with the emotional challenges of caring for patients with ALS and their caregivers. There was a bimodal distribution of the two most reported methods for coping. The first was the use of the participants' multidisciplinary clinic team or colleagues who treat patients with ALS at other clinics (45%). Subjects used their clinic teams to vent frustrations and share their decisions regarding patient care for validation or new ideas. Similarly, they reported that they used humor at the clinic team meetings. No participant elaborated on what it meant to use humor and what that entailed. These coping methods are consistent with a previous study on ALS care providers (Bromberg et al., 2011). Additionally, subjects reported that they spoke with other physicians in the same field at ALS academic meetings and conferences.

The second most frequently reported method of coping was to compartmentalize (45%). Participants reported that it was important to separate their experiences at work from their home lives. For some, compartmentalizing simply meant to avoid thinking about work in nonwork settings. For example, one physician stated, "I guess the way I cope is that I don't think about it when I'm not at work." Others described how they compartmentalized their feelings and emotions related to work. For example, one subject discussed how he compartmentalized his emotions after his patient deaths. "I don't go to funerals, it's kind of like my line. I can be sad with the patient and the family all the way to their death, but I just can't go to a funeral a week. And I just can't be in a situation where I'm trying to decide 'Well, whose funeral do I go to and whose don't I go to?' It's just too much for me. . . . I can't be sad for years for everyone who dies because I just can't do that. So for me, I just kind of draw the line, which is I help them all the way through that point and then I kind of have to separate a little bit emotionally because obviously I wouldn't be able to survive if I did that." Many physicians noted that they believed that it would be impossible for them to stay in their career without using compartmentalization as a method to cope.

Some participants reported the use of alcohol as a means to cope with the emotional challenges, though reports were infrequent. One subject reported that he drank alcohol as a way to delineate the end of his work day and the beginning of his home life after work. In this way, alcohol appears to be a stimulus to foster compartmentalization. For example, this participant stated, "And I've certainly said 'Well, tonight is the night that I need to go home and have a beer.' Um, and certainly have felt like I've used that as

a coping mechanism. Not in any, uh, dangerous way, or, but you know, to try to just kind of switch from being at work to not being at work."

Finally, a small number of subjects reported using family to cope. Two participants reported that they talked to their spouses, and two reported that they spent time with their children to cope. The physician who stated that he used alcohol to help him transition between work and home also noted, "There's kind of the joke that tonight's the night to go hug the kids. But, you know, I think maybe family time and spending — trying to be more in the moment with family can be therapeutic."

Communication training.

The results revealed that every study participant learned to communicate the diagnosis, prognosis, and need for end-of-life decisions by observing attending physicians and other mentors while they were in training. This observation usually occurred in residency or fellowship, but occasionally included medical school. Most had a positive orientation toward observation and believed that it is the best way to learn these skills.

Participants overall believed that additional training or a formal course in communication during their education would have been helpful at the graduate school level, but they generally did not believe that they required any further training at this time in their careers. One subject believed that additional training in this area would still be helpful. Similarly, only one participant reported that he received formal training in breaking bad news and empathy at the institution at which he was working. This physician believed that these training experiences are useful, and he used them as an opportunity to receive feedback from his colleagues.

Participants also learned to communicate with patients "on the fly," as one referred to it. That is, they learned to communicate by trial and error while treating patients. Many spoke of using nonverbal and verbal feedback from patients to tailor their approach to communicating the diagnosis, prognosis, and need for end-of-life decisions. This feedback helped the physicians to understand when it was best to provide information, pause, provide comfort, or end the conversation and schedule another visit to continue to provide information and make plans or coordinate resources. Participants stated that patients varied in their acceptance of and coping with the disease, and some patients prefer to receive information upfront versus other patients who would benefit from receiving it in multiple visits. Many noted that it was important to tailor their visits with each patient and to be mindful of the patient's needs. This skill was learned from years of experience through practicing medicine.

Resources for coping.

Participants believed their peers in the same subspecialty or similar subspecialties were a resource for coping. Over half (64%) reported that they spoke with their colleagues and believed that camaraderie was useful. Many reported that they spoke with their multidisciplinary clinic team after clinic meetings, and during this time, they discussed patient cases, feelings toward patients, and frustrations.

Although some subjects (27%) reported that they were unsure of the resources available, most reported that they were aware of institutional resources available to them through their place of employment (e.g., ombudsmen, employee assistance programs). However, most stated that they did not believe that they needed these resources at this time or would use them in the future if the need arose.

Some subjects mentioned that they would access psychological help if they felt that they needed a resource to help them cope with the emotional experience of caring for patients with ALS and their caregivers. However, they believed that psychological services were not necessary for them.

Very few participants were likely to speak to a spouse/partner or social support about the emotional experiences that had related to work. However, the two physicians who reported that they would speak to a spouse had spouses employed the medical field. It is unclear from the data why subjects were generally reticent to discuss work with their spouses/partners or social supports. It could be due to the belief that compartmentalizing was the most effective method of coping, and compartmentalizing included not discussing work at home or in social settings.

Burnout.

Of the three participants (27%) who admitted that they were experiencing burnout at the time of their interviews, one reported that it was solely due to institutional demands. This subject discussed the bureaucracy that caused stress for him, such as insurance companies, assessments from the hospital administration, and required trainings that he believed detracted from his time and ability to provide the best care for his patients. The other two subjects reported that burnout was caused by both the emotional demands of caring for patients with ALS and their caregivers and to other work-related factors, such as being understaffed. Interestingly, these two participants volunteered information about the deaths of their parents. They mentioned that they were better able to identify with and care for patients and their caregivers due to their own experiences with loss. One reported that his choice to enter this specialty was partly

influenced by the death of his parents. One of this participant's parents died from a chronic illness, and the perceived lack of resources at the end of life made him decide to care for patients with ALS, rather than another field in which he would not frequently confront death.

Similarly, the other subject who reported burnout discussed the death of her parent, who also died from a chronic illness. She reported that her experience with her parent's illness led her to realize the difficulty that her patients and their caregivers experience at the end of life, and this helped her to better identify with her patients' caregivers. This participant repeatedly emphasized her ability to empathize with her patients and their caregivers, and she reported that she tried to cope with the emotional experience of caring for patients with ALS and their caregivers by putting herself in their shoes.

The physicians who reported that they were experiencing burnout due to caring for patients with ALS were two of the youngest participants and worked fewer years with ALS patients than those who did not report burnout. This is consistent with other studies in which physicians could experience burnout at any stage in their career (Dyrbye et al., 2009; Peisah et al., 2009; Ramirez et al., 1995). Additionally, the results are congruent with those of past studies in which more experienced physicians appeared to develop more effective coping strategies (Peisah et al., 2009). Though the results of the present study are limited by the small sample size and an even smaller number of people who admitted to feelings of burnout, death of a parent from a chronic illness may be correlated with burnout. This may result from a reactivation or reexperiencing of grief.

ALS provider grief and burnout.

As previously stated, the two participants who admitted burnout and discussed the death of a parent reported that this loss helped them to better identify with patients and their caregivers. These physicians volunteered information about their losses and how this has affected their interactions with patients and their caregivers; the semistructured interview did not elicit this information. They reported that they were unable to provide the best care for their patients because of a lack of resources (i.e., staff) at their clinics. Both participants reported that clinic staff were overextended because they were understaffed, and this led to physical and emotional exhaustion at the end of clinic days.

In addition to parent death and lack of clinic resources, both participants also verbalized a sense of responsibility and taking on the burden of the patient's disease. As one stated, "I think it's hard for me because I know that I'm kind of setting a contract with them, in a way, saying that, you know, I'll be there for you, you know, whether it be emotionally, or medically, and just knowing that I'm kind of taking on that burden. And I guess in a way I'm just trying to take the burden from the patient and the caretaker and putting it on myself. And, um, carrying that burden, it's very hard for me."

ALS provider grief and resource theory.

The participants who mentioned a parent's death and a lack of clinic resources reported more diffuse boundaries between themselves and their patients. These subjects reported feeling a higher degree of personal responsibility for their patients than other participants in this study. They explicitly reported that their history of loss increased their ability to feel empathy for patients and their families. Unfortunately, this personal responsibility and empathy did not appear to be adaptive, due to their reports of distress,

and instead may negatively impact their ability to provide care for their patients. One participant noted that she had to transfer some of her patients to other members of the treatment team. She stated "my emotional attachment has gotten too intense, and I'm — it's not good for me to see them anymore. So I've tried to put a wall up a little bit like that."

The connection between parental death, a lack of clinic resources, and feelings of personal responsibility are connected through the ALS provider grief and resource theory. This theory, developed from the data, is partly based on Sanders's integrative theory of bereavement. Sanders's theory, as described earlier, asserts that there are five phases of bereavement: shock, awareness of loss, conservation−withdrawal, healing, and renewal. The participants' personal experiences with death, coupled with continuous exposure to death and the limited resources and supports at work could contribute to burnout. This may be due to reexperiencing their personal losses through their patients. Previous research supports the notion that continuous exposure to death at work with a limited time to grieve results in burnout (Dougherty et al., 2009). A lack of clinic resources may be a moderator for physician burnout that is related to their own grief. Subjects who experienced personal losses may have been susceptible to burnout because they frequently confronted death in their care for their patients. However, the lack of clinic resources that led to overwork, taking work home, limited time for patients, and believing that they were not able to provide the best possible care appears to foster burnout. It is surmised that the interplay between the lack of clinic resources and previous personal losses leads to physician burnout. This is the basis of the ALS provider grief and resource theory.

Participants in this study who reported burnout due to the emotional impact of treating patients with ALS may be stalled in the third phase of Sanders's theory, conservation−withdrawal. Individuals in the conservation−withdrawal phase experience withdrawal, despair, diminished social support, and helplessness, along with physiological and psychological symptoms such as weakness, fatigue, the need for more sleep, weakened immune system, hibernation, obsessional review, grief work, and a turning point (Sanders, 1999). They may be stalled in phase 3 as a result of constantly reliving their losses through their care for ALS patients and their caregivers and having limited supports at work or the ability to take time to process their grief for their patients. They also reported feeling both emotionally and physically exhausted, which is consistent with the conservation−withdrawal phase of Sanders's theory.

Although most participants did not believe that were experiencing burnout, they did offer their conceptualizations of what burnout meant to them.

The concept of burnout.

Most participants (64%) believed that neurologists who treat patients with ALS are at risk for burnout. Three subjects (27%) reported that they did not believe that neurologists in this field are likely to burn out, and one (9%) reported that neurologists may be at risk. As previously noted, three physicians were experiencing burnout. The remaining participants either denied burnout or reported that they had difficult days, but that these days were isolated occurrences. In this way, the subjects conceptualized burnout as a chronic experience that extends beyond days of acute stress.

Though the participants offered multiple definitions of burnout, there was a trimodal distribution of conceptualization of burnout. When subjects were asked what

burnout meant to them, 45% reported that it would mean that they would change to a different field in medicine and end their work with patients with ALS or would leave medicine altogether. This was also mentioned as a way that physicians would cope with burnout. Several subjects (36%) reported that they believed burnout would include a loss of empathy for their patients. Finally, more than half (55%) reported that burnout would include emotional fatigue.

Maslach's three-factor structure of burnout includes emotional exhaustion, or feelings of being "over-extended or depleted of one's emotional resources," depersonalization, or "a negative, indifferent, or overly detached attitude to others", and reduced personal accomplishment, or "a decline of feelings of competence and successful achievement in one's work" (Taris, Schreurs, & Schaufeli, 1999, p. 223). Although none of the participants stated that burnout includes all of these factors, many mentioned aspects of the Maslach three-factor structure. Though not explicitly stated, changing to a different field in medicine or leaving medicine may be considered reduced personal accomplishment in the three-factor structure. Others either explicitly or implicitly reported depersonalization. For example, two participants used the colloquialism "going through the motions" to describe how they would know that they were burned out. Finally, several subjects also described emotional exhaustion and reported that they occasionally felt emotionally exhausted after a particularly difficult day. However, this temporary depletion was typically limited to a brief period (1 day).

The results revealed that the most frequently reported method of coping with future professional burnout would be to leave their career (27%) or similarly, change from direct care (9%) or decrease their hours at work (9%). Other reported methods of

coping with burnout were to seek treatment from a mental health professional (18%) or seek consultation from their professional mentors (18%). Others reported that they used alcohol, "shut down" for the night after work, used exercise and sports, used optimism (adopt a "glass-half-full" mentality), asked for feedback from others, and simply decided to not think about work to cope with burnout or tough days.

Interestingly, the participants who reported that they were experiencing burnout described the least concrete methods of coping or admitted that they were simply not dealing with it at the time. Given the limited utilization of concrete coping strategies, it appears that these physicians could benefit from social problem solving.

Social problem solving is the act of solving real-world problems in the natural environment and is based on the social problem solving theory of coping, initially developed by D'Zurilla and Goldfried (1971) and later revised by D'Zurilla, Nezu, and Maydeu-Olivares (2004). The word *social* indicates that that these real-world problems affect an individual's functioning in a social environment. Social problem solving states that the connection between problem solving and an individual's adjustment lies in his or her problem-solving abilities. These abilities act as moderators and mediators between the individual's problems and his or her adjustment and mental health (Bell & D'Zurilla, 2009). In social problem solving theory, life stressors can either be major negative events (death, divorce) or daily problems (car trouble, disagreements). Social problem solving states that the major negative events and daily problems influence each other, and these stressors have a direct impact on an individual's well-being that can be moderated or mediated by problem-solving coping (Bell & D'Zurilla, 2009). Problem-solving is defined as a "self-directed cognitive-behavioral process by which an individual, couple,

or group attempts to identify or discover effective solutions for specific problems encountered in everyday living" (D'Zurilla et al., 2004, p. 12).

Social problem solving theory is relevant to the participants in this study, as there are multiple real-world stressors that must be navigated to achieve well-being and to decrease the likelihood of burnout. These physicians could benefit from learning to identify and test their solutions to help them better cope with burnout and alter their work environments, rather than completely leaving their specialty, changing from direct patient care, or leaving medicine altogether. Utilization of better coping strategies can positively impact both the physicians and their patients, as there are established repercussions of burnout on patient care (Bellini, Baime, & Shea, 2002; Brazeau, Schroeder, Rovi, & Boyd, 2010; Shanafelt, Bradley, Wipf, & Back, 2002; Shanafelt & Dyrbye, 2012; Williams, Manwell, Konrad, & Linzer, 2007).

Limitations.

There are limitations of this study. First, the data obtained was limited to answers to the questions asked by the researcher. The information sought in this study was largely based on previous studies of oncologists. There may be unexplored constructs and "blind spots" that are pertinent to the experiences of neurologists who treat patients with ALS.

Though theoretical saturation was reached for this study and the sample size is similar to that of other qualitative studies (n = 11), the sample was relatively homogeneous. Most participants were men (91%) in their 40s (55%). Therefore, the generalizability of the results is limited. The results of this study may not be representative of the experiences of all neurologists who treat patients with ALS.

This study may be biased in a variety of ways. Sampling bias may have occurred because neurologists who agreed to participate in this study may have factors or personality attributes that differentiate them from those who chose not to participate. Therefore, there may be a common feature that the subjects have that makes it difficult to generalize to other ALS providers or physicians. This could include altruism, strong positive or negative feelings about caring for their patients, a lighter workload, or more time to dedicate to participating in research. These individuals could have used better coping strategies or experienced less stress than their nonparticipating counterparts. Conversely, they may have been so devoted to their work that they spent more of their free time engaged in work-related activities than others. Additionally, the participants in this study were generally leaders in their fields who were committed to research, as we initially contacted NEALS members. This factor may also skew the data.

As with any qualitative study, there may be biases in the way that the data was coded and the themes were identified. Though the data was triangulated among coders, the coders in this study were trained within the same theoretical orientation (cognitive behavioral), and this may have skewed the coding process.

Replication of the study.

If other researchers were to replicate this study, there are some changes that may be beneficial. First, in an ideal study, qualitative interviews would be conducted face-to-face rather than via telephone. This would allow researchers to observe the participants' nonverbal communication. Additionally, face-to-face interviews may help improve rapport during the interview process and could encourage more in-depth responses from the subjects.

Future studies would benefit from gathering a more heterogeneous sample. Participants could be recruited via additional sources. To increase the generalizability of this study, subjects should include neurologists who do not work within a multidisciplinary clinic or engage in research, and more women should be recruited.

Implications.

One implication of this study is providing support for neurologists and other physicians who treat patients with terminal illnesses. The participants enlisted colleagues in their multidisciplinary clinics and at other sites for coping and support. Similarly, Balint groups provide a forum for physicians to express and process their emotions related to the stressors of work. These groups are composed of physicians and are moderated by a psychologist and a physician. Balint groups have been shown to increase medical students' empathic abilities (Airagnes et al., 2014), prevent burnout and improve job satisfaction (Kjeldmand & Holmstrom, 2008), and improve therapeutic communication skills (Bar-Sela, Lulav-Grinwald, & Mitnik, 2012).

Neurologists and others who care for patients with terminal illnesses may benefit from increased training in communication, communicating bad news, discussing difficult topics, and matters related to bedside manner. The subjects in this study believed that this training would be helpful during medical school or in their graduate medical education. Neurologists who treat patients with ALS need advanced communication skills due to the unique aspects of caring for patients with chronic and terminal illnesses. A review of the literature indicated that there is no previous research regarding communication skills training for neurologists. However, Bylund et al. (2010) reviewed the Comskil Training Curriculum, a communication skills training program for oncology

fellows. This program addresses 26 communication skills necessary for oncologists' patient care, which is congruent with the skills for neurologists who care for patients with ALS. The Comskil Training Curriculum consists of didactics, demonstration videos, and role play and includes the following modules: breaking bad news, shared decision making about treatment options (including clinical trials), responding to patient anger, discussing prognosis, discussing the transition from curative to palliative care, and discussing DNR [do not resuscitate] orders. Bylund (2010) et al. found that their oncology fellows increased their use of multiple communication skills, with no increase in time spent in consultations. This training curriculum may be useful for neurologists who treat patients with ALS. Many of the topics addressed in the Comskil Training Curriculum were noted in the data as areas that present challenges or discomfort for the participants (e.g., patient and caregiver anger, revealing the diagnosis). Improved training in communication skills may help increase the confidence levels of less-experienced physicians and could mediate stress related to difficult clinical tasks, such as breaking bad news.

Physicians may also benefit from training in problem-solving and coping strategies for work-related stress and burnout. There is currently no standardized training for medical students in these areas. Many of the participants in this study reported that they would either leave medicine or their specialty if they experienced burnout, and some noted that they had already decreased their time in direct patient care or transferred patients to another neurologist due to issues related to burnout. Neurologists may benefit from learning problem-solving skills to help them generate and utilize alternative coping skills to decrease the likelihood of burnout. Although there is no literature regarding the

use of social problem solving with neurologists or other physicians to address burnout, there is considerable support for its use in other populations, including caregivers of individuals with ALS (Murphy, Felgoise, Walsh, & Simmons, 2009). Social problem solving can help neurologists identify coping strategies or lifestyle changes to use to decrease burnout symptoms and avoid leaving their specialty or the field of medicine, thus improving patient care and physician quality of life.

Future directions.

There are several future directions for research in neurologists who treat patients with ALS. Future researchers may choose to utilize the information obtained in the present study to construct an objective self-report questionnaire to gather information from a larger sample of neurologists. Some particular themes of interest include neurologists and burnout, grief related to patients' deaths, and the experience of communication the diagnosis to a patient.

Second, this study analyzed the work-related experiences of those who treat patients with ALS. Future research may focus on other aspects of neurologists who choose to care for patients with ALS and other terminal illnesses. For example, studying personality characteristics and strengths of successful neurologists who are content in their work with ALS patients may help medical students and residents to decide if this specialty is appropriate for them. Helping physicians to find their best match for specialization can lead to less burnout, less physician turnover, and better patient care.

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Appendix A

Recruitment letter.

November 23, 2015

Dear Dr. ,

I am a student at the Philadelphia College of Osteopathic Medicine and I am conducting a research study to partially fulfill requirements for a Psy.D. in Clinical Psychology. This research study, "Neurologists' emotional experiences in caring for individuals with Amyotrophic Lateral Sclerosis: An exploratory study", will be conducted under the supervision of Stephanie H. Felgoise, Ph.D., A.B.P.P., and Zachary Simmons, M.D. This study is approved by PCOM's institutional review board.

Neurologists with expertise in treating ALS are needed. This study aims to learn how neurologists cope with death and dying so that attention may be given to these topics in medical training and for in-practice professionals. Participation requires a 45-60 minute telephone interview. All participants' identifying information will remain confidential and responses will be de-identified. In addition to your participation, I would greatly appreciate if you would pass this information to colleagues who may also choose to participate.

Interested participants can reply to ashleypax@pcom.edu to learn more or make arrangements for participation. Informed consent paperwork is attached to this e-mail. If you choose to participate, this completed document can be scanned and e-mailed to ashleypax@pcom.edu, faxed to 215-871-6458, or returned via mail if you prefer.

Thank you for your time and consideration.

Sincerely,

Ashley Hennessey, M.S., Predoctoral Candidate

Recruitment e-mail.

Dear Dr. ,

As you may know, I have a longstanding interest in quality of life (QOL) in ALS patients. What has been far less studied is the emotional challenge neurologists face in providing care for these terminally-ill patients, and the coping mechanisms they utilize to do so. I would greatly appreciate it if you would read the attached information about a study we are doing to address these important issues, and if you would consider participating in this study. I believe the information gained will be of great value to those of us who care for these patients, and ultimately will benefit the patients themselves and their caregivers.

Sincerely,

Zachary Simmons, MD

Professor of Neurology and Humanities

Director, Neuromuscular Program & ALS Center

Penn State Hershey Medical Center

Appendix B

Demographics questionnaire.

1. Age
2. Year of graduation from medical school
3. Type of degree (MD/DO)
4. Year of completion of residency
    a. Additional specialized training beyond neurology in motor neuron diseases (fellowships)
    b. Type and year of completion
5. Number of years spent caring for patients as a significant part of your practice
6. Percent of time spent in direct care to patients with ALS
7. Approximate number of treated patients with ALS in your current practice
8. Work in a group or independent practice
9. Affiliated with a university-based hospital (yes/no)
10. Participation in research related to ALS
    a. Clinical trial/research
    b. Basic science research

Appendix C

Semistructured Interview Questions:

1. What is it like to care for patients with ALS and their caregivers? What is this experience like for you/please tell me your thoughts and feelings related to it.
2. What rewards do you perceive are associated with treating patients with ALS and their caregivers?
3. Tell me about the emotional reactions you experience when working with your patients with ALS and their caregivers.
4. What are the greatest challenges that you encounter when working with patients with ALS and their caregivers?
5. How do you cope with the emotional challenges of working with patients with ALS and their caregivers? How do you cope with or address your emotional reactions to working with patients with ALS and their caregivers?
6. What resources do you believe are available to you to help you cope with the emotional challenges of treating patients with ALS and their caregivers? What do you wish was available to you?
7. What communication training or other training experiences related to relaying bad news and coping with the emotional challenges of caring for patients have you had that especially prepared you for treating patients with ALS at their end-of-life and their caregivers? What do you wish you had? How have you learned to communicate the diagnosis, prognosis, and need for end of life decisions with your patients? Tell me what these conversations are like for you.

8. Do you think professionals in this field are likely to experience burnout? What does burnout mean to you? Have you ever experienced burnout? If not, how would you know if you had it? How did you/would you deal with it?