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Philadelphia College of Osteopathic Medicine

Department of Psychology

SOCIAL PROBLEM SOLVING AND FACTORS THAT CONTRIBUTE TO THE
CONSIDERATION OF HASTENED DEATH AMONG ALS PATIENTS

By Kristen Labin Bekelja

Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

June 2011

**PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by Kristen Labin Bekelja
on the 21st day of June, 2011, 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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ABSTRACT

The purpose of this study was to examine social problem-solving characteristics and other factors that contribute to the desire to hasten death among ALS patients. Participants completed six measures including: the ALS Functional Rating Scale-Revised, two item Hopelessness Scale, Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Scale, ALS Specific Quality of Life Instrument-Revised, Social Problem-Solving Inventory-Revised, and the Schedule of Attitudes Toward Hastened Death. Data gathered was analyzed, using hierarchical multiple regressions, and a Pearson product-moment correlation. Results revealed that the factors of hopelessness, global quality of life, bulbar function, and negative emotion significantly predicted the desire to hasten death among ALS patients. Problem solving characteristics were not found to be related to the desire to hasten death.

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CHAPTER 1

Statement of the Problem

Amyotrophic lateral sclerosis is a terminal illness. The progressive, degenerative, and unpredictable nature of ALS forces patients and their families to face a barrage of painful emotional and physical situations. Each medical appointment brings with it more news of the patient's deteriorating condition, and uncertainty for the future. As patients lose physical function, they may mourn the loss of their independence and express concerns about being a burden to their caregivers (McCluskey, 2007). Because of physical losses, patients with ALS may experience increased feelings of hopelessness over time due to increasing disability (McCluskey, 2007). Because there is no known cure for ALS, and the course and progression of this disease can be highly unpredictable, it is best that discussions and decisions about end-of-life practices begin upon diagnosis (McCluskey, 2007).

The average life expectancy after diagnosis of ALS is two to five years (Houseman, 2008). The main objective of ALS treatment is to afford individuals the opportunity to live the remainder of their lives in the most comfortable manner possible. As the disease progresses, this task becomes increasingly more difficult. Respiratory failure is the most common cause of death in individuals with ALS. Therefore, many patients with ALS hold significant worries about this process and cite fear of choking, and suffocation as reasons they would consider hastening death (Maessen, Veldink, Onwuteaka-Philipsen, de Vries, Wokke, van der Wal, & van den Berg, 2009).

The wish to hasten death or to request physician-assisted suicide among ALS patients raises many legal and ethical concerns. The topic of physician-assisted suicide can bring about strong emotions for all parties involved in the conversation. For this reason, it is important that

physicians be aware of their feelings toward this topic and of their possible reactions to it. If a physician reacts in a negative manner, or the patient perceives the physician's reaction to be negative, this could jeopardize the patient's care and cause the patient to be reluctant in talking about other issues (Bascom, & Tolle, 2002). The topic of physician-assisted suicide, if brought up by the patient, is an important area to explore. Often times, when the topic is explored, there is an uncovering of other aspects of the patient's condition that can be addressed without having to undergo a hastened death or physician assisted suicide (Baumrucker, 2006). For example, if a patient expresses a lack of meaning in life, these thoughts can be explored to assist the patient in finding other areas of life where he or she may be able to feel a renewed sense of meaning, and thus dispel the desire to die.

Exploring factors and problem-solving patterns that contribute to the desire for a hastened death is an important area of study. A better understanding of the psychological experience of individuals with ALS as they near end-of-life can be obtained by uncovering the factors and problem-solving patterns that contribute to a desire for a hastened death. Understanding the characteristics that may influence a person to consider hastened death will allow healthcare professionals to explore these wishes with the patient, examine his or her problem-solving orientation, and uncover any other concerns that may be leading to the desire for this procedure.

Purpose of the Study

The purpose of the present study is to determine the factors and problem-solving patterns that would lead to the consideration of hastened death among individuals with ALS. This study will examine not only the functional abilities, quality of life, hopelessness, spirituality, and social problem-solving skills of the patient, but also how these factors impact the desire to hasten death. By examining the social problem-solving skills and other characteristics associated with the

desire for a hastened death, healthcare professionals will be able to determine which experiences of the patient influence the desire to die and determine those areas of intervention designed to address this desire. It is thought that if healthcare providers are able to address the factors that influence the desire to die, then fewer individuals with ALS would express this desire.

Relevance of Study

This study is relevant to the fields of neurology and psychology. In examining the factors and social problem-solving patterns that contribute to the consideration of hastened death, healthcare providers will be better able to understand the experience of ALS patients. The ability to better understand the experiences of individuals with ALS may allow healthcare providers to utilize strategies that will increase the quality of life and encourage a sense of meaning for ALS patients at the end of life. The ability to discuss the wish to die with ALS patients may cultivate a greater sense of control and meaning in life as patients near death.

Chapter 2

Amyotrophic Lateral Sclerosis

What is ALS?

Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular disorder characterized by the degeneration of the upper and lower motor neurons (Houseman, 2008). ALS produces weakness, atrophy, and spasticity in all voluntary muscles beginning segmentally, and then progressing to encompass the entire body, and eventually cause respiratory failure (Lomen-Hoerth, Murphy, Langmore, Kramer, Olney, & Miller, 2003). The most common type of onset in ALS, which accounts for approximately sixty to eighty percent of patients, involves unexplained weakness in a limb (Mitsumoto & Rabkin, 2007). Onset can also occur in the swallowing and speaking muscles, which is known as bulbar ALS. Some individuals develop initial symptoms of ALS in their respiratory muscles. These individuals tend to have the poorest prognosis in regard to life expectancy (Houseman, 2008).

Prognosis, incidence, and prevalence.

The cause and pathogenesis of ALS is unknown, and there is no known cure (Mitsumoto & Rabkin, 2007). The average life expectancy following a diagnosis of ALS is two to five years. The manner in which the disease progresses, however, is unpredictable with approximately ten percent of individuals surviving ten years or longer (Houseman, 2008). ALS symptoms can appear in individuals between the ages of twenty and ninety years; however, the incidence is highest among those forty to seventy years old (Houseman, 2008). ALS affects approximately 0.2 to 2.4 individuals per 100,000, with white men being the most frequently affected (Mitsumoto & Rabkin, 2007).

Diagnosis.

Diagnosis of ALS during the early stages of onset can be difficult, because up to eighty percent of motor neurons can be lost before the first clinical symptom appears (Mitsumoto & Rabkin, 2007). Individuals with ALS are often diagnosed approximately nine to eleven months after symptom onset (Mitsumoto & Rabkin, 2007). Diagnosis of ALS requires symptoms to be present in more than one of four body regions involving both upper and lower motor neuronal degeneration and progressive spreading of motor loss within or between body regions (Mitsumoto & Rabkin, 2007). There is no specific diagnostic test for ALS (Mitsumoto & Rabkin, 2007).

TREATMENT

Because of the terminal nature of ALS, interventions for this disease focus mainly on symptom management (Houseman, 2008). Common symptoms associated with ALS include: respiratory insufficiency, fatigue, difficulties with mobility, pain, dysarthria, dysphagia, problems with secretions, involuntary emotion expression disorder, depression, insomnia, and constipation (Houseman, 2008). The only approved medication treatment for ALS at this time is riluzole, which is often prescribed in a fifty milligram dose and taken orally, twice daily. This medication has been shown to hinder the onset of respiratory failure and ventilator dependence, and extend survival by about two months (Mitsumoto & Rabkin, 2007). The symptoms of respiratory insufficiency and dysphagia pose significant difficulties for patients because these symptoms interfere with the ability to deliver oxygen and nutrition to the body (Mitsumoto & Rabkin, 2007). Because of the debilitating and progressive nature of ALS, decisions about the preferred treatments of the individual must begin at diagnosis (Houseman, 2008).

Life-sustaining treatments.

The interventions aimed at treating the symptoms of respiratory insufficiency and dysphagias have the potential to prolong life in individuals with ALS. The main cause of death in ALS is respiratory failure (Lomen-Hoerth, et al. 2003). Additionally, weight loss due to the inability to chew and swallow is associated with decreased respiratory capacity and briefer survival (Mitsumoto & Rabkin, 2007). The interventions to treat the symptoms of respiratory insufficiency and dysphagia, however, can be invasive and pose further risks to an individual's health such as infection or diminished quality of life (Mitsumoto & Rabkin, 2007).

Treatment of respiratory insufficiency.

In order to manage symptoms of respiratory insufficiency, individuals with ALS must decide upon the level of intervention they feel comfortable with, and also make decisions about utilizing further interventions as their disease progresses. Most ALS patients develop hypoventilation which results in increased levels of carbon dioxide and the symptoms of morning headaches, poor quality of sleep, restlessness, and nightmares (Baumrucker, 2006). Often, the primary treatment for respiratory insufficiency is bilevel positive airway pressure, or BiPAP (Mitsumoto & Rabkin, 2007). BiPAP is a non-invasive intervention which provides varying pressures of air to the patient via a mask, and essentially assists the weakened respiratory muscles in performing inhalation and exhalation (Houseman, 2008). The use of noninvasive, positive pressure ventilation by mouth can help the patient avoid a tracheotomy and continue to maintain a reasonable quality of life.

Eventually, however, respiratory capacity begins to fail regardless of the assistance that the individual receives from BiPAP. When this happens, patients and families are forced to consider the utilization of long-term mechanical ventilation (LTMV); this is an invasive

procedure in which a tracheotomy is performed in order to allow respiration to be controlled mechanically (Mitsumoto & Rabkin, 2007). Undergoing a tracheotomy can assist in respiratory function and postpone death; however, it has not been found necessarily to increase quality of life (Baumrucker, 2006). The decision to undergo LTMV should be considered prior to the point in the disease progression when an individual would require it (McCluskey, 2007).

The request to receive LTMV indicates the desire to prolong life. It is imperative that patients delineate advance directives with regard to terminating LMTV before they undergo this intervention. Patients with LTMV can reach a “locked in” state, and be unable to express their desires clearly. Further, if patients are able to express their desires, it is difficult to determine the cognitive capacity of patients in this state. The inability to communicate desires and the uncertainty of cognitive ability on the part of the patient can lead to ethical dilemmas for the physician if advance directives are not in place before the implementation of LTMV (Couillard, & Brownell, 2009). Although it is clear that those patients who decide to receive LTMV do so to prolong life, it is unclear whether or not the desire to hasten death may develop as the disease progresses and patients reach a “locked in” state.

Treatment of dysphagia.

Dysphagia can also pose major difficulties for individuals with ALS because they may experience trouble in chewing and swallowing. This difficulty with chewing and swallowing can lead to a decrease in nutrient intake as well as in weight loss (Houseman, 2008). The placement of a percutaneous endoscopic gastrostomy (PEG), or feeding tube, can assist individuals in obtaining the necessary nutrition to maintain a healthy weight and increase their survival. Individuals with PEG can continue to consume foods orally; however, this process can be time

consuming and laborious so the PEG can assist in delivering the proper level of nutrition (Houseman, 2008).

Decision-making processes and treatment.

Because of the progressive and unpredictable nature of ALS, patients and their families are constantly being faced with the uncertainty of continual loss (McCluskey, 2007). The deterioration of function associated with ALS forces patients and their families to embark on a journey of constant coping with change and adaptation. The patient is challenged with grief at each loss that decreases his or her independence and autonomy (McCluskey, 2007).

Information and the potential decisions that the individual will be faced with in regard to treatment should begin upon diagnosis. It is important that physicians relaying this information ensure the patients and their families that there are interventions to address virtually all of the symptoms of ALS, and that there is an abundance of information available to aid in the decision-making processes (Mitsumoto & Rabkin, 2007).

It has been found that the lack of or the insufficient amount of information with regard to available interventions can lead patients to feel hopeless, believing that there are limited options. This feeling of hopelessness may subsequently cause individuals to increase their desire to die and hasten death (Kelly, Burnett, Pelusi, Badger, Varghese, & Roberson, 2003). By increasing patients' knowledge of medical interventions available, an increase in the sense of security and control and a decrease in levels of hopelessness may result (Kelly, Burnett, Pelusi, Badger, Varghese, & Roberson, 2003).

Ongoing change and adaptation in decision making.

The decision making processes involved with ALS include making choices about utilizing mechanical interventions to sustain life, or forgoing these interventions to allow the

natural progression of the disease to end life (King, Duke, & O'Connor, 2009). It has been found that individuals with ALS continuously live with uncertainty, and they cycle through the cognitive processes of perceiving change, reacting to it, appraising it, adapting to it, adjusting to it, sensing well-being, and facing another change as the disease progresses (King, Duke, O'Connor, 2009).

At each stage in this decision making process, individuals with ALS adjust to change in varying manners. The well-being and psychological functioning of patients largely depends on how they perceive and react to the constant changes encountered. It was determined that the factors influencing individuals in adapting or not adapting to changes involve maintaining self-esteem, control, and protection of self-image (King, Duke, & O'Connor, 2009). It was found that those individuals who internalized the changes associated with their disease as affecting who they were as persons suffered decreases in self-esteem, but those who were able to react to the change as a challenge to be faced were able to sustain their self-esteem. Further, those individuals who perceived the disease as controlling their lives and well-being suffered greater psychological distress than those who were able to adapt and change their routines to feel more fully in control (King, Duke, & O'Connor, 2009). The manner in which individuals conceptualize themselves in regard to their self-esteem and level of control over the disease can determine the decision making processes employed, as well as determine the interventions utilized or refused as the disease progresses (King, Duke, & O'Connor, 2009).

The decision to undergo invasive life-sustaining treatments.

The most life threatening characteristics of ALS include dysphagia, and respiratory insufficiency. Treatments for these symptoms can be invasive and require advanced planning. Advanced planning is essential because patients with ALS may reach a point in disease

progression where they are unable to articulate choices and receive certain interventions based on the progression of their illnesses (Mitsumoto & Rabkin, 2007). Individuals with ALS who demonstrate the capacity to make rational decisions and the ability to weigh the potential risks and benefits of the medical interventions available to them are able to accept or refuse any treatment, even if the refusal of these treatments could lead directly to harm or to a hastened death (McCluskey, 2007). The decisions to accept or refuse the interventions of PEG and tracheotomy can be particularly complicated and controversial. Both of these treatments have the ability to sustain life, but are also invasive and can pose significant risks to the patient (Mitsumoto & Rabkin, 2007).

Percutaneous endoscopic gastrostomy (PEG) and long term mechanical ventilation (LTMV).

The intervention of PEG addresses the symptoms of dysphagia, allowing patients to receive their nutritional needs via a tube. Adequate nutrition as well as hydration is imperative for individuals with ALS because it increases their rate of survival. Symptoms of dysphagia are often associated with weight loss. Without the intervention of PEG, individuals may require an hour or more to consume a meal, and have difficulty receiving oral medications. It has been demonstrated that PEG reduces these difficulties, decreases the burden on caregivers, and allows the individual to receive the adequate level of nutrition optimal for survival (Mitsumoto & Rabkin, 2007). Despite these benefits, however, some patients choose to delay the use of PEG, or refuse it all together (Mitsumoto & Rabkin, 2007). The decision to delay the initiation of PEG can further complicate prognosis and treatment because this intervention cannot be utilized once respiratory deterioration has progressed (Mitsumoto & Rabkin, 2007).

With regard to interventions designed to address respiratory insufficiency, the majority of individuals agree to the intervention of BiPAP, or non-invasive ventilation, when difficulty with breathing begins to interfere with sleep, and when forced vital capacity falls below fifty percent (Houseman, 2008). Non-invasive ventilation has been found to prolong life as well as to improve dyspnea, sleep quality, mental alertness, energy, and quality of life (Mitsumoto & Rabkin, 2007). With the progression of the disease, however, and the further decline of respiratory function, non-invasive ventilation interventions become insufficient in extending life. At this point in disease progression, the utilization of LTMV is required to prolong survival (Mitsumoto & Rabkin, 2007). It has been found that the majority of patients with ALS refuse LTMV (Houseman, 2008). Those who do accept LTMV must set in place advance directives concerning the time when the intervention should be discontinued. The nature of LTMV allows the patient to survive; however, the disease continues to progress and eventually the patient will reach a locked-in state and be unable to delineate his or her desire to terminate treatment (Mitsumoto & Rabkin, 2007).

In a study examining the preference and treatment choices of patients with ALS, it was found that preferences for life-sustaining treatments were related to the “attachment to life” (Albert, Murphy, Del Bene, & Rowland, 1999, p. 3). “Attachment to life” was defined and measured via a Likert scale that evaluated responses from patients concerning the amount that they agreed or disagreed with statements focusing on whether or not they had a strong will to live, found meaning in their lives, looked forward to something each day, had long term goals they expected to accomplish, looked to the future, and the levels of distress if their lives ended soon (Albert, Murphy, Del Bene, & Rowland, 1999). Patients who articulated a strong will to live were more likely to consider PEG placement and LTMV (Albert, Murphy, Del Bene, &

Rowland, 1999). These results, however, did not account for the aspect that “attachment to life” could change as the disease progressed to more advanced stages; further, it was found that patients who had been living with ALS for a longer period of time demonstrated a lower rate of “attachment to life” (Albert, Murphy, Del Bene, & Rowland, 1999). Results from this study also demonstrated that depression and hopelessness were not related to the preference for the life-sustaining treatments of PEG and LTMV. It was reported that the refusal of these interventions may be representative of opinions regarding how these interventions would impact quality of life (Albert, Murphy, Del Bene, & Rowland, 1999).

Social Problem Solving

Major Concepts of Social Problem Solving

Social problem solving can be defined as the process of alleviating a problem and increasing the adaptive functioning of individuals in their natural environment. The major concepts involved in the social problem-solving model include: problem-solving, problem, and solution (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

Problem-solving involves the cognitive-behavioral manner in which individuals recognize effective solutions for specific problems. This process involves identifying a multitude of solutions that have the potential to be effective, and increases the likelihood of implementing an effective solution strategy from other alternatives identified. The process of problem-solving can have goals designed to change the actual problematic situation, decrease the emotional distress that the problem situation produces, or both (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). A problem, according to the social problem-solving model, involves any life circumstance in which an immediate response for adaptive functioning is not clear to an individual due to the presence of one or more complications (D’Zurilla, Nezu, & Maydeu-

Olivares, 2004). A solution involves the coping strategies that result from the problem-solving process. An effective solution is one that allows the individual to achieve the problem-solving goal, whether it is changing the problematic situation or decreasing emotional distress, while producing other positive consequences and reducing negative consequences (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

Problem-Solving Orientations and Styles

Social problem-solving is a multidimensional process that involves two broad components: problem orientation and problem-solving skills. Problem orientation refers to the metacognitive process in which a set of schemas, or core beliefs, interact to reveal individuals automatic thoughts, judgments, and feelings when faced with problems; it also involves their overall problem-solving ability (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). Problem-solving skills are the cognitive and behavioral actions that an individual engages in as a means of understanding problems, and identifying effective ways of coping with problems (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

There are two problem-orientation dimensions: positive problem orientation and negative problem orientation. A positive problem orientation involves a productive cognitive set that leads individuals to consider problems as challenges, to believe that problems are solvable, to believe that they are successful at solving problems, and to believe that effective problem solving takes time and effort. In addition, individuals with this problem orientation demonstrate commitment to the problem-solving process rather than the tendency to avoid problems (Nezu, D’Zurilla, Zwick, & Nezu, 2004). A negative problem orientation involves a cognitive set that often leads individuals to perceive problems as momentous threats to their well-being, to feel

doubt about their ability to solve problems effectively, and to experience frustration when confronted with problems (Nezu, D’Zurilla, Zwick, & Nezu, 2004).

Three problem-solving styles are identified in the social problem solving model. These styles include: rational problem-solving, impulsivity-careless style and avoidance style (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). Rational problem solving is characterized as the rational, purposeful, and methodical application of successful problem-solving skills. The social problem-solving model recognizes four main problem-solving skills including: problem definition and formulation, generation of alternative solutions, decision making, and solution implementation and verification (D’Zurilla, & Goldfried, 1971). Individuals who have a rational problem-solving style utilize these skills when approaching a problem.

When taking part in problem definition and formulation, individuals attempt to gain clarity and gain insight into the problem by collecting as many facts and details about the problem as possible. They also categorize the difficulties and challenges inherent in the problem, and set realistic problem-solving goals (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). Throughout the generation of alternative solutions stage, individuals bring the problem-solving goals to their attention and attempt to brainstorm as many solutions as possible, including conventional and non- conventional approaches. In the decision-making phase, individuals attempt to foresee the outcomes of the various solutions, evaluate them, and then decide upon the solution that has the greatest potential to be effective (D’Zurilla, Nezu, & Maydeu-Olivares, 2004). Finally, individuals take part in solution implementation and verification. During this process, individuals evaluate the result of their chosen solution by implementing it to the problematic situation and assessing its effectiveness (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

The impulsivity-carelessness problem-solving style involves a pattern distinguished by constricted, impulsive, careless, rushed, and deficient attempts at utilizing problem-solving skills. An individual using this type of problem-solving style may consider only a few alternative solutions and impulsively choose to implement the first solution he or she thinks of, regardless of whether or not it is the best solution for the problem (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

The avoidance problem-solving style involves a pattern of marked procrastination, submissiveness, and reliance. An individual with this type of problem-solving style will often avoid problems and problem-solving for extended periods of time, wait for problems to resolve on their own, and try to place the responsibility of solving problems on other people (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

The social problem-solving model has been empirically tested and been found to predict that the most effective problem-solving outcomes are the result of individuals having a positive problem orientation and utilizing a rational problem-solving style. It is believed that an individual’s problem-solving orientation serves as a motivational factor in how a problem is approached, and the problem-solving style determines the identification and implementation of possible solutions (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

Social Problem-Solving and Negative Affectivity

It has been recognized that social problem-solving exemplifies a significant coping process that increases an individual’s ability to manage problematic situations. The ability to better manage problems may serve to reduce the development of psychological and emotional distress. An examination of the relationship between problem-solving and depression has found that poor problem-solving patterns can function both as a susceptibility factor for depression, as

well as a consequence of depression (Nezu, Wilkins, & Nezu, 2004). This indicates that the inability to carry out and implement effective problem-solving skills can lead to an increase in emotional distress. In turn, this emotional distress could also interfere with an individual's ability to utilize effective problem-solving strategies (Nezu, Wilkins, & Nezu, 2004). It has been further noted that effective problem solvers demonstrate greater capability in recovering from depressive episodes than do ineffective problem solvers (Nezu, Wilkins, & Nezu, 2004).

Social problem-solving has been found to be a moderator of stress-related depressive symptoms. Nezu and Ronan (1988) conducted a study demonstrating that individuals identified as effective problem solvers under high levels of stress reported significantly lower depressive symptoms than individuals identified as ineffective problem solvers under similar levels of stress (Nezu & Ronan, 1988). These findings highlight the importance of problem-solving training as a means both of preventing depression, and of assisting in the recovery from a depressive episode (Nezu & Ronan, 1988). This implies, therefore, that clinical interventions designed to teach effective problem-solving skills can increase the overall adaptive functioning of individuals and improve their psychological well-being (Nezu & Ronan, 1988).

Problem-Solving Therapy

Problem-solving therapy is a relational/problem-solving model in which social problem-solving serves as a central tenet in assisting individuals to increase their adaptive functioning and to decrease the role of stress in their overall well-being (Nezu, D'Zurilla, Zwick, & Nezu, 2004). The model of problem-solving therapy incorporates Richard Lazarus's relational model of stress (Lazarus, 1999). This model indicates that the quality and strength of an individual's stress response is determined by the cognitive appraisal and coping style of the individual (Nezu, D'Zurilla, Zwick, & Nezu, 2004). The cognitive appraisal of a situation involves the manner in

which an individual assesses the personal meaning of a stressful situation, and coping refers to the cognitive and behavioral strategies an individual utilizes to manage the stressful situation (Nezu, D’Zurilla, Zwick, & Nezu, 2004).

The two main types of coping involve problem-focused coping, and emotion-focused coping. Problem focused coping is characterized by actions aimed at changing the problematic situation for the better, and emotion focused coping attempts to control the emotions that are a result of the problematic situation (Nezu, D’Zurilla, Zwick, & Nezu, 2004). In general, problem focused coping is often used when stressful situations are perceived as controllable, and emotion focused coping is utilized in those situations deemed to be unchangeable (Lazarus, 1999).

Problem-solving therapy identifies stress as a product of the reciprocal relationship between stressful life events, emotional stress responses, and problem-solving coping. When assessing clinical problems, the problem-solving therapist works to uncover major negative life events, daily problems, emotional stress responses, problem-orientation deficits, problem-solving skills insufficiencies, and solution implementation difficulties (Nezu, D’Zurilla, Zwick, & Nezu, 2004). As a result of the assessment of these areas, problem-solving therapy can then be implemented to improve the individual’s problem orientation and problem-solving skills. The improvements of these dimensions are then thought to increase adaptive coping, improve psychological well-being, and to decrease the negative effects of stress (Nezu, D’Zurilla, Zwick, & Nezu, 2004).

Social Problem-Solving and Relevance to ALS Patients

Problem-solving therapy has been found to be an efficacious treatment for a variety of populations and conditions. In a comparative study of social problem-solving therapy with reminiscence therapy for the treatment of depression in older adults, social problem-solving

therapy was found to be significantly more effective in decreasing the symptoms of depression (Arean, Perri, Nezu, Schein, Christopher, & Joseph, 1993). Further, social problem-solving therapy has been examined and been found to be effective with medical and cancer patient populations (Nezu, Nezu, Felgoise, & Zwick, 2003). Among the medical populations, social problem-solving therapy has been utilized to decrease psychological distress, and to increase overall quality of life (Nezu, Nezu, Felgoise, & Zwick, 2003).

The progressive nature of ALS and the constant decisions and crises that ALS patients face as their disease progresses makes social problem-solving a relevant theory and approach for this population. Using the social problem-solving perspective, healthcare providers may begin to gain a deeper understanding of the problems faced by ALS patients and those characteristics that may lead them to decide to hasten death. Further, social problem-solving therapy can assist ALS patients in coping with their illness, in decreasing their negative emotional responses, and in increasing their overall quality of life.

SUICIDE

Suicide Risk in the General Population

Suicide involves the act of taking one's own life. Demographic variables of those who commit suicide reveal that these individuals are more likely to be men, to have a lower socioeconomic status, to be white, single, and to have fewer years of education (Wenzel, Brown, & Beck, 2009). Research studies examining demographic characteristics associated with suicidal acts reveal that older males who are single, divorced, or widowed and who have a lower socioeconomic status are at the greatest risk for suicide (Wenzel, Brown, & Beck, 2009).

Demographic variables alone, however, cannot predict suicide. Other factors that may contribute to the likelihood of suicidal acts include the presence of a psychiatric disorder,

substance abuse, a history of child abuse, and a history of suicide in the family (Wenzel, Brown, & Beck, 2009). Depression and especially hopelessness are significant predictors of suicidal behavior. It has been found that elevated levels of hopelessness, despite the level of depression, are correlated with elevated levels of suicidal plans (Wenzel, Brown, & Beck, 2009). Substance abuse lowers inhibitions and can lead an individual to act on impulses toward suicide. In addition, a history of child abuse and traumatic experiences are related to the greater likelihood of the development of psychiatric disorders that are correlated with suicidal behaviors (Sunnqvist, Westrin, & Träskman-Benz, 2008). A family history of suicide may teach an individual that suicide is a viable option with regard to problem solving (Wenzel, Brown, & Beck, 2009).

Deficits in social problem-solving skills are a further predictor of suicidal behaviors. Individuals who attempt suicide often indicate that the reason for the attempt was that they saw no other option in coping with their life circumstances. It has been found that individuals who engage in suicidal ideation have poorer problem solving skills than those who do not engage in this behavior (Wenzel, Brown, & Beck, 2009). Poor problem solving skills, as delineated in the social problem-solving model, can be viewed as the inability to develop solutions to problems, the avoidance of making efforts to solve problems, and limited beliefs in one's capability to solve problems (Wenzel, Brown, & Beck, 2009). Social problem-solving deficits can be related to emotional troubles and to psychiatric disorders because the stress resulting from these deficits can lead to feelings of hopelessness when faced with difficult situations (Wenzel, Brown, & Beck, 2009).

Poor social problem-solving ability has been found to predict hopelessness and suicidal intent (Nezu, Wilkins, & Nezu, 2004). According to social problem-solving theory, individuals

who demonstrate a negative problem-solving orientation would likely view a problem as a major threat, would doubt their ability to solve it, and would become easily upset and frustrated.

Individuals with this type of orientation may adopt a dysfunctional problem-solving style as a result of their distress and lack of confidence in their ability to solve the problem. Individuals utilizing poor problem-solving skills may react to a negative life event using either an impulsive/careless, or avoidant problem-solving style.

When adopting an impulsive problem-solving style, an individual may act hastily on the first solution to the problem that comes to mind without fully understanding and identifying the problem. He or she may fail to recognize alternative solutions and act on a solution that does not minimize risk. Unfortunately, individuals with this problem-solving style may act impulsively on suicidal ideations because they perceive this to be a viable solution to their problems.

Individuals with avoidant problem-solving patterns would likely avoid the problematic situation and hope that it will resolve on its own. This style, however, could cause the individual to experience a greater sense of hopelessness because he or she may feel a complete lack of control over resolving the problem. This increased sense of hopelessness could lead the individual to feel that there are limited options, increasing the risk of suicidal behaviors.

Suicide Risk in Older Populations

Older adults have been found to have the highest steady rate of suicide in most societies (Leenaars, 2003). Risk factors associated with suicide among older adults include: psychiatric disorders, personality traits, physical illness, and social characteristics (Harwood, & Jacoby, 2000). A study examining the course of suicidal ideation and the predictors of change in depressed older adults found that over time, increasing age was correlated with increasing suicidal thoughts. It was determined that thoughts of suicide among older adults are treatment

resistant ,regardless of gender and race (Cukrowicz, Duberstein, Vannoy, Lynch, McQuoid, & Steffens, 2009). Some decreases in suicidal ideation over the first two months of psychological treatment were found among older adults; however, after this initial reduction, suicidal ideation remained constant. It was further noted that treatment-related reductions in suicidal ideation were less evident as age increased (Cukrowicz, Duberstein, Vannoy, Lynch, McQuoid, & Steffens, 2009).

Variables that appear to be motivating factors in regard to elderly suicide include intolerable psychological pain, cognitive restriction, incapability of adjustment, and difficulties with interpersonal relationships (Leenaars, 2003). These variables can also be linked to difficulties with social problem-solving. It has been found that older adults who attempt suicide are attempting to escape psychological pain, especially the feelings of hopelessness and helplessness. The motivation towards a suicidal act is that it will provide relief from suffering (Leenaars, 2003). Cognitive restriction, or rigidity in thinking, involves a narrowing in focus and leads individuals to perceive suicide as the only solution. According to social problem-solving theory, this perception could be the result of a negative problem-solving orientation because the individual lacks confidence in his or her ability to cope. This orientation could further lead to the adoption of an impulsive/careless problem-solving style which could cause the individual to engage in suicidal behavior. The inability to adjust is related to a deficit in coping skills in managing psychological distress and in challenging life situations. From a social problem-solving perspective, this inability to adjust may be the result of an avoidant problem-solving style. Individuals with this problem-solving style may avoid the problem which leads to greater feelings of hopelessness because the person feels there is nothing he or she can change about the

situation. Finally, problems with interpersonal relationships could lead to social isolation which is further related to suicidal ideation (Wenzel, Brown, & Beck, 2009).

Suicide Risk in Individuals with Terminal Illness

Individuals with advanced medical conditions and terminal illnesses are at elevated risk for suicide when compared with the general population. (Gibson, Breitbart, Tomarken, Kosinski, & Nelson, 2006). Frequently, individuals with terminal illness who are contemplating suicide have various means of achieving this goal, such as combining potent medications; they do not have to engage in violent acts (Werth, & Richmond, 2009). Further, if unable to perform the suicidal act independently, terminally ill patients may request assistance from a physician, decide to withdraw from a life-sustaining treatment, or stop eating and drinking in order to hasten death (Werth, & Richmond, 2009). ALS patients, in particular, have been found to demonstrate higher rates of the desire to hasten death when compared with other patients with terminal illnesses (Tolle, Tilden, Drach, Fromme, Perrin, & Hedberg, 2004).

HASTENED DEATH

The request to hasten death by terminally ill patients is a controversial topic. The procedures to hasten death could involve withdrawing life-sustaining treatments, terminal sedation, cessation of eating and drinking, physician assisted suicide, and euthanasia. Withdrawing life-sustaining treatments is a legal and ethical procedure that is determined in advanced directives specified by the patient. Terminal sedation involves the administration of medications, with the primary goal being relief from suffering, and the secondary effect being death (Werth, 2004). Cessation of eating and drinking is considered a type of withholding life-sustaining treatments (Werth, 2004). Physician assisted suicide involves the administration of a prescription for a lethal dose of medication that the patient takes on his or her own or through

assistance from a family member or caregiver; euthanasia involves the administration of a lethal dose of medication by a physician, usually in the form of an injection (McCluskey, 2007).

Demographic variables of individuals requesting physician assisted suicide in Oregon, where it is legal, include: being of European-American decent, being married, and being more highly educated (Kleespies, Hough, & Romeo, 2009). Some of these demographic variables are in opposition to those variables present among individuals in the general population who are most likely to attempt suicide. The factors contributing to suicide ideation among terminally ill patients appear to be different from those of the general population (Gibson, Breitbart, Tomarken, Kosinski, & Nelson, 2006).

Desire for Hastened Death among Terminally ill patients.

It has been found that fifty to seventy percent of terminally ill cancer patients have expressed possible interest in the future in euthanasia and physician assisted suicide (Wilson et al., 2000). It was deemed that this interest was especially present if patients feared that their pain and physical symptoms would become unbearable. It has been suggested that the fear of future pain and of depression are the most significant factors related to the interest of hastened death, through euthanasia, and physician assisted suicide (Wilson et al., 2000).

Other factors, however, have also been identified as contributing to the desire of hastened death among individuals with terminal illness. A systematic review of the literature related to the desire to hasten death among patients with advanced disease found that variables predicting a desire to die were complex and multifactorial (Hudson et al., 2006). Psychological, existential, and social reasons appear to play a more pronounced role in the desire to hasten death than do physical symptoms such as pain. The most common factors identified in relation to the desire to

hasten death have been: being a burden on others, losing autonomy, existential concerns, fear of the future, depression, hopelessness, and physical symptoms (Hudson, 2006).

Studies examining the wish to hasten death among individuals in palliative care settings have revealed a significant level of interest in physician assisted suicide. Johansen, Hølen, Kaasa, Loge, and Materstvedt (2005) conducted a qualitative study examining the attitudes towards, and wishes for, euthanasia among advanced cancer patients at a palliative medicine unit. Results from this study revealed that fear of future pain as well as poor quality of life were the most frequently cited reasons for having a positive attitude towards euthanasia and physician-assisted suicide (Johansen, Hølen, Kaasa, Loge, & Materstvedt, 2005). Further, individuals' rights to choose the point at which they could end their suffering was an additional reason for holding a positive attitude toward euthanasia and physician-assisted suicide (Johansen, Hølen, Kaasa, Loge, & Materstvedt, 2005). Respondents' reasons for holding negative attitudes toward euthanasia and physician assisted suicide involved religious and ethical views as well as the belief that taking life is wrong (Johansen, Hølen, Kaasa, Loge, & Materstvedt, 2005).

Another study examining the factors associated with the wish to hasten death among terminally ill patients in palliative care settings found that fourteen percent of the sample expressed a high desire to hasten death (Kelly, Burnett, Pelusi, Badger, Varghese, & Robertson, 2003). Factors contributing to this increased desire to die included elevated levels of depression symptoms, being admitted to a hospice care setting, feeling as if the individual was a great burden to others, minimal family cohesion, fewer social supports and decreased satisfaction with social supports, increased levels of anxiety, and the increased experience of uncomfortable physical symptoms (Kelly et al., 2003). Depressive symptoms were deemed to be the most significant factor in determining the wish to hasten death, followed by the admittance into a

hospice care setting, and feeling like a burden to others. Physical symptoms of illness were much less significant in predicting the wish to hasten death than were psychological and social factors (Kelly et al., 2003).

Depression.

The role that depression plays in the wish for a hastened death among terminally ill patients has been inconsistent. Some of the literature cites depression as playing a major role in the decision to hasten death, yet other studies posit the idea that it does not play as large a role (Ganzini & Dobscha, 2003). One reason for this may be that the ability to make an accurate diagnosis of depression within the context of terminal illness can be a difficult task. Although it has been found that ten to twenty-five percent of terminally ill cancer patients meet criteria for Major Depressive Disorder, the many somatic symptoms that constitute the DSM-IV criteria may be due to the physical aspect of the terminal illness and thus confound the accuracy of the diagnosis (Ganzini & Dobscha, 2003).

Nonetheless, depression has been found to be a main factor in the desire to hasten death among terminally ill individuals. In a study examining the factors of pain, depression, social support, hope, and anxiety among those individuals that would contemplate a hastened death, it was found that the main motives that differentiate individuals who contemplate a hastened death from those who do not include depression, social support, and hope (Arnold, 2004). It is thought, however, that if depression is present in individuals contemplating a hastened death, treatment and remission of the depressive symptoms may also bring about the remission of the desire to hasten death (Arnold, 2004).

Ganzini, Goy, and Dobscha (2005) studied fifty-eight Oregon residents with terminal illness who either explicitly had requested physician assisted suicide or had contacted an aide in

a dying advocacy organization. It was found that approximately one in four patients who requested physician assisted suicide had clinical depression, but more than three - quarters of the patients who received a lethal prescription did not (Ganzini, Goy, & Dobscha, 2005). These results suggest that the majority of individuals in Oregon who request assistance in dying do not have a depressive disorder (Ganzini, Goy, & Dobscha, 2005). It appears, in fact, that depressed patients are less likely to have the motivation, energy, focus, and determination needed to make the request to hasten death and follow through with the legal requirements mandated in Oregon (Ganzini & Back, 2003). Additionally, patients in Oregon who request physician assisted suicide do not appear to be socially vulnerable. Patients appear to request physician assisted suicide due to psychological and existential factors (Ganzini & Back, 2003). These factors revolve around the desire to maintain control and independence, as well as the feeling that these patients have in determining that they are ready to die. The assessment of a poor quality of life also contributes to the desire for physician assisted suicide (Ganzini & Back, 2003).

Hopelessness.

Hopelessness and poor prognosis have been found to be distinct entities among individuals with terminal illness. Neither hopelessness nor suicidal ideations are directly related to disease severity (Sullivan, 2003). Psychological adjustment and disease prognosis are mediated by individual coping styles. The adoption of a more passive coping style is associated with an increase in depression and hopelessness (Sullivan, 2003). According to social problem-solving theory, individuals who adopt an avoidant problem-solving style would demonstrate a passive coping style and thus would likely experience an increase in hopelessness and depression.

For the terminally ill patient, suicide or hastened death may seem like the only hope when all other hope is lost (Sullivan, 2003). The ability to identify reasons for living has been identified as a protective factor against suicide (Sullivan, 2003). Hopelessness has been found to be more predictive of the desire to hasten death at the end of life than is depression. It has been found that individuals without a clinical diagnosis of depression, but with high levels of hopelessness are more likely to desire a hastened death (Breitbart & Heller, 2003). Further, hopelessness has been shown to influence the decision making processes of terminally ill patients (Sullivan, 2003).

Religion and spirituality.

Spirituality can be defined as a complex and multidimensional aspect of the human experience. It involves cognitive, emotional, and behavioral components (Anandarajah & Hight, 2001). The cognitive components of spirituality are thought to include the search for meaning, purpose, and truth in life, along with the beliefs and values by which an individual lives. The emotional, or experiential, component of spirituality involves feelings of hope, love, connection, inner peace, comfort and support. The behavioral aspect of spirituality involves the manner in which an individual externally exhibits his or her spiritual beliefs and spiritual state. This can include a person's active participation in a religion or church group (Anandarajah, & Hight, 2001). Religion can be defined as an organized system of beliefs, practices, and symbols that serve to bring about closeness to a higher power. It also can represent a relationship with and responsibility towards others within a community (Koenig, George, Titus, & Meador, 2004).

Religion and spirituality play important roles in providing meaning to the dying process for terminally ill individuals. It appears that these factors provide alternate forms of hope for the dying patient, including hope for an afterlife, salvation, and nirvana (Sullivan, 2003). It has been

found that religious well-being may provide protective factors against depression and despair. A study examining the effects of spirituality and religion on end-of-life despair in terminally ill cancer patients found that patients with higher levels of spiritual well-being were less likely to desire a hastened death, have suicidal ideation, and hopelessness (McClain, Rosenfeld, Breitbart, & Galiotta, 2002).

Religion has also been found to impact and improve quality of life of patients at the end-of-life. It is believed that religion may provide effective coping mechanisms to assist individuals in facing their terminal illnesses (Okon, 2005). Religion and spirituality are thought to influence quality of life by increasing subjective well-being. It has been hypothesized that religious practices and spirituality enhance well-being by advocating a wholesome lifestyle, offering systems of existential meaning, creating personal relationships with the divine, and guaranteeing social support and community integration (Ellison, 1991). In particular, religious practices have been found to be strongly associated with quality of life among ALS patients (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004). It has also been found that over time and over disease progression, ALS patients' levels of faith and peace that are found in religion increase quality of life (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004).

Cultural and spiritual beliefs, however, could impact the manner in which individuals receive and accept information about their diagnosis. For example, Navajo Native Americans believe that language not only describes reality, but also that it actually shapes it. Information, therefore, regarding an individual's prognosis and the discussion of advanced directives may be perceived as threatening to an individual's well-being. Talking about advance directives with a Navajo man or woman may be considered a major violation of Navajo values and beliefs (Werth, Blevins, Toussaint, & Durham, 2002).

Further, some cultures may depend on their religion to a greater extent than is normally practiced in the U.S. health care system (Werth, Blevins, Toussaint, & Durham, 2002). It is important to recognize that individuals' religions may affect all aspects of their lives. It may direct their actions and instill meaning in life circumstances (Okon, 2005). When an individual is diagnosed with a terminal illness, he or she may believe there is a spiritual reason for the terminal illness, pray for help in making treatment decisions, or view his or her situation as a test of faith (Crawley et al., 2000). When individuals present with such beliefs it is important that the healthcare team maintain respect for the patient's beliefs yet remain mindful of ethical standards of practice (Werth, Blevins, Toussaint, & Durham, 2002).

Loss of function and autonomy.

Concerns about the loss of dignity and autonomy further predict the desire for hastened death among terminally ill patients. Pearlman et al. (2005) conducted a qualitative study examining the motivational factors of thirty-five individuals who pursued a hastened death. Loss of function was identified as an influencing factor in the decision to hasten death among two-thirds of this sample (Pearlman et al., 2005). It was stated that loss of function for these patients represented the transition from life to death and thus decreased their will to live. In addition, two-thirds of the study participants pursued a hastened death due to concerns that their illness was deteriorating their sense of self (Pearlman et al., 2005). Patients reported expressing worries about losing personality, identity, and aspects of themselves that gave them meaning and personal dignity. Many patients also identified not wanting to be remembered as ill and frail as additional reasons for pursuing a hastened death (Pearlman et al., 2005). The loss of independence was perceived as a loss of their sense of control which was further linked to pursuing a hastened death (Pearlman et al., 2005).

Another common motivation for hastened death involved fears about future quality of life and of dying (Pearlman et al., 2005). These fears were often associated with other motivating factors including losing control, decrease in physical functioning, being a burden on family members, and the losing one's sense of self. In addition, negative experiences with dying in the past were further motivating factors for pursuing a hastened death (Pearlman et al., 2005).

The participants in this study were noted to have reflected upon hastening their deaths over a prolonged period of time, and to have reviewed, repetitively, the benefits and risks of living versus dying. It was found that when the illness or treatment began to affect the characteristics of the individuals that provided meaning in life, such as the sense of control and the sense of self, the option of hastened death was considered more readily as a means of stopping this process (Pearlman et al., 2005). The severe loss of function, including bodily integrity and control, can lead to an existential suffering because the individual begins to lose his or her personal sense of self. The loss of a personal sense of self can lead to the withering away of meaning in life (Pearlman et al., 2005).

Self-perceived burden.

The feeling of being a burden to others has been referred to as self-perceived burden (SPB). SPB can be defined as an empathetic unease stemming from the care needs of an individual that results in the experience of guilt, distress, feelings of responsibility and a decreased sense of self (McPherson, Wilson, & Murray, 2007). Supportive relationships are identified as essential for terminally ill patients. Within the domain of trusting relationships, hope is able to grow because connecting with friends and family allows the terminally ill individual to develop alternate forms of hope, as well as purposes in life (Sullivan, 2003).

Survey data has revealed, however, that one of the most feared aspects of dying is being a burden to others (Sullivan, 2003).

Relationship factors as well as social support appear to play an important role in predicting the desire for hastened death. Feelings in regard to being a burden and being dependent on others highlight the need for addressing these issues and examining the interplay on how these concerns may influence individuals' decisions to hasten death (Hudson et al., 2006).

Pain.

The experience of pain appears to influence the desire for a hastened death among terminally ill patients. In a study examining the attitudes toward, and wishes for euthanasia in advanced cancer patients on a palliative medicine unit, it was indicated that the will to live diminished as pain increased (Johansen, Hølen, Kaasa, Loge, & Materstvedt 2005). Respondents in this study reported that as the pain increased, it occupied their attention, and their lives became pain. This life of pain was determined to represent a life without meaning and worth, and thus a wish for physician assisted suicide increased. The wish for physician assisted suicide appeared to fluctuate with the respondents' experiences of pain. Quality of life was also closely related to pain levels in this study (Johansen, Hølen, Kaasa, Loge, & Materstvedt 2005). Additionally, a qualitative study examining the motivational factors influencing individuals to pursue a hastened death found that feeling weak, tired, and uncomfortable increased the desire for this procedure. Pain was a major influencing factor in this study because individuals described it as unbearable, preoccupying, and consuming (Pearlman et al., 2005).

In contrast to these studies, it appears that if individuals are not acutely experiencing pain, this factor does not greatly influence their considerations of a hastened death. It has been

found that patients do not appear to make requests for physician assisted suicide due to physical symptoms such as pain or fatigue; however, the fear of their physical conditions worsening can impact the desire for this procedure (Ganzini & Back, 2003). In addition, it has been hypothesized that the fear of pain in the future may contribute to the consideration of hastened death as an option. This possibility has been supported by research conducted in Oregon where twenty-six percent of patients requesting physician assisted suicide expressed concern about increased levels of pain due to their illnesses (Sullivan, Hedberg, & Fleming, 2000).

Decision making process toward hastened death in terminally ill patients.

With regards to decision making about hastening death, patients are considered competent if they meet the legal standards of: being able to express an unwavering choice; being able to comprehend the risks, benefits, and alternatives of their decision; being able to understand and relate the information to themselves, and the ability to identify logical, rational reasons for their requests (Ganzini & Dobscha, 2003). Depression can limit the ability of individuals to meet these legal standards. Individuals suffering with depression may make decisions that are counter to their values, personality, and goals (Ganzini & Dobscha, 2003). Further, it has been found that mild to moderate levels of depression do not significantly influence attitudes toward life-sustaining treatments; however, severe depression does (Ganzini, Lee, Heintz, Bloom, & Fenn, 1994).

In considering the decision to hasten death, depression may limit the ability of terminally ill patients to identify alternate choices, find meaning in their lives, and cope effectively (Ganzini & Dobscha, 2003). As mentioned, poor social problem-solving skills have been identified both as a vulnerability factor, and as a consequence of depression. Individuals with deficit problem-solving skills may be less likely to recognize alternative solutions and they lack confidence in

their abilities to cope. It has been found, however, that when suicidal patients are recognized and receive interventions, the majority change their minds, indicating that this desire may fluctuate (Ganzini & Dobscha, 2003). This finding further indicates that when terminally ill patients receive assistance in addressing their problems, they may adopt a more adaptive mode of coping. It has been found that depression is the most consistent risk factor associated with the desire for a hastened death among individuals with terminal illness (Ganzini & Dobscha, 2003). Wilson et al. (2000) found that individuals with terminal illnesses who request a hastened death are more likely to have Major Depressive Disorder, experience a greater amount of hopelessness, report greater feelings of loss of control, and increased weakness and fatigue when compared with those who would not make this request (Wilson et al., 2000).

In contrast to these findings indicating that depression is a major factor contributing to the desire for a hastened death, Bharucha, Pearlman, Back, Gordon, Starks, and Hsu (2003), found that Major Depressive Disorder was not an influencing factor in individuals who requested and pursued physician assisted suicide. In Oregon, where physician assisted suicide is legal, physicians have described patients who actively seek this intervention as focused, determined, strong-willed, and stubborn (Ganzini, Dobscha, Heintz, & Press, 2003). It has been hypothesized that although depression may increase the consideration of hastened death, the aspects of apathy and impairments in volition associated with Major Depressive Disorder could deter individuals' abilities in persuading others of the need for this intervention (Ganzini & Dobscha, 2003). To further support this hypothesis, studies conducted in Oregon have found that individuals who actively pursue physician assisted suicide or hastened death are not depressed, but rather they desire the ability to remain in control of their lives, and want to avoid being dependent on others (Ganzini & Dobscha, 2003).

A study examining the wish to hasten death among terminally ill patients revealed that the wish for this procedure seemed to be fluctuating, ambivalent, future oriented, and hypothetical (Kelly et al., 2003). Four major reasons were identified as influencing the wish for physician assisted suicide. These reasons included: fear of pain in the future; having experienced pain in the past or having current pain; concerns about poor quality of life in the future, and worries involving hopelessness in the future (Kelly et al., 2003). The ambivalent nature of the respondents' wishes for physician assisted suicide may signify underlying meanings other than the actual desire to die. These transient wishes for physician assisted suicide may reflect a desire to control pain, reduce feelings of hopelessness, and find a better way of coping with the fear of pain (Kelly et al., 2003). The act of wishing for physician assisted suicide may reflect a coping strategy in which the individual is able to practice a private, inner ability to choose and have an option to end their suffering. These wishes, therefore, may represent a positive psychological coping strategy in which the individuals can obtain a feeling of control (Kelly et al., 2003). The individual's right to determine when and how he or she wants to die has been found to be an additional, important reason for positive attitudes toward physician assisted suicide (Kelly et al., 2003).

In a study examining the desire for euthanasia or physician assisted suicide in palliative cancer care, three hundred and seventy-nine individuals in palliative cancer care were interviewed. The majority of the individuals in the study, approximately fifty-nine percent, disclosed that they would prefer euthanasia to be a legal practice (Wilson et al., 2007). When compared with the individuals in the study who were opposed to the legalization of this procedure, those that were in favor were younger, and less religious. Individuals who identified themselves as being in favor of the legalization of euthanasia most frequently cited autonomy,

suffering, perceived futility, compassion, experience, and the concern for others as the reasons for holding that opinion (Wilson et al., 2007). They voiced the belief that individuals with terminal illnesses should have the opportunity to make autonomous decisions with regard to the situation and timing of their deaths. Euthanasia, to these individuals, was viewed as an act of compassion and altruism on the part of the physician because it would decrease the stress and burden on family members and caregivers (Wilson et al., 2007).

Individuals opposed to the legalization of euthanasia in this study cited religious concerns, moral opposition, negative possibilities, physicians' roles, and unnecessary action as the reasons for their opinion. Some of these study participants viewed euthanasia as unnecessary in the presence of good palliative care. They also voiced the idea that the implementation of this procedure could be especially stressful for the physician (Wilson et al., 2007).

The lack of, or insufficient amount of information on the possible interventions available to alleviate suffering may also lead patients to feel hopeless and as if they have no other options. This feeling of hopelessness may subsequently cause individuals to increase their desire and wish for physician assisted suicide (Kelly et al., 2003). Increasing patients' knowledge of medical interventions that are available may increase their sense of security and control as well as decrease their wishes for physician assisted suicide (Kelly et al., 2003).

Because of the irreversible nature of physician assisted suicide or hastened death, it is imperative that healthcare workers be aware of the ambivalent nature of these wishes, and explore all possible reasons contributing to the expression of these wishes (Kelly et al., 2003). Guidelines for healthcare professionals should focus on how to respond to the request for hastened death because desires for this type of intervention may fluctuate (Hudson et al., 2006). Responses to these requests should focus on identifying underlying factors contributing to the

requests, as well as implementing interventions that can increase dignity and quality of life (Hudson et al., 2006).

Desire for Hastened Death Among Individuals with ALS

It has been found that patients with ALS demonstrate higher rates of the desire to hasten death than do patients with other types of terminal illnesses (Tolle, Tilden, Drach, Fromme, Perrin, & Hedberg, 2004). A study conducted in Sweden found that ALS patients were at a higher risk of suicide than individuals with multiple sclerosis, Parkinson's disease, and most malignant cancers (Fang et al., 2008). In 1999, after the enactment of the Oregon Death with Dignity Act in 1997, it was found that assisted suicide accounted for 0.04 percent of cancer patients' deaths in Oregon, and five percent of deaths among ALS patients (Sullivan, Hedberg, & Fleming, 2000). It is apparent that ALS patients are more likely to pursue a hastened death than are other terminally ill patients (Sullivan, Hedberg, & Fleming, 2000).

A study examining the attitudes of patients with ALS and their caregivers toward assisted suicide, found that fifty-six percent of the patients were willing to consider assisted suicide as a viable option (Ganzini, Johnston, McFarland, Tolle, & Lee, 1998). Those who considered assisted suicide as a desirable option were less religious, had greater degrees of hopelessness, and lower levels of quality of life (Ganzini, Johnson, McFarland, Tolle, & Lee, 1998).

Additionally, a study examining those individuals who actually pursued a hastened death, found that these patients had greater levels of hopelessness, increased interest in suicide, and viewed religion as less important (Albert et al., 2005).

In Oregon, individuals willing to consider physician assisted suicide as an option did not indicate differing levels of pain, disability, social support, use of hospice care, or levels of depression when compared with those patients who would not consider PAS. It was further

found that social support, level of disability, perception of being a burden, and pain and suffering were not associated with attitudes toward hastened death in this population (Ganzini, Johnson, McFarland, Tolle, & Lee, 1998). In examining those who actually pursued hasten death it was revealed that these individuals were neither more likely to be male, older, to be more highly educated, or to live alone, nor did they have unmet needs or utilize fewer services than those who did not hasten death. Further, those requesting hastened death did not report significantly different ratings in how burdened they perceived their families to be in providing care (Albert et al., 2005).

In Sweden, ALS patients were found to be approximately six times more likely to commit suicide when compared with individuals in the general population. Women seemed to be at an elevated risk; however, this difference was not deemed to be significant (Fang et al., 2008). The relative risk for suicide was found to be highest throughout the first year after the initial hospitalization for ALS; this risk remained elevated for three years after the initial hospitalization. This study reveals that ALS patients in Sweden, especially those that are diagnosed with the disease at a younger age, are at a higher risk of death by suicide (Fang et al., 2008).

It appears that the factors that contribute to the consideration of a hastened death among ALS patients may be slightly different from those factors that contribute to the consideration of this procedure among individuals with other terminal illnesses. The main aspects found to lead to the consideration of this procedure among ALS patients appear to be level of physical functioning, quality of life, hopelessness, and level of religious beliefs (Ganzini, Johnson, McFarland, Tolle, & Lee, 1998; Albert et al., 2005). It is unclear if these characteristics will generalize to a broader ALS population because the majority of the studies on hastened death

and ALS have been conducted in Oregon, and some European countries where physician assisted suicide is legal.

Physical function.

Shortly after a patient is diagnosed with ALS, it is imperative that he or she be educated about what the course of the disease will entail. This description should involve the many options and decisions the patient will encounter as the disease progresses (Baumrucker, 2006). It is important that the physician make the patient aware of their right to choose or refuse interventions, including those interventions that will sustain life. It has been found that, frequently, the request for PAS among ALS patients may indicate that the individual does not understand the options available for end of life care. Patients requesting PAS may instead be seeking an increase in symptom management should their suffering also increase (Bascom & Tolle, 2002). It is the physician's responsibility, therefore, to make sure the patient understands his or her treatment options and then to respect the patient's autonomy in making intervention choices (Baumrucker, 2006).

In a study designed to gain an understanding of the wish to die among individuals with ALS, eighty patients were enrolled in the study and fifty-three died over the follow-up period. Of the fifty-three patients who passed away, ten expressed the wish to die, and three pursued a hastened death. Among the three individuals who hastened death, it was reported that they requested a relief from suffering; when they were informed that the increase in palliative care would have the secondary effect of decreasing their respiratory muscle strength and hastening death, they persisted with their requests (Albert et al., 2005).

It was found that patients who expressed a wish to die were less likely to use a feeding tube or nasal ventilation at baseline. They were also more likely to admit to thinking about

suicide, to have discussed this desire with someone, and to have scored significantly higher on the Schedule of Attitudes toward Hastened Death (Albert et al., 2005). All three patients who actually pursued hastened death were women; two of the three had adult children serving as their caregivers; they reported greater levels of suffering at baseline, and none of them used a feeding tube (Albert et al., 2005). This study found that patients who reported a desire to die were committed to that desire, and patients who hastened death perceived living to be unbearable due to the degree of their disability, regardless of their levels of care and love from their families (Albert et al., 2005).

Quality of life.

Quality of life is a subjective, personal experience that is not wholly related to physical symptoms and functional abilities (Bascom & Tolle, 2002). It is defined, rather, as the integration of physical characteristics such as symptoms of illness or wellness, psychological processes including emotional reactions and beliefs, and social features including interpersonal relationships and social support (Bremer, Simone, Walsch, Simmons, and Felgoise, 2004). In Oregon and Washington it has been found that fifty-six percent of patients surveyed would consider assisted suicide. This high percentage signifies that the quality of care in end stage ALS is insufficient (Baumrucker, 2006). If a patient requests PAS or hastened death, it is the physician's responsibility to assess the patient's condition and make sure that everything has been done to maximize his or her comfort and quality of life (Baumrucker, 2006).

In addition to managing the physical symptoms, a major focus of ALS treatment involves maintaining and improving quality of life (McLeod & Clarke, 2007). Quality of life for ALS patients has been found to correlate with suffering, social support, feeling like a burden to others, and hopelessness (Ganzini, Johnston, & Hoffman, 1999). Although health-related quality of life

focuses on individual's physical health and overall functional ability, quality of life focuses on other non-medical factors such as purpose, meaning in life, and capacity for personal growth (Robbins, Simmons, Bremer, Walsh, & Fischer, 2001).

It has been found that individuals with ALS maintain their quality of life as their physical function deteriorates (Robbins, Simmons, Bremer, Walsh, & Fischer, 2001). Because of the major loss of motor function associated with ALS, it is evident that psychological and existential factors significantly contribute to the quality of life of individuals with this disease (Robbins, Simmons, Bremer, Walsh, & Fischer, 2001). Nygren and Askmark (2006) found that despite disease progression and worsening of symptoms, the overall quality of life of individuals with ALS changed only slightly over time. It was determined that the existential domain involving social support, depression, socioeconomic status, and religiosity are deemed to be most important in contributing to quality of life (Nygen & Askmark, 2006).

It is hypothesized that in the initial stages of a progressive disease such as ALS, patients may direct their attention for quality of life upon physical functioning and disability; however, as the disease progresses, this attention may shift to more psychosocial and spiritual realms (Clarke, Hickey, O'Boyle, & Hardiman, 2001). It has been found that patients who are in the later stages of the disease process are significantly more likely to identify psychosocial aspects of their experience and focus on characteristics that could maximize the quality of the time they have left to live (Clark, Hickey, O'Boyle, & Hardiman, 2001). This shift of focus on what constitutes quality of life may account for the minimal change in quality of life observed among ALS patients as the disease progresses. It is thought that as individuals with ALS approach the inevitable fate of death, they may develop more clarity and appreciation for what is most

important to them and the ability to shift their attention to those aspects that will add to their quality of life (Clarke, Hickey, O'Boyle, & Hardiman, 2001).

In a study comparing ALS patients who have positive quality of life with those who have negative quality of life, it was found that characteristics other than physical deterioration, such as meaning in life, spirituality, personality, and social factors influence positive quality of life (Nelson, Trail, Van, Appel, & Lai, 2003). The factors that contribute to positive quality of life amongst ALS patients were incorporated into the development of the ALS-Specific QOL instrument (Simmons et al., 2006). This instrument examines the factors of negative emotion, interaction with people and the environment, intimacy, religion, physical symptoms, and bulbar function (Simmons et al., 2006).

Although this measure was not used in the Nelson, Trail, Van, Appel, and Lai (2003) study comparing patients with negative QOL and positive QOL, it appears that many of the factors measured on the ALSSQOL-R were uncovered in this study. For instance, it was found that of those patients with negative quality of life, forty-eight percent experienced a decline in the quality of their close relationships (Nelson, Trail, Van, Appel, & Lai, 2003). The quality of close relationships is measured by the intimacy and interaction with people and with their environment factors of the ALSSQOL-R.

It was also found that disease related stress involving impairment in activities of daily living, increased dependency, and speech difficulties further influenced the presence of negative quality of life (Nelson, Trail, Van, Appel, & Lai, 2003). These factors are measured in the ALSSQOL-R in the areas of physical function and bulbar function (Simmons et al., 2006).

Internal personality traits as well as relationships with family and friends were also found to be significant sources of support that positively influence quality of life of individuals with

ALS (Nelson, Trail, Van, Appel, & Lai, 2003). To support this, it has been determined that family and friends have the strongest impact on quality of life among ALS patients (Neudert, Wasner, & Borasio, 2004). These factors are measured on the ALSSQOL-R in the domain of interaction with people and the environment (Simmons et al., 2006).

Religiosity and spirituality were also found to increase positive quality of life in ALS patients because these domains offer reassurance and tranquility (Nelson, Trail, Van, Appel, & Lai, 2003). Religion is a factor on the ALSSQOL-R (Simmons et al., 2006).

In addition, stress due to relationship problems, mood changes, and physical aspects of the illness negatively influenced quality of life (Nelson, Trail, Van, Appel, & Lai, 2003). These concepts are measured by the negative emotion factor on the ALSSQOL-R. Changes in lifestyle, in work, in leisure, and finances were also found to impact quality of life negatively (Nelson, Trail, Van, Appel, & Lai, 2003).

Religion.

ALS patients along with their caregivers who held strong religious beliefs and practices were much less likely to consider assisted suicide a viable option when compared with those who were less religious (Ganzini, Johnston, McFarland, & Lee, 1998). In addition, it has been found that ALS patients who express an interest in hastening death consider religion to be less important in their lives (Albert et al., 2005).

Religion is associated with positive quality of life. It is thought that religious beliefs offer patients who have terminal illnesses positive coping strategies as they face impending death (Okon, 2005). A longitudinal study examining the role of positive self-perception and religiosity on quality of life among ALS patients found that religious practices were strongly associated with quality of life. It was further found that self-perceived health was also related to positive

quality of life (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004). In addition to the perception of overall health, search for meaning in life was also related to quality of life. It appears that the ability to maintain a positive self-perception and search for meaning are related to the practice of religion and overall quality of life (Bremer, Simone, Walsh, Simmons, & Felgoise, 2004).

Religion and spirituality have been found to be related to the maintenance of well-being among individuals with ALS. It is thought that spirituality may provide comfort for individuals when faced with a terminal illness. Spiritual well-being has been described as involving two components; these include being religious, and an existential domain (McLeod, & Clarke, 2007). It has been found that when an individual has a relationship with God through his or her religion and also has a sense of purpose in life, his or her level of quality of life is higher (Dal Bello-Haas, Andrews-Hinders, Bocian, Mascha, & Wheeler, 2000).

Hopelessness.

Many patients facing death experience periods of depressed mood. These periods of depression often reflect normal reactions to loss as opposed to clinical depression (Bascom & Tolle, 2002). The physical symptoms of ALS can mimic the physical symptoms of depression. Therefore the cognitive aspects of depression such as anhedonia, guilt, loss of self-worth, and pervasive sadness should be used to determine the diagnosis of depression (Bascom & Tolle, 2002).

The presence of depression, however, does not appear to be the most important predictor for the consideration of a hastened death among ALS patients. Hopelessness, rather, appears to correlate with the desire for this procedure more strongly (Ganzini, Johnson, McFarland, Tolle, & Lee, 1998). The ALSSQOL-R inquires about hopelessness by asking patients to rate the item

“I have felt hopeless” on an eleven point Likert scale, with zero indicating not at all and ten indicating very much (Simmons et al., 2006). Hopelessness can also be assessed by inquiring about an individual’s belief in reaching future goals, and asking if the individual believes things are changing for the better (Everson et al., 1996).

The main factor influencing patients with ALS to consider PAS appears to be hopelessness (Appel, 2004). It has been found that patients who express a wish to die reported significantly more hopelessness, and reduced optimism, than those who were not expressing this wish (Albert et al., 2005). It is the responsibility of healthcare providers, therefore, to assist ALS patients in finding hope and courage in other areas of their lives regardless of the absence of a cure (Appel, 2004).

Decision making process of hastened death among ALS patients.

Often times the will to live is based on the transcendent, existential aspects of meaning in life and worthiness (Bascom & Tolle, 2002). It has been found that what may be perceived as depression in the end stages of ALS may be better described as existential suffering, or an overall loss of meaning and purpose. The concept of loss of meaning is evaluated on the ALSSQOL-R. It is assessed by asking patients to rate the statement, “My life has been purposeful and meaningful” on an eleven point Likert scale, with zero indicating strongly disagree and ten indicating strongly agree (Simmons et al., 2006).

The decision to hasten death may be the result of end of life despair. The broader syndrome of end of life despair includes: suffering, loss of interest in living, lack of pleasure, diminished interest in activity, and negativity (Albert et al., 2005). Religion and spirituality are lower in patients who demonstrate end of life despair. For patients demonstrating this syndrome, the ability to control their dying process brought about an increase in relief, and a decrease in

suffering (Albert et al., 2005). It has been found that depression symptoms were less severe in those ALS patients who were able to act on the wish to die. It was further noted that perceptions of control over disease management increased in patients who were able to hasten death (Albert et al., 2005). It is important to give patients with this syndrome increased control at the end of life because control can be considered an aspect that adds dignity to the dying process (Albert et al., 2005).

It has been noted that many patients with ALS are seeking a safe and comfortable death. The desire for death among these patients may not be a sign of depression, per se, but rather the wish to face death fully content and fulfilled (Bascom & Tolle, 2002). Research conducted in Oregon reveals that patients who pursue PAS have the wish to control the circumstances and timing of their deaths (Bascom & Tolle, 2002). It has been found that only one-third of patients who received lethal prescriptions in Oregon actually used them. This indicates that the mere possession of the medication provides the individual with a sense of control that decreases his or her concerns about death (Bascom & Tolle, 2002). Individuals with ALS who receive a lethal prescription often report feeling safer and in greater control as the disease progresses toward death. The observation that many individuals do not use the lethal prescription indicates that the increase in the sense of control over the disease decreases the mental health suffering (Baumrucker, 2006).

In addition, it has been demonstrated that the majority of the patients who reported that they would request a lethal prescription indicated that they would keep the medication accessible for potential use at a future time. In this study, only one patient indicated that (he/she) would use the lethal prescription immediately if it were available (Ganzini, Johnston, McFarland, & Lee, 1998). These results are consistent with other findings among terminally ill patients; some

individuals gain emotional relief in knowing that controlling the timing and circumstances of their death is an option (Ganzini, Johnston, McFarland, & Lee, 1998). Being able to control the timing and circumstances of death may be especially important for ALS patients because the inability to engage in functional activities, and maintain independence leads to a distressing loss of autonomy (Ganzini, Johnston, McFarland, & Lee, 1998). These findings further support the observation that the majority of patients who request PAS do not persist with this request if their concerns are addressed effectively (Bascom & Tolle, 2002).

Identifying, and incorporating into treatment those factors that contribute to quality, and meaning in life among ALS patients is an important area of intervention. The use of social problem-solving therapy may assist patients in identifying alternative solutions for increasing their quality of life and sense of meaning. Focusing on these factors in the social problem-solving model can lead to the development of coping strategies that will allow the patients to increase their adaptive functioning and focus on those areas that are important to them. The ability to focus on those important areas of life may aid in enhancing quality of life as the disease progresses. By delineating the areas of their lives that are most significant, ALS patients may be able to bring about the cultivation of beneficial coping strategies that will afford greater levels of meaning as the disease progresses, and a decrease in the desire to hasten death (Neudert, Wasner, & Borasio, 2004).

The current study seeks to examine social problem-solving and how this relates to factors that influence the consideration of hastened death among ALS patients. By exploring these constructs the most beneficial areas of intervention to improve quality of life will be identified, as will also be an increased understanding of the desire to hasten death among ALS patients. The constructs that will be examined include: physical function as defined by the ALS

Functional Rating Scale- revised (ALSFRS-R); global quality of life as measured by the McGill Quality of Life Single-Item Scale, ALS specific quality of life as defined by the ALSSQOL-R, which includes negative emotion, interaction with people and the environment, intimacy, religion, physical symptoms, and bulbar function; hopelessness as measured by two items addressing goals for the future, and hope that things will change for the better, and an item on the ALSSQOL-R; spirituality as measured by the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp); the desire to hasten death as measured by the Schedule of Attitudes Toward Hastened Death; and social problem-solving orientation and styles as measured by the Social Problem-Solving Inventory-Revised Short Version (SPSI-R:S).

CHAPTER 3

Research Hypotheses

There are three research hypotheses of the current study. They are as follows:

- 1.) Hopelessness will account for the greatest amount of variance in the desire to hasten death, followed by global quality of life, then spirituality, and finally physical function which is predicted to account for the least amount of variance.
- 2.) Factors of ALS Specific Quality of Life instrument (ALSSQOL-R) will determine the desire to hasten death. The factor of negative emotion will account for the greatest amount of variance in the desire to hasten death, followed by religion, interaction with people and the environment, intimacy, bulbar function, and finally, physical symptoms will account for the least amount of variance.
- 3.) Social problem-solving orientation and styles will correlate with the desire to hasten death.

Justification for Hypotheses

This study is designed to examine the factors and social problem-solving styles and orientations that may contribute to the desire to hasten death among individuals with ALS. The literature supports the factors of hopelessness, global quality of life, spirituality and physical function as contributing to the desire to hasten death among ALS patients. Based on the literature, it was hypothesized that hopelessness would contribute most significantly to the desire to hasten death, followed by low levels of global quality of life, then low levels of spirituality, with physical function contributing least significantly to this desire.

This study also examined the factors of the ALS Specific Quality of Life instrument (ALSSQOL-R) and how they contributed to the desire to hasten death. It was hypothesized that

negative emotion would contribute most significantly to the desire to hasten death, followed by religion, interaction with people and the environment, intimacy, bulbar function, and finally physical symptoms. Examining the factors of the ALSSQOL-R and how these contributed to the desire to hasten death will allow clinicians to identify factors that could predict the desire to hasten death among ALS patients. By examining these factors, the ALSSQOL-R will be able to be used as a clinical instrument in identifying those patients that are at risk for considering a hastened death.

Social problem-solving orientation and styles were also believed to correlate with the desire to hasten death. Based on social problem-solving theory, it was hypothesized that a negative problem-solving orientation and impulsive/careless and avoidant problem-solving styles would contribute to the consideration of hastened death. It was believed that individuals who perceived problems as threats to their well-being, and felt doubt about their ability to solve problems, as demonstrated by scores indicating a negative problem-solving orientation, would be more likely to consider hastened death. It was additionally believed that if individuals demonstrated constricted and impulsive attempts at problem-solving, or avoided problem-solving they would demonstrate the consideration to hasten death. It was further hypothesized that a positive problem orientation and rational problem-solving style would not contribute to the desire to hasten death among ALS patients. It was believed that patients who perceived problems as challenges and believed in their ability to solve problems would be less likely to consider hastened death. It was further believed that individuals who approached problems in a purposeful and methodical manner and applied successful problem-solving skills would be less likely to consider hastened death.

CHAPTER 4

Methodology

Overview.

This study was quantitative and was designed to examine the factors and social problem-solving orientations and styles that influence the consideration of a hastened death among ALS patients. Through a thorough review of the literature, the factors of physical function, quality of life, hopelessness, and religion were identified as having an influence on the desire to hasten death. These constructs were examined, using objective measures to determine the level of impact they have in predicting the desire to hasten death. The construct of social problem-solving was also examined to determine the types of problem orientations and problem-solving styles that may contribute to the desire to hasten death.

Design and design justification.

The design of this current study was a cross-sectional observational design. Objective measures were utilized to determine how the variables of physical function, global quality of life, ALS specific quality of life, hopelessness, and spirituality predict the desire to hasten death. Multiple regressions were performed to determine the amount of variance each factor contributed to the desire to hasten death. Social problem-solving orientation and styles and how they contribute to the desire to hasten death were also examined, using a correlational method. A correlational method was deemed appropriate because it would hopefully demonstrate those problem-solving orientations and styles which best predicted the desire to hasten death.

Participants.

Participants included those individuals who had received a diagnosis of ALS or MND, including upper motor neuron and lower motor neuron disease. Individuals involved in this

study had access to and used the internet. Demographic variables were collected, including date of birth, gender, ALS symptom onset and site of symptom onset, date of ALS diagnosis, active participation in religious groups, religious orientation, mental health history, history of experiencing traumatic events, history of past suicide attempts, use of psychiatric medications, whether or not the individuals attend an ALS support group, and if they attend an ALS multidisciplinary clinic. This study was limited to those individuals residing in the United States, because some of the measures being utilized were not validated for international populations. Sixty-nine individuals completed the study.

Inclusion criteria.

Individuals eligible to participate in this study had received a diagnosis of ALS, and were at various stages in the disease process. Study participants included males and females, eighteen years or older, who resided in the United States. All participants were able to read and understand English at the sixth grade level, and had the capacity to complete self-report measures via the internet. All individuals in this study had access to the internet, the ability to communicate via this medium, and were members of the social networking website PatientsLikeMe.com.

Exclusion criteria.

Individuals who did not have a diagnosis of ALS, and those under the age of eighteen were excluded from this study. Individuals residing outside of the United States were also excluded from this study because some of the measures being employed were not validated for international samples. Caregivers of ALS patients were not included in this study.

Recruitment.

Individuals were recruited for this study through the social networking website, PatientsLikeMe.com. PatientsLikeMe.com is a health website that enables patients with certain illnesses to connect with one another and share their treatment and symptom experiences. PatientsLikeMe hosts a community specifically for patients with ALS. Through PatientsLikeMe, ALS patients are able to communicate, empathize, share experiences, post symptoms, and treatments, and share what has been successful for them. A link to this study was sent to one hundred and fifty members of the PatientsLikeMe website. By hosting this study through the PatientsLikeMe website, it was thought that patients could converse with other patients, if needed, about their thoughts and feelings regarding the terminal aspect of their disease. It has been found repeatedly that social support is vital to helping ALS patients cope with their illness. By working with PatientsLikeMe, it was hoped that patients would be able to find support in discussing the terminal aspect of their disease in a forum that was safe and conducive to open communication. Because the topic of hastened death is so rarely addressed, it was further thought that by hosting this study through the PatientsLikeMe website, the stigma of discussing this topic would begin to dissipate and patients would be able to obtain the support and encouragement needed to address these concerns.

A brief description of the study, along with a link to the survey, was sent to one hundred and fifty individuals who had joined the PatientsLikeMe website within thirty days of the study initiation. Before participants entered the research study a page providing detailed information regarding the sensitive nature of the study topic was presented. The inclusion and exclusion criteria were also presented on this page along with information regarding the ability to take a rest break while completing the assessments if so desired, and links to resources for those individuals who may have felt distress when thinking about their own deaths.

Informed consent.

The study was anonymous so the identity of the individuals who participated was not able to be identified. All data obtained in this study went into a database that did not contain identifying information. Before individuals took part in the measurements, however, there was a disclaimer informing the participants that the subject matter was of a sensitive nature with regard to the consideration of death and suicide.

Measures.*ALS functional rating scale (ALSFERS-R)/ALSFERS-revised.*

The ALSFRS-R is a questionnaire-based scale that examines the level of physical function of ALS patients in carrying out activities of daily living. The ALSFRS-R examines four factors including: gross motor tasks, fine motor tasks, bulbar functions, and respiratory function (Cedarbaum et al., 1999). The scale is composed of twelve items that are scored on a five point Likert scale ranging from zero (indicating dependence, or the inability to complete a task) to four (indicating no need for assistance). The ALSFRS-R is scored by adding up the individual item scores. A high score of forty-eight indicates limited physical dysfunction, and a low score of zero indicates complete dependence on others to complete activities of daily living (Cedarbaum et al., 1999).

The ALSFRS-R has been used in clinical trials as well as in clinical practice. It has been found to demonstrate sufficient internal consistency as well as construct validity when compared with the ALSFRS, Sickness Impact Profile, and an independent measure of pulmonary function (Cedarbaum et al., 1999). The ALSFRS-R has also been demonstrated to be a stronger predictor than ALSFRS for survival among ALS patients (Cedarbaum et al., 1999). The original ALSFRS did not weigh the variable of respiratory dysfunction relative to the limb and bulbar function

variables equally. This was a weakness of that measure. The ALSFRS-R distributed equal weight to these variables, and appears to have become a more sensitive and reliable measure (Cedarbaum et al., 1999). A self-administered version of the ALSFRS-R has also been developed. This version has been found to show high reliability when compared with the standard evaluator-administered ALSFRS-R (Montes et al., 2006). In addition, the self-administered ALSFRS-R demonstrates a level of sensitivity to change over time comparable with the evaluator-administered ALSFRS-R (Montes et al., 2009).

The ALS-specific quality of life instrument-revised (ALSSQOL-R).

The ALSSQOL is a questionnaire-based quality of life instrument that measures the factors of negative emotion, interactions with people and the environment, intimacy, religiosity, physical symptoms, and bulbar function (Simmons et al., 2006). The ALSSQOL-R contains fifty items, ranging from zero (indicating the least desirable situation) to ten (the most desirable situation) that are scored on a Likert scale. The ALSSQOL-R produces an average for each individual ranging from zero to ten. This score is calculated by taking a sum of all the items completed by that individual, and then dividing that sum by the number of questions answered (Simmons et al., 2006).

The ALSSQOL-R has demonstrated content, face, concurrent, convergent, and discriminant validity through its comparison with the MQOL-SIS, WHOQOL-BREF, SEIQoL-DW, BSI, ALSFRS, IIR, and the FACIT-SP-12 (Simmons et al., 2006). The ALSSQOL-R is useful in clinical trials because it inquires into areas of quality of life broader than physical dysfunction. The variables examined in this instrument reveal that quality of life is not wholly determined by physical function, and that spiritual, existential, and social domains contribute to the level of this construct (Simmons et al., 2006). A potential weakness of this instrument is that

the score reflects a narrow range of numbers; therefore, the instrument may not be as sensitive to changes in scores over time (Simmons et al., 2006). This is not a true weakness, however, since quality of life has been shown to remain constant among ALS patients even as physical function declines. Further, regardless of the narrow range of scores, the ALSSQOL-R allows the evaluator to identify areas of concern that may need further intervention (Simmons et al., 2006).

Functional assessment of chronic illness therapy-spiritual well-being scale (FACIT-Sp).

The FACIT-Sp is a questionnaire instrument designed to assess overall spiritual well-being, sense of meaning and peace, and role of faith in illness (Peterman, Min, Brady, Pharm, & Cella, 2002). The FACIT-SP is a twelve item measure. Each item is rated on a zero (not at all) to four (very much) Likert scale. Results from the FACIT-Sp include subscale scores for sense of meaning and peace, role of faith in illness, and an overall spiritual well-being score (Peterman, Min, Brady, Pharm, & Cella, 2002).

The FACIT-Sp has been found to have good internal consistency and reliability as well as a significant correlation to quality of life measures (Peterman, Min, Brady, Pharm, & Cella, 2002). It has also demonstrated sufficient convergent validity when compared with five other measures of spirituality and religion (Peterman, Min, Brady, Pharm, & Cella, 2002). Overall, the FACIT-Sp has been found to be a psychometrically sound measurement for spiritual well-being among patients with chronic illnesses and with cancer (Peterman, Min, Brady, Pharm, & Cella, 2002).

Hopelessness.

Hopelessness can be defined as the holding of negative expectancies about oneself and the future (Everson et al., 1996). To assess hopelessness in this study, a two item hopelessness scale will be borrowed from a study conducted by Everson et al., 1996, in which the role of

hopelessness and risk of mortality were examined to determine the impact on the incidence of myocardial infarction and cancer (Everson et al., 1996). The hopelessness scale utilized in this study was derived from a battery of psychosocial questionnaires. The items identified to assess hopelessness include: "I feel that it is impossible to reach the goals I would like to strive for" and "The future seems to me to be hopeless, and I can't believe that things are changing for the better." In past studies, responses for these items have been scored on a five point Likert scale ranging from zero (absolutely agree) to four (absolutely disagree). The items on this scale would be reverse scored and summed in order to yield a hopelessness score (Everson et al., 1996). If scored in this manner, the scores would range from zero, indicating a low level of hopelessness, to eight, indicating a high level hopelessness (Everson et al., 1996). The two items in this measure have been found to be moderately correlated ($r = .53$), indicating some internal consistency (Everson et al., 1996). In this study the two items were rated either "True" and scored as one, indicating agreement with the statement, or "False" and scored as zero. The responses to the items were then added together; a score of zero indicated a low level of hopelessness, and a score of two indicated a high level of hopelessness. The manner in which this measure was scored in this study led to less variability among the hopelessness scores obtained.

Social problem-solving inventory-revised short version (SPSI-R:S).

The Social Problem-Solving Inventory-Revised Short version is a condensed version of the Social Problem-Solving Inventory-Revised. The SPSI-R:S is a twenty-five item self-report instrument that assesses five problem-solving characteristics. The SPSI-R:S is composed of five scales including positive problem orientation (PPO), negative problem orientation (NPO), rational problem solving (RPS), impulsivity/careless style (ICS), and avoidance style (AS). In

order to assess these characteristics, the measure asks individuals to rate how they would typically respond to problems, utilizing a five point Likert scale ranging from the description of “not at all true of me” to “extremely true of me.” The SPSI-R:S produces five raw data scores that can be converted to standard scores with a mean of ten and standard deviation of fifteen. Elevated scores on the PPO and RS reflect more effective problem-solving skills and elevated scores on the NPO, ICS, and AS reflect probable deficits in problem-solving skills.

In developing the SPSI-R:S, a normative sample of 2312 individuals was utilized. Participants ranged in age from adolescents to older adults, and were described as both “normal” and “distressed” (D’Zurilla, Nezu, & Maydeu-Olivares, 1995). When examined with college students, internal consistency for the scales ranged from .76 for PPO to .92 for RS, and test retest reliability ranged from .72 for PPO to .88 for NPO (D’Zurilla, Nezu, & Maydeu-Olivares, 1995).

Schedule of attitudes toward hastened death.

The Schedule of Attitudes Toward Hastened Death is a twenty item, true-false instrument that measures a medically ill patient’s desire to hasten death. The measure was designed to capture various aspects of the desire to die including: concerns about future quality of life, social and personal aspects, and direct thoughts about ending one’s life (Rosenfeld et al., 1999). The Schedule of Attitudes Toward Hastened Death has been demonstrated to be a highly reliable, valid measure of the desire to die among HIV/AIDS patients. The total score yielded from the Schedule of Attitudes Toward Hastened Death has been shown to correlate significantly with the clinician rating on the Desire for Death Rating Scale (Rosenfeld et al., 1999). It has also been shown to be significantly related with levels of pain intensity and physical symptom distress. A factor analysis revealed that this measure supports a single factor structure (Rosenfeld et al.,

1999). Although this measure has been validated on HIV/AIDS patients, the items contained on this instrument appear appropriate to use with other terminally ill populations.

Procedure.

A brief description of the study, along with a link, was sent to one hundred and fifty members of the ALS community on the social networking website, Patientslikeme.com. This is a health website designed so that individuals with various illnesses might connect with other patients and share their experiences, symptoms, and treatments. It hosts an online community specifically for ALS patients. A message was sent to potential study participants. This message included a disclaimer warning individuals of the sensitive nature of the study topic, indicating not to proceed if they felt uncomfortable thinking about their own death. The inclusion and exclusion criteria were also provided in this message along with instructions on the ability to take rest breaks if so desired, and links to resources for those who may have felt distress when thinking about their own deaths. Once participants clicked on the link that was sent to them via the message from the PatientsLikeMe website, they were led to the survey, which was also hosted by the PatientsLikeMe website.

Individuals consented to participate in the study by reviewing informed consent materials that delineated the nature of the study and ensured the anonymity of those who participated. Those who consented to participate in the study were prompted to click on the link that allowed them to begin filling out the survey. The participants were asked initially to answer demographic information questions including: marital status, whether or not they had children, how many people they lived with, who they lived with, their active participation in religious groups, their religious orientation, mental health history, history of experiencing traumatic events, history of past suicide attempts, use of psychiatric medications; they were also asked if they attended an

ALS support group, and whether or not they attended an ALS multidisciplinary clinic. The PatientsLikeMe website provided demographic information that had already been collected from the patients upon initiation of their PatientsLikeMe membership. Information provided by the website included: sex, age, ALS symptom onset and site of symptom onset, date of ALS diagnosis, and scores from the ALSFRS-R. The measures were then presented to the participants in the following order: ALSSQOL-R, two item Hopelessness Scale, FACIT-Sp, Schedule of Attitudes Toward Hastened Death, and the SPSI-R:S. If participants chose to take a break while completing the measures they were prompted to re-visit the site at a later time to complete the measures. After the participants completed the demographic information and measures they were asked to provide feedback on the survey and thanked for their participation. The time required to complete the materials in this study without taking a rest break was approximately twenty minutes.

CHAPTER 5

Statistical Analysis

Hypothesis 1: Hopelessness will account for the greatest amount of variance in the desire to hasten death, followed by global quality of life, then spirituality, and finally physical function, which is predicted to account for the least amount of variance.

The data obtained for the first hypothesis in this study were analyzed using hierarchical multiple regression. The scores of the hopelessness measure were entered into a regression equation followed by the scores of global quality of life, spirituality, and physical function. It was predicted that hopelessness would account for the greatest amount of variance when predicting the desire to hasten death, followed by global quality of life, then spirituality, and finally physical function. By using hierarchical multiple regression, the factors identified in the literature as contributing to the desire to hasten death were examined to determine their variance in predicting this desire.

Hypothesis 2: Factors of the ALS Specific Quality of Life Instrument- Revised (ALSSQOL-R) will determine the desire to hasten death. The factor of negative emotion will account for the greatest amount of variance in the desire to hasten death, followed by religion, interaction with people and the environment, intimacy, bulbar function, and finally, physical symptoms will account for the least amount of variance.

To test the second hypothesis a hierarchical multiple regression equation was also used. The factors of the ALSSQOL-R were entered into the multiple regression equation hierarchically to determine the amount of variance each factor accounted for when predicting the desire to hasten death. Based on the literature, the factor of negative emotion was predicted to account for the greatest variance and was entered first; this was followed by religion, interaction with people and the environment, intimacy, bulbar function, and finally physical symptoms.

Hypothesis 3: Social problem-solving orientations and styles will correlate with the desire to hasten death.

The third hypothesis was tested using a Pearson product-moment correlation. It was predicted that good problem-solving skills as evidenced by a positive problem orientation and rational problem solving style would produce a negative correlation with the desire to hasten death because it was not believed that these factors would predict the desire to hasten death. It was further believed that poor problem-solving skills as evidenced by a negative problem orientation, impulsivity/carelessness style, and avoidance style would positively correlate with the desire to hasten death. It was hoped that by analyzing the data in this manner the problem-solving factors that most significantly predict the desire to hasten death would be identified.

The demographic information obtained in this study was analyzed using descriptive statistics. The frequencies, means, medians, modes, and standard deviations were calculated and examined to determine the personal characteristics of those who completed the study.

Descriptive Statistics

The descriptive statistics and frequencies were used to summarize and understand basic features of the data collected for this sample (see Table 1 and Table 2). One hundred and fifty individuals with ALS were contacted to participate in this study. All of the individuals were members of the social networking website, PatientsLikeMe.com, and were contacted through that network. Of the one hundred and fifty individuals contacted, sixty-nine individuals completed the survey, resulting in a forty-six percent response rate. Some individuals partially completed the measures, and information was provided by PatientsLikeMe on the ALSFRS-R scores for most of the individuals contacted to participate in the study. PatientsLikeMe also

provided information on age, duration from ALS diagnosis, duration from first symptom, and the site of disease onset for those who were contacted to participate in the study.

Table 1

Descriptive Statistics

	Overall sample		
	M	SD	n
Age	54.14	9.849	150
Duration from ALS diagnosis (days)	1079.27	1055.379	140
Duration from first Symptom (days)	1735.42	1355.901	148
Site of disease onset			
Arms			46
Bulbar region			29
Legs			50
Respiratory muscles			4

Table 2

Demographic Data of the Sample

	Overall sample	
	%	n
Sex		
Male	59.42	41
Female	40.57	28
Marital status		
Married	83.8	62
Widowed	4.1	3
Divorced or separated	5.4	4
Never married	6.8	5
Children		
Had children	85.1	63
Did not have children	14.9	11
Living Arrangement Status		
Lived with one other individual	37.8	28
Lived with two other individuals	24.3	18
Lived with three other individuals	18.9	14
Lived with four other individuals	10.8	8

Lived alone	8.1	6
Who Participants Lived with		
Spouse	37	27
Spouse and son	13.7	10
Spouse and daughter	16.4	12
Spouse, son, and daughter	5.5	4
Paid caregiver	2.7	2
“Other relative”	2.7	2
Spouse, son, and “other relative”	2.7	2
Daughter and grandchild	2.7	2
Spouse, and “other relative”	2.7	2
Other combinations of people participants lived with	9.5	7
Church attendance/ spiritual community		
Gatherings attendance	50	37
Religion practiced		
Christianity	50	37
Catholicism	17.6	13
Protestantism	10.8	8
Judaism	2.7	2
Jehova’s Witness	1.4	1
Buddhism	1.4	1
Not religious	14.9	11

Attendance to a multi-disciplinary ALS clinic and ALS support group.

Seventy-four participants provided information regarding whether or not they attend a multi-disciplinary ALS clinic and ALS support groups. The majority of the participants (n=56, 75.7%) indicated that they attend a multi-disciplinary ALS clinic. Additionally, thirty-three participants (44.6%) reported attending an ALS support group.

Mental health history and use of psychiatric medications.

Seventy-four individuals provided information about whether or not they had a history of mental illness prior to being diagnosed with ALS. A small number (n=4, 5.4%) of individuals endorsed a history of mental illness prior to being diagnosed with ALS. Only four individuals provided information regarding whether or not they take medication for a psychiatric condition. Of that four, two people indicated taking psychiatric medications.

History of suicide attempt.

Seventy-four individuals provided information regarding past suicide attempts. Only two participants (2.7%) indicated that they had attempted to commit suicide in the past.

History of traumatic events.

Seventy-four individuals provided information regarding experiencing traumatic events in the past. The majority of the sample (n=50, 67.6%) denied experiencing any traumatic events in their past. Of the remaining participants, five (6.8%) indicated experiencing a severe life threatening accident; four (5.4%) indicated exposure to a natural or man-made disaster; three (4.1%) indicated enduring emotional abuse; two (2.7%) endorsed being exposed to a natural or man-made disaster and having experienced a severe life-threatening accident; two (2.7%) endured physical and emotional abuse and were exposed to a natural or man-made disaster; one (1.4%) experienced emotional abuse and was a victim of and witness of domestic violence; one

(1.4%) endured emotional abuse and witnessed domestic violence; one (1.4%) endured sexual abuse and experienced a severe life-threatening accident; one (1.4%) endured physical and emotional abuse; one (1.4%) experienced sexual and emotional abuse and was a victim of domestic violence, and one (1.4%) endured sexual and emotional abuse.

Overall quality of life score.

Seventy-four individuals answered the McGill Quality of Life Single-Item Scale that asked them to rate their overall quality of life, considering their physical, emotional, social, spiritual, and financial well-being over the past seven days on a scale of zero to ten. The mean score in the normative data for the McGill Quality of Life Single-Item Scale is 7.1, with a standard deviation of 2.1 (Simmons et al., 2006). The scores obtained in this study on this item ranged from two to ten. The average score was 6.41, with a median of 7, and a standard deviation of 1.937. These scores fall within a normal range when compared with the sample upon which the psychometric qualities of this measure were developed.

ALS functional rating scale- revised (ALSFRS-R).

Scores for the ALSFRS-R were provided by the social networking website, PatientsLikeMe.com. When individuals with ALS join PatientsLikeMe.com, they are asked to complete the ALSFRS-R as a means of connecting with other individuals who are at a similar stage of disease progression. Individuals contacted to complete the survey were those who had joined PatientsLikeMe.com and completed the ALSFRS-R within thirty days of the study initiation date. Valid ALSFRS-R scores were provided for all one hundred and fifty individuals contacted to complete the survey. Scores for the ALSFRS-R can range from zero to forty-eight. Higher scores indicate a higher level of physical abilities. The psychometric properties of the ALSFRS-R reveal a mean score of 27.0, with a standard deviation of 7.2 (Cedarbaum et al.,

1999). Scores provided for the sample contacted for this study ranged from zero to forty-eight. The average score was 27.12, with a median of 29.5, and a standard deviation of 11.572. These scores are consistent with the sample upon which the normative data of the ALSFRS-R was obtained.

Social problem-solving inventory-revised: short form (SPSI-R:S).

Sixty-nine valid responses were obtained for the SPSI-R:S. The SPSI-R:S yields six scores, a total problem solving score, and five subscales including; positive problem orientation (PPO), negative problem orientation (NPO), rational problem solving (RPS), impulsivity/careless style (ICS), and avoidance style (AS) . Scores obtained on this measure are converted into standard scores with a mean of 100 and a standard deviation of 15. Scores falling within the range of 85 to 115 are considered to be in the normal range. The overall problem solving score obtained from this sample ranged from 81 to 131. The average score was 106, with a median of 106, and a standard deviation of 10.68. Scores for positive problem orientation ranged from 67 to 135. The average score was 103.65, with a median of 106, and a standard deviation of 14.63. Negative problem orientation scores ranged from 78 to 141. The average score on this subscale was 93.913, with a median of 91, and a standard deviation of 13.44. Rational problem solving scores ranged from 70 to 137. The average score was 102.56, with a median of 101, and a standard deviation of 13.27. Scores obtained on the impulsive/carelessness style subscale ranged from 77 to 133. The average score was 96.35, with a median of 93, and a standard deviation of 10.49. Avoidance style subscale scores ranged from 76 to 138. The average score on this subscale was 94.36, with a median of 93, and a standard deviation of 11.84. As a group, all of the mean scores obtained on each scale of this measure fell within a normal range. This indicates that, as a group, the participants who completed this measure demonstrated problem-solving

abilities that were consistent with the mean scores obtained by the sample upon which the normative data were collected for this measure.

Functional assessment of chronic illness therapy-spiritual well-being scale (FACIT-Sp).

Valid responses for the FACIT-Sp were obtained from sixty-nine individuals. Scores on this measure can range from 0 to 48. Validation studies of the FACIT-Sp have found the mean score of this measure to be 38.5, with a standard deviation of 8.1 (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). Scores obtained from the participants in this study ranged from 11 to 48. The average score obtained on this measure was 32.85, with a median of 34, and a standard deviation of 9.87. The average score obtained on this measure is somewhat lower than the overall average norm. The mean obtained, however, falls within the normal range. This indicates that the individuals who completed this study demonstrated an overall slightly lower level of spirituality than the group upon which the normative data were collected.

Schedule of attitudes toward hasten death (SATHD).

Sixty-nine valid responses were obtained for the SATHD. Scores on the SATHD can range from 0 to 20, with zero indicating the least desire for death. Normative data collected for this measure reveals a mean of 3.05, with a standard deviation of 3.80 (Rosenfeld et al., 1999). The scores obtained in this study ranged from 0 to 17, with higher scores indicating an increased desire to hasten death. The average score obtained was 5.2, with a median of 4, and a standard deviation of 3.8. The average score obtained in this study is slightly higher than the mean demonstrated in the normative data; however, the mean obtained in this study falls within a normal range. The scores obtained indicate that the participants in this study, on average,

demonstrated a slightly higher desire to hasten death than the group upon which the normative data were collected.

Hopelessness measure.

Seventy-one valid responses were obtained for the hopelessness measure, which consisted of two questions that were scored either one for “true,” or zero for “false.” The scores ranged from zero to two. The average score was .83; the median was 1, and the standard deviation was .84. As mentioned previously, the scoring used in this study was different from the scoring upon which this measure was developed. Comparisons between the normative group and the participants in this study, therefore, cannot be made.

ALS-specific quality of life instrument-revised (ALSSQOL-R).

Seventy-one valid responses were obtained for the ALSSQOL-R. The ALSSQOL-R yields a total quality of life score, and six subscale scores, including: negative emotion, interactions with people and the environment, intimacy, religiosity, physical symptoms, and bulbar function. The normative data for the ALSSQOL-R reveal the mean score of the subscales to be 7.1, with a standard deviation of 1.3. Scores for total quality of life obtained in this study ranged from 1.17 to 8.43. The average total quality of life score was 6.27, with a median of 6.58, and a standard deviation of 1.46. This score falls within the normal range and is consistent with the normative data of this measure. The negative emotion scores ranged from 1.69 to 9.38. The average negative emotion score was 6.34, with a median of 6.53, and a standard deviation of 1.72. This score is comparable with the normative data of this measure. Scores on the interactions with people and the environment subscale ranged from 2.55 to 10. The average score was 7.58, with a median of 7.81, and a standard deviation of 1.63. This score falls within the normal range when compared with the normative data for this measure. The intimacy

subscale had scores ranging from 1.43 to 10. The average score was 5.4, with a median of 5.7, and a standard deviation of 2.00. This score is slightly lower than the average score obtained in the normative data for this measure. Scores on the religiosity subscale ranged from 0 to 10. The average score was 5.83, with a median of 6.75, and a standard deviation of 3.58. This score is slightly lower than the average score obtained from the sample upon which the normative data were collected. The physical symptoms scores ranged from .17 to 9.17. The average score was 5.9, with a median of 6, and a standard deviation of 1.83. This score is comparable with the average score obtained from the normative sample. Bulbar function scores ranged from 1 to 10. The average score was a 6.37, with a median of 6.8, and a standard deviation of 2.81. This score falls within a normal range when compared with the average score obtained from the normative sample.

Correlations

Pearson product-moment correlations were conducted on all of the scores obtained from the measures employed in this study. The variables included in the Pearson product-moment correlations analysis were the: SATHD total score, Hopelessness total score, ALSSQOL-R total score, the six ALSSQOL-R subscale scores of negative emotion, interactions with people and the environment, intimacy, religiosity, physical symptoms, and bulbar symptoms, the ALSFRS-R total score; the SPSI-R:S total score was also included, along with the five subscale scores of positive problem orientation, negative problem orientation, rational problem solving style, impulsive/carelessness problem solving style, and avoidant problem-solving style.

Desire to Hasten Death, Hopelessness, and Quality of Life.

Table 3

Correlations between the SATHD and the ALSSQOL-R and Hopelessness Measure

	SATHD
<hr/>	
Hopelessness	
Total score	.439**
ALSSQOL-R	
Total score	-.450**
Negative emotion	-.387**
Interaction with people and the environment	-.316**
Bulbar symptoms	-.323**
Physical symptoms	-.258*

Note ** $p < 0.01$, * $p < 0.05$

These results indicate that an individual's level of hopelessness and quality of life are related to the desire to hasten death. Additionally, a higher level of disease-related ALS symptoms could increase the desire to hasten death.

Table 4

Correlations between the Hopelessness Measure and ALSSQOL-R

	Hopelessness Total score
ALSSQOL-R	
Total score	-.523**
Negative emotion	-.512**
Interaction with people and the environment	-.490**

*Note ** $p < 0.01$*

These results indicate that in addition to relating to the desire to die, individual's feelings of hopelessness also relate to their quality of life.

Quality of Life and Problem Solving.

Table 5

Correlations between the SPSI-R:S and the ALSSQOL-R and ALSFRS-R

	SPSI-R:S			RSP	ICS	ASC
	Total	PPO	NPO			
ALSSQOL-R						
Total score	.264*	.278*	-.378**	-	-	-
Negative emotion	.365**	.362**	-.418**	-	-	-
Interaction with people and the environment	.374**	.383**	-.397**	.265*	-	-
Intimacy	.296*	.317**	-.293*	-	-	-
Religiosity	-	-	-	-	.318**	.249*
Bulbar function	-	-.252*	-	-	-	-
Physical symptoms	-	-	-	-	-	-
ALSFRS-R						
Total score	-	.263*	-	-	-	-

Note ** $p < 0.01$, * $p < 0.05$

The correlation between negative problem orientation and overall quality of life indicates that individuals with ALS who approach problems with a negative outlook, and perceive

problems as momentous challenges that will affect their well-being, may maintain a lower level of overall quality of life.

The correlations between the ALSSQOL-R negative emotion subscale, SPSI-R:S total score, and SPSI-R:S negative problem orientation subscale could indicate two types of relationships. First, it could suggest that an individual's level of negative emotion could influence the manner in which a problem is approached. For instance, an individual with less negative emotion may approach a problem with a more positive outlook. Conversely, this relationship could indicate that an individual's problem may influence his or her outlook, or the manner in which the problem is approached.

The relationship between the ALSSQOL-R subscale of interaction with people and with the environment, the SPSI-R:S total score, the SPSI-R:S positive problem orientation subscale score, and the SPSI-R:S negative problem orientation subscale score indicates that the level of interaction individuals with ALS have with other people and with the environment relates to whether or not they approach problems in a positive or negative manner. Further, the small correlation found between the interaction with people and the environment subscale of the ALSSQOL-R and the rational problem solving style subscale of the SPSI-R:S indicates that a relationship exists between ALS patients who have more interactions with their environment and with other people and the adoption of a rational problem-solving style.

The correlation between the intimacy subscale of the ALSSQOL-R and the SPSI-R:S positive problem orientation subscale suggests that a relationship exists between ALS patients who have higher levels of intimate relationships and interactions and the likelihood that they may approach problems with a more positive outlook.

Interestingly, a relationship was found to exist between the religiosity subscale of the ALSSQOL-R, the impulsive/careless problem-solving style subscale of the SPSI-R:S, and, to a lesser extent, the avoidant problem-solving style subscale of the SPSI-R:S. This suggests a relationship between one's level of religiosity and the employment either of an impulsive/careless style of solving problems, or an avoidant style of solving problems. This may indicate that individuals with higher levels of religious beliefs may make quick decisions based on what they perceive as the right decision according to their faith. Conversely, individuals with higher levels of religious beliefs may avoid problems if they believe that by placing their faith in a higher power their problems will resolve.

The correlations found between the SPSI-R:S positive problem orientation subscale, the bulbar function subscale of the ALSSQOL-R, and the ALSFRS-R total score indicate that higher levels of bulbar and overall physical functioning may relate to a more positive approach to managing and solving problems.

Physical Functioning and Physical Symptoms of ALS.

Table 6

Correlation between the ALSSQOL-R Physical Symptom Subscale and the ALSFRS-R

	ALSFRS-R
	Total score
ALSSQOL-R	
Physical Symptoms	.339*

*Note *p<0.01*

As has been found in all previous research on ALS physical function and quality of life, it can be seen that physical function does not appear to be related to quality of life for ALS patients. Interestingly, in this study neither hopelessness nor the desire to hasten death was found to be related to an individual's level of physical function as measured by the ALSFRS-R. The desire to hasten death, however, was found to be related to the physical symptoms and bulbar function subscales of the ALSSQOL-R. These findings are likely due to the fact that the ALSFRS-R measures actual physical limitations; the physical symptoms and bulbar function subscales of the ALSSQOL-R measures an individual's perception of physical problems.

Hypotheses

Hypothesis 1.

Hopelessness will account for the greatest amount of variance in the desire to hasten death followed by global quality of life, then by spirituality, and finally by physical function, which is predicted to account for the least amount of variance.

Supported.

Table 7

Summary of Hierarchical Multiple Regression Analysis with the SATHD as Criterion-

Hypothesis 1

Step	Predictor variable	R ²	ΔR ²	ΔF
1	Global quality of life	.195	.195	16.238
2	Hopelessness	.294	.099	9.229

*p<.05

Hypothesis 2.

Factors of the ALS Specific Quality of Life Instrument- Revised (ALSSQOL-R) will determine the desire to hasten death. The factor of negative emotion will account for the greatest amount of variance in the desire to hasten death, followed by religion, interaction with people and with the environment, intimacy, bulbar function; finally, physical symptoms will account for the least amount of variance.

Supported.

Table 8

Summary of Hierarchical Multiple Regression Analysis with the SATHD as Criterion-Hypothesis 2

Step	Predictor variable	R ²	ΔR ²	ΔF
1	Negative emotion	.150	.150	11.832
2	Bulbar function	.229	.078	6.708

*p<.05

Hypothesis 3.

Social problem-solving orientation and styles will correlate with the desire to hasten death.

Not supported.

Table 9

Pearson Correlations between the SPSI-R:S and the SATHD

	SATHD
SPSI-R:S	
Total score	-.043
PPO	-.107
NPO	.164
RPS	.042
ICS	-.082
ASC	-.055

Overall Description of the Sample.

The sample obtained for this study was a comparable representation of the ALS population as a whole. Individuals diagnosed with ALS are most often between the ages of forty and seventy, with the average age of diagnosis being fifty-five (ALS Association, 2011). There have been cases of ALS found in younger people in their twenties and thirties; however, ALS is more prevalent among older adults (ALS Association, 2011). The average age of individuals who participated in this study was fifty-four, with the youngest individual being nineteen, and the eldest eighty-three. Overall, the ages of the participants who completed this survey were comparable with the ALS population as a whole.

In the general population, ALS has been found to be approximately twenty percent more prevalent in men than in women (ALS Association, 2011). As individuals age, however, the incidence of ALS among men and women has been shown to even out (ALS Association, 2011). The ALS CARES Database indicates that approximately sixty percent of ALS patients are male (ALS Association, 2011). For this study, ninety males (60%) and sixty (40%) females were contacted to complete the survey. Of those individuals contacted, forty-one (approximately 60%) males and twenty-eight (approximately 40%) females participated in the study.

After diagnosis, approximately fifty percent of ALS patients live at least three years or longer, twenty-five percent live five years or more, and up to ten percent live ten or more years (ALS Association, 2011). Of the individuals contacted to participate in this survey, one hundred and forty provided information regarding the length of time since they had been diagnosed. The average time since diagnosis was approximately three years.

Prior research suggests that ALS patients demonstrate the desire to hasten death at a rate higher than other terminally ill patients (Tolle, Tilden, Drach, Fromme, Perrin, & Hedberg,

2004). Much of the research on this topic has been conducted in Oregon and in other European countries where physician assisted suicides are legal. Characteristics that have been identified as leading to the consideration of hastening death among ALS patients include: level of physical functioning, quality of life, hopelessness, and level of religious beliefs (Ganzini, Johnson, McFarland, Tolle, & Lee, 1998; Albert et al., 2005).

This study sought to identify factors that could influence the desire to hasten death among the broader ALS population in the United States. The measures utilized in this study captured the factors of quality of life, hopelessness, physical functioning, and religion. The ALSSQOL-R was used to assess quality of life, along with six variables that influence quality of life including: negative emotion, interaction with people and with the environment, intimacy, religiosity, bulbar function, and physical symptoms. The ALSFRS-R was utilized to assess physical functioning, and a two-item hopelessness measure was employed to measure hopelessness. In addition, the FACIT-Sp was included to look more closely at spirituality, and the SPSI-R:S was used to examine how the participants in the study generally approach solving problems.

Overall the sample obtained for this study demonstrated good variability on the measures employed. Moderate levels of physical functioning were found, indicating some physical dysfunction as a result of ALS symptoms. When compared with the psychometric properties of the ALSFRS-R, the scores obtained in this study are similar. The normative data of the ALSFRS-R reveal a mean of 27.0, with a standard deviation of 7.2 (Cedarbaum et al., 1999). The mean obtained for the ALSFRS-R in this study was 27.12, with a standard deviation of 11.572. These scores are consistent with the sample upon which the normative data of the ALSFRS-R were obtained.

This sample also demonstrated good variability in quality of life as measured by the McGill Quality of Life Single-Item Scale, and the ALSSQOL-R. The mean score in the normative data for the McGill Quality of Life Single-Item Scale is 7.1, with a standard deviation of 2.1 (Simmons et al., 2006). The mean score obtained in this study was 6.41, with a standard deviation of 1.937. These scores fall within a normal range when compared with the sample upon which the psychometric qualities of this measure were developed. The scores obtained in this study on the ALSSQOL-R were also comparable with the psychometric properties of this measure. The normative data for the ALSSQOL-R reveal the mean score of the subscales to be 7.1, with a standard deviation of 1.3 (Simmons et al., 2006). All of the mean subscales scores obtained in this sample for total quality of life ($M=6.27$, $SD=1.46$), negative emotion ($M=6.34$, $SD=1.72$), interactions with people and with the environment ($M=7.58$, $SD=1.63$), physical symptoms ($M=5.9$, $SD=1.83$), and bulbar function ($M=6.37$, $SD=2.81$) are comparable with the mean scores revealed in the psychometric properties of this measure. The mean score obtained for the intimacy subscale ($M=5.4$, $SD=2.00$) from this sample, however, was slightly lower than the mean score obtained in the normative data for this measure. In addition, the average religiosity subscale score ($M=5.83$, $SD=3.58$) obtained in this study was also slightly lower than the average score obtained from the sample upon which the psychometric properties for this measure were developed. This indicates that the sample obtained for this study had levels of intimate interactions and religiosity that were somewhat lower than the sample upon which this measure was developed.

The hopelessness measure employed in this study involved two items that were scored on a scale of zero to one. The scores obtained in this study ranged from zero to two. The average score was .83, with a standard deviation of .84. The scoring used in this study was different from

the scoring upon which this measure was developed; therefore, comparisons between the normative group and the participants in this study cannot be made.

Participants in this study also demonstrated good variability on the scores obtained for the FACIT-Sp. Validation studies of the FACIT-Sp reveal the mean score of this measure to be 38.5, with a standard deviation of 8.1 (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). The average score obtained from the participants in this study was 32.85, with a standard deviation of 9.87. The average score obtained by the sample in this study is somewhat lower than the overall average norm. This indicates that the individuals who completed this study demonstrated an overall slightly lower level of spirituality than the group upon which the psychometric properties of this measure were developed.

Good variability in scores was also demonstrated by the participants in this study on the SPSI-R:S. Scores obtained for the SPSI-R:S were converted into standard scores with a mean of 100 and a standard deviation of 15. All of the average scores obtained on the subscales of this measure fell within a normal range when compared with the normative data of this measure. This indicates that, as a group, the participants in this study demonstrated problem-solving abilities that were consistent with the mean scores obtained by the sample upon which the normative data were collected for this measure.

The average scores obtained in this study on the SATHD tended to be slightly higher than the normative data of this measure. The psychometric properties for this measure demonstrate a mean score of 3.05, with a standard deviation of 3.80 (Rosenfeld et al., 1999). Higher scores on this measure indicate an increased desire to hasten death. The average score obtained from the participants in this study was 5.2, with a standard deviation of 3.8. The mean score obtained from this sample indicates that, on average, the participants demonstrated desire to hasten death

that was slightly higher than the group upon which the normative data for this measure was collected.

CHAPTER 6

Discussion

Discussion of the Hypotheses

The goal of this research was to identify and understand those factors and problem-solving styles which may influence the desire to hasten death among ALS patients. Three hypotheses were developed for this study. Two of the hypotheses focused on identifying factors that influence the desire to hasten death, and one examined possible problem-solving styles and orientations that would relate to the desire to hasten death. The two hypotheses identifying factors that influence the desire to hasten death were partially supported, but the third hypothesis was not supported.

The first hypothesis examined the factors of hopelessness, global quality of life, spirituality, and physical function, including how these aspects relate to the desire to hasten death. Hierarchical multiple regressions was used to analyze this hypothesis. The factors of hopelessness and global quality of life were found to relate significantly to, or predict, the desire to hasten death, but spirituality and physical function did not. Global quality of life contributed approximately twenty percent in the variability in scores when predicting the desire to hasten death. Hopelessness contributed approximately an additional ten percent over global quality of life in accounting for the variability of scores when predicting the desire to hasten death. This indicates that an individual's level of hopelessness along with global quality of life can reliably predict approximately thirty percent of the variability in the desire for a hastened death. This finding is noteworthy because it speaks to the need of health care providers, caregivers, and family members to address these areas of a patient's life.

As found in previous research, and in this current study, hopelessness is predictive of the desire to hasten death. Further, individuals without a clinical diagnosis of depression, but with

high levels of hopelessness are more likely to desire a hastened death (Breitbart & Heller, 2003). It has been thought that hopelessness may influence the decision making process of terminally ill patients (Sullivan, 2003). The items used to assess hopelessness in this study examined the individual's hope for the future and the fact that things will change, as well as their ability to strive toward goals.

Because of the terminal nature of ALS, it seems that hope, especially for the future, may be an area that healthcare professionals are reluctant to address. Owing to its relationship with the desire to die, however, it is imperative that healthcare professionals be able to talk with patients and assess their levels of hopelessness as well as help them identify aspects of their lives that they can continue to feel hopeful about. To do this, healthcare providers can explore with patients different areas of their lives and consider the possibility of a different way of thinking about hope. For instance, healthcare providers may consider talking with patients about how, even though their disease is terminal, they may continue the experience of being present for momentous events, even if being present means from the spiritual domain, depending on the patient's religious and spiritual beliefs. Also, healthcare providers may be able to help patients feel optimistic about the legacies they are able leave behind in terms of feeling hopeful and proud of their loved ones' ability to care for and continue to raise their families, or the healthcare providers may feel hope in encouraging patients to realize that they will be able to set a positive example for their friends and family of facing death in a dignified manner.

Because ALS is an incurable disease, it may seem daunting for healthcare providers to address the issue of hopelessness with patients. If, however, healthcare providers are able to help patients explore and identify areas in their lives about which they can feel hopeful, this may help the patient experience a cognitive shift. Cognitive shift, by definition, means that patients may

be able to alter the manner in which they think about their disease and, considering their situations, what hope can mean for them, and what it may look like if it does not entail living for many years into the future.

As found in previous research, a common motivation for hastened death involves concerns about quality of life (Pearlman et al., 2005). Global quality of life was assessed by means of an item asking participants to consider all parts of their lives including physical, emotional, social, spiritual, and financial over the previous week and rate their overall quality of life on a scale of zero to ten, with zero indicating “very bad,” and ten indicating “excellent.” Because global quality of life, as assessed in this manner, relates to the desire to hasten death, it is important for healthcare providers to ask patients about these aspects of their lives and to consider whether or not there is anything that can be done to improve these areas of functioning. Again, due to the terminal nature of ALS, a more holistic approach to patient care is warranted in order to improve the remaining part of the lives they have left to live. A consideration of only the medical aspects of patients’ conditions could unfortunately lead to a desire to end their lives prematurely.

This information is especially poignant for caregivers and family members of ALS patients. By being aware that these aspects could lead to a patient’s desire to die, family members and caregivers can be educated on how to recognize these characteristics in patients and help these patients communicate with their healthcare providers in order to find resources that can address their needs.

The second hypothesis of this study looked at the specific aspects of quality of life more closely to determine which of those factors, as measured by the ALSSQOL-R, predicted the desire to hasten death, as measured by the SATHD. Hierarchical multiple regressions were used

to analyze this hypothesis. The aspects of quality of life that were found to predict, significantly, the desire to hasten death included bulbar function and negative emotion. It was found that the factor of bulbar function contributed an additional seven percent in accounting for the variability of scores over the fifteen percent predicted by negative emotion when predicting the desire to hasten death. Thus, considering the various aspects that influence quality of life, it appears that individuals' perceptions of bulbar function along with their levels of negative emotion can predict whether or not they would express the wish to hasten death.

The finding that the perception of bulbar function may influence the desire to hasten death is significant when considering that physical function has not been found to influence quality of life significantly among ALS patients. In a dissertation project examining whether or not verbal communication affected quality of life in ALS patients, it was found that a comparison of ALS patients having no impairment in bulbar functioning with those having varying levels of bulbar impairment, the most significant differences in quality of life were found between those patients with no impairments, and those who were demonstrating the first signs of impairment (Duff, 2007). Further, no significant differences were found among ALS patients who demonstrated varying levels of bulbar impairment. This suggests that the initial signs of bulbar function impairment have the most significant impact on quality of life in ALS patients (Duff, 2007). These findings, along with the findings of this study, speak to the unique aspects of bulbar function and how these aspects influence an individual's overall experience of life.

This study used the factor of bulbar function, as measured by the ALSSQOL-R when predicting the desire to hasten death. Bulbar function, as measured by the ALSSQOL-R, looks at an individual's perception of bulbar function, rather than his or her actual, objective measure of bulbar function. The use of a subjective measure of bulbar function, such as the subscale of the

ALSSQOL-R, versus an objective measure of bulbar function may produce different outcomes when predicting the desire to hasten death. It is possible that individuals with similar objective measures of bulbar function may differ in the manner in which they perceive this functioning and thus, in how it affects their quality of life, and in their desires to hasten death. It is important to make note of this because a low level of bulbar dysfunction may be tolerable for one patient, but intolerable for another. If healthcare providers do not consider how a patient's perception of his or her bulbar function can impact that patient, the providers may make faulty assumptions and presume that the individual's low level of bulbar dysfunction is not impacting his or her desire to die. For this reason, it is extremely important that healthcare providers take special care to explore with patients how they perceive their bulbar functioning and the manner in which this is impacting their experiences of the disease, quality of life, and desire to hasten death.

Bulbar function refers to the individual's ability to speak and to swallow. These aspects influence ALS patients' ability to communicate with others, eat, drink, and control their saliva. This part of functioning, or deterioration of function, could also lead to an increased risk of, and fear of choking. The symptom of dysphagia, or difficulty swallowing, is often associated with weight loss. Individuals who suffer from this symptom, and who do not have the intervention of PEG, may require an hour or longer to consume a meal, and they will often have a difficult time receiving oral medications (Mitsumotor & Rabkin, 2007). In a study focused on gaining an understanding of the wish to die among ALS patients, it was found that none of three individuals who sought and completed a hastened death had the percutaneous endoscopic gastrostomy (PEG) intervention (Albert et al., 2005). This finding, along with the results of this study, speaks to the profound impact that bulbar function can have on an ALS patient's desire to live.

Among other terminally ill patients, loss of function has been identified as an influencing factor in the desire to hasten death. It has been acknowledged that loss of function may represent the transition from life to death, and thus decrease an individual's will to live. In a study examining hastened death among terminally ill patients, it was found that two-thirds of the study participants pursued a hastened death due to concerns that their illness was deteriorating their sense of self (Pearlman et al., 2005).

Impaired bulbar function can have profound effects on an individual. Losing the ability to speak and communicate with others could lead to an increase in withdrawal and isolation, as well as the feeling that life is less worth living. Additionally, the inability to feed oneself could lead to a loss of dignity and to feelings of embarrassment that one is no longer able to take care of some of his or her basic needs.

The fear of choking adds another dimension of suffering resulting from bulbar dysfunction. In a study examining end of life practices in ALS patients in the Netherlands, it was found that informal caregivers of patients who completed either euthanasia or physician assisted suicide more frequently reported fear of choking, loss of dignity, no chance for improvement, being dependent on others and fatigue as the reasons why patients chose to shorten their lives (Maessen et al., 2009). It is evident from this information that the loss of the ability to swallow and speak has a weighty impact on an individual's feelings with regard to living. The fear of choking likely leads to a great deal of anxiety about the manner in which one will pass. It seems that to avoid such a painful situation, individuals in the Netherlands may choose to opt for a hastened death. In addition, concerns about loss of dignity, and being dependent on others could possibly be related to bulbar dysfunction. With the progression of the disease, patients often lose their independent ability to feed and communicate effectively which could lead to

frustration and distress. Overall, based on the results of this study it appears that paying particular attention to patients' perceptions of bulbar function is an important aspect of patient care that should not be overlooked when considering the possible outcomes, including the wish to shorten one's life.

Negative emotion, as measured by the ALSSQOL-R, examines ALS patients' mood states, along with their goals and feelings about the future. Aspects of hopelessness are captured in items that comprise this factor. As discussed previously, hopelessness has been found to be a significant contributor to the desire to hasten death. In addition to hopelessness, depression has been found to be a consistent risk factor associated with the desire to hasten death (Ganzini & Dobscha, 2003).

It has been thought that individuals suffering with depression may make decisions that are counter to their values, personality, and goals (Ganzini & Dobscha, 2003). It should be noted that individuals may express the desire to hasten death; however, this expression can be transient. For this reason, it is extremely important that these desires be examined and explored closely to identify any underlying reasons that may be able to be addressed effectively. In a study that examined the response to requests for physician assisted suicide, it was found that most patients' desires for physician assisted suicide diminish when their underlying worries are uncovered and directly addressed (Bascom & Tolle, 2002).

Because the desire to hasten death can be a transient desire, it is recommended that physicians reassess this aspect of a patient's state to see how it may arise or diminish at any point during treatment. Asking about the desire to hasten death may be a difficult area for physicians to feel comfortable addressing. Because of this, it is recommended that physicians address this desire initially by normalizing these thoughts and explaining that sometimes people with ALS

think about ending their lives prematurely in order to avoid some of the more uncomfortable aspects of the disease. Asking about the desire to hasten death in this manner may help patients feel comfortable in discussing those symptoms or other aspects of the disease that they are particularly worried about and thus allow the physician to address those concerns and explain ways in which these symptoms can be treated to increase the patient's comfort and reduce anxiety. If a patient indicates that he or she is not having thoughts about hastening death during one appointment, it is recommended that at the next appointment the physician ask about this desire again to assess whether or not this desire has developed for the patient. The physician can do this by reminding the patient how he or she had asked about the desire to hasten death at the last appointment. The physician can then talk about how the medical community is aware that patients may think about this desire from time to time and ask if the patient has experienced any of these thoughts since the last appointment, and if so, what in particular the patient is concerned about that would lead him or her to consider this action.

To help to reveal even further the factors that may be motivating a patient's desire for physician-assisted suicide, it is recommended that doctors discuss with their patients their expectations and concerns, choices for end-of-life care, goals, worries about being a burden for their families, physical symptoms, sense of meaning, quality of life, and depression (Bascom & Tolle, 2002). It is important that physicians take time and care in addressing these concerns because not responding to these concerns could lead to an increase in feelings of hopelessness for the patient.

In addition to physicians and healthcare providers, it is important that family members and caregivers be aware of aspects of ALS patients' disease state that may lead to the desire to hasten death. Being informed of factors that could lead to this desire, family members and

caregivers will be better equipped to recognize these aspects and assist patients in finding and connecting with resources that may be able to alleviate their suffering.

Related to bulbar function, ALS patients may experience the negative emotion of anxiety around the progression of the state of the disease, fears about possible outcomes of their disease, and the manner in which they may die. It is important to ask patients if they are experiencing any such anxieties and fears in order to educate and assist them in coping with these fears. As mentioned previously, anxiety around choking, in particular, seems to be a significant, influential factor in the desire to hasten death. Educating patients on the likelihood of this outcome and assisting them in coping with this fear may help patients manage thoughts of choking more effectively and decrease their anxiety with regards to that outcome.

The third hypothesis tested in this study sought to determine if there is a correlation between a participant's problem-solving orientation and style, as measured by the SPSI-R:S, and the desire to hasten death, as measured by the SATHD. A Pearson-product correlation was used to test this hypothesis. Results from this analysis determined that there was no correlation between the desire to hasten death and problem-solving styles or orientations.

Because problem-solving skill deficits have been linked to suicide, this result speaks to the reality that the consideration and pursuit of a hastened death is fundamentally different from the thought of and act of suicide. It has been found that individuals who take part in suicidal ideation have poorer problem solving skills than those who do not (Wenzel, Brown, & Beck, 2009). Further, poor problem solving ability has been found to predict hopelessness and suicidal intent (Nezu, Wilkins, & Nezu, 2004). The desire to hasten death, however, does not appear to be related to deficit problem-solving skills.

Although hopelessness is related both to suicidal ideation and to the desire to hasten death, it is important to consider the differences between these two actions. Suicide has been thought of as an impulsive act that a person may pursue when he or she sees no other option in coping with a situation (Wenzel, Brown, & Beck, 2009). In a study examining the motivations for hastened death, however, it was found that participants were noted to have reflected upon hastening their deaths over a prolonged length of time, and to have repeatedly reviewed the benefits and risks of living versus dying (Pearlman et al., 2005). The amount of consideration and thought represented by this result reveals a rational approach rather than an impulsive style to problem-solving. This finding reveals that patients put a great deal of thought into this decision; this therefore further enforces the recommendation for healthcare providers and physicians to explore the underlying reasons for these desires.

To demonstrate further how the desire to hasten death is fundamentally different from an impulsive suicidal act, many studies have described this desire as giving the individual a sense of control over his or her circumstances. In Oregon, it has been found that individuals who actively pursue physician-assisted suicide are often not depressed, but rather desire the ability to remain in control of their lives and avoid being dependent on others (Ganzini & Dobscha, 2003). Further, it has been found that some individuals gain emotional relief in knowing they may have the option of controlling the timing and circumstances of their deaths (Ganzini, Johnston, McFarland, & Lee, 1998). The desire to hasten death, therefore, may not merely be a desire to end one's life, but rather represent a positive coping strategy in which an individual can attain a feeling of control (Kelly et al., 2003).

In order to increase patients' sense of control, physicians can make an effort to involve patients further in decisions around those interventions that they may desire, including palliative

care, hospice, and assistive devices. By being involved in these decisions, patients may feel as though they have a way of controlling some aspects of their disease, and thus prevent the disease from taking full control over their lives. Also, physicians can talk to patients about how they spend their days and encourage them to take part in activities that they find enjoyable.

Encouraging patients to take part in activities that maximize their enjoyment and positive experiences may allow patients to recognize that they can continue to maintain a sense of control over what they do and how they feel. Another way to address a patient's problem of feeling as though he or she lacks control could involve a healthcare provider helping the patient explore the problem of lacking control, and assisting him or her in developing an exhaustive list of solutions to that problem. The healthcare provider could then support the patient in looking at the possible costs and benefits of each possible solution, and then help him or her consider which solution would yield the best outcome. By doing this, the healthcare provider may be able to help the patient see that there could possibly be things that the patient can control, or he or she may be able to help change the manner in which the patient thinks about what he or she perceives to be a lack of control.

Because ALS is a terminal illness, patients may think of the consideration and pursuit of a hastened death as a reasonable option to cope with their disease. For this reason, it further speaks to the importance of talking directly with patients about their concerns and those options they have for treatment interventions. Educating patients on options they have to relieve their suffering may decrease the desire to hasten death. Further, helping patients set forth advanced directives can assist them in feeling a sense of control over how they wish to be treated as their disease progresses. All of these aspects can help patients feel as though their concerns are being

addressed and help them maintain a sense of control with a disease that is so often unpredictable and unreliable in its progression and course.

Relevance of this Study to the Theory and Practice of Psychology

This study is relevant to the theory and practice of clinical psychology in many ways. The factors that were found to relate to the desire to hasten death included hopelessness, global quality of life, bulbar function, and negative emotion. The state of hopelessness is significant in the theory and practice of clinical psychology because it is often related to feelings of depression or feeling as though aspects of a person's life will not get better. The state of hopelessness can be addressed through psychological interventions. Clinicians can assist patients in viewing their situations differently as well as help them identify alternate areas of their lives where they may be able to find hope.

An individual's level of global quality of life is relevant to the theory and practice of clinical psychology. The aspects that were asked to be considered when thinking about global quality of life in this study were: physical, emotional, social, spiritual, and financial. Clinical psychologists adopt a holistic view of patients when they consider the problems they struggle with and how these aspects impact patients' overall well-being. The factors being considered in global quality of life capture this view. By considering all of these aspects and incorporating them into treatment, clinicians may be able to help patients focus on and improve different areas of their lives that may be causing them problems.

The factor of negative emotion is relevant to the theory and practice of psychology. Negative emotion can be described as a person's mood state, including how the person thinks about the future, along with any feelings of depression or anxiety. These aspects of a person's condition are addressed through psychological intervention. By assisting individuals in

examining the manner in which they think about aspects of their situations, clinical psychologists can help them evaluate their negative emotions and adopt a more adaptive mode of thinking.

Further, psychological interventions can assist individuals in increasing their behavioral engagement to enhance their ability to obtain positive experiences from their environments.

Bulbar function may not be obviously related to the theory and practice of clinical psychology; however, when considering the impact these symptoms have on patients' lives, it does become relevant. Bulbar symptoms involve an individual's ability to speak and swallow. Impairments in these abilities could lead to isolation due to difficulty communicating, fears of choking, and to loss of dignity as a result of not being able to take care of some of one's basic needs independently. Clinical psychologists can assist with these aspects of bulbar function. By addressing patients' feelings around these issues, clinicians can help individuals evaluate their thinking and adopt alternative manners of thinking to decrease the anxiety around these issues. In addition, clinical psychologists can assist patients in problem solving when challenges arise, and help them identify and evaluate alternative solutions for the problems they face.

Recommendations for Future Research

Recommendations for future research include: examining the aspect of locus of control and the desire to hasten death, looking more specifically at bulbar symptoms and the initiation or refusal of PEG intervention and the desire to hasten death, and exploring correlations between personality characteristics and the desire to hasten death.

The idea of controlling one's circumstances and timing of death among ALS patients was discussed extensively in the literature. This aspect of a patient's experience was not examined in this study, but it seems to be an important area to mull over when considering the aspects of a patient's experience that may lead to the desire to hasten death. The ability to control the

circumstances and timing of death may help patients feel as though they can maintain a sense of control with a disease that has taken so much of their control away. This aspect of a patient's experience is interesting to think about because it seems counter to what one might assume when considering a person who would want to hasten his or her death.

Looking more specifically at bulbar symptoms and the initiation to or refusal of PEG intervention and the desire to hasten death is another area recommended for future research. Examining this aspect of a patient's experience more closely may be able to be determined the extent to which these symptoms influence the desire to die. It seems that the ramifications that these symptoms have on a patient's experience are profound. Being able to learn more about that experience and being able to base recommendations on that information would serve to enhance the knowledge and resources that healthcare professionals are able to provide.

Exploring correlations between personality characteristics and the desire to hasten death is recommended for future research. Based on some of the literature, it appears that those individuals who pursue and complete a hastened death tend to be determined, strong willed, and focused. It would be interesting to explore whether or not these personality characteristics comprised the majority of individuals who would consider this outcome, or if there are other characteristics that could lead to this desire. By uncovering specific personality characteristics that may contribute to the desire to hasten death, clinicians may be better able to identify individuals who may desire this outcome. Further, being aware of the personality characteristics that may influence this desire can be useful in educating family members and caregivers on what aspects?? to consider if their loved one expresses this desire.

Limitations of the Current Study

There are some limitations of this study. Although there were one hundred and fifty individuals contacted to take part in the study, only sixty-nine individuals actually completed all of the measures presented in the survey. This relatively small sample size is a limitation because it raises the question of whether or not the findings of this study can be generalized to the ALS population at large. The demographics of the sample are similar to those of the general ALS population; however, because of the small size, it is unclear whether or not a true representation was captured. In addition to the sample size, another limitation concerning the sample involves characteristics of the individuals who completed the survey. The sample consisted exclusively of individuals who are members of the social networking website, PatientsLikeMe.com. Mere membership in this social networking website may assume that individuals who took part in this study may tend to seek out and find value in building a social support network. This sample characteristic could limit the findings of this study because the literature suggests that patients who have a strong social support network may be less likely to consider a hastened death.

The disclaimer that was presented to the potential participants at the onset of the study could have also been a limitation. Participants were informed before entering the survey that there were questions that pertained to a hastened death and suicide. It is possible that if an individual was experiencing distress, or seriously considering these options, he or she may have opted out of taking part in the study. Conversely, individuals were aware of the nature of the study before completing the measures; therefore, this may have influenced the manner in which they responded to the questions if they, for some reason, wanted to present themselves as dealing effectively with their illnesses.

The two-item hopelessness measure employed in this study poses an additional limitation. The original development and validation of this measure was based on each item being scored on a four point Likert scale. This type of scoring led to greater variability in the scores obtained for this measure. In this study, however, the measure was implemented as having the respondents rate the items either as “true,” with a score of one, or as “false,” with a score of zero. This type of implementation led to less variability in the scores obtained for this measure. It should be noted, however, that regardless of this limitation, hopelessness was found to be a significant predictor of the desire to hasten death even with less variability in the scores obtained. Therefore, although this limitation led to less information about the variability between hopelessness scores, it was still able to determine that hopelessness contributes significantly to the desire to hasten death.

Summary and Conclusions

The factors that were found to contribute to the desire to hasten death among ALS patients who completed this study included: hopelessness, global quality of life, bulbar function, and negative emotion. Although the sample obtained for this study was small, the characteristics of the participants were comparable with the general ALS population. Because of the similarities of the study participants to the general ALS population, it is thought that the results of this study can be generalized to the ALS population regardless of the small sample size that was obtained.

The factors of hopelessness, global quality of life, bulbar function, and negative emotion when considering the desire to hasten death among ALS patients are relevant to the practice and theory of psychology. By taking a holistic perspective of the ALS patients’ experiences, the field of psychology can be of great value in helping healthcare providers better serve their ALS

patients. Psychologists can assist ALS patients, or other healthcare providers who work closely with ALS patients, in identifying ways to help them develop alternative ways of thinking about their challenging circumstances. In addition, psychologists can help family members of ALS patients cope more effectively with their loved one's possible desire to hasten death, and help them address these concerns to reveal any underlying aspects that may be influencing these desires.

The finding of bulbar function being related to the desire to hasten death is especially poignant because there are medical interventions that can help decrease the distress these symptoms impose. The initiation of the PEG intervention may help decrease some of the distress caused by bulbar dysfunction; however, further research is needed to understand this relationship more clearly. Although there are medical interventions that could help alleviate the distress caused by bulbar dysfunction, psychological interventions to address the fears and anxieties associated with these symptoms may also serve to bring about some relief in patients' experiences.

Problem solving orientations and problem solving styles were not found in this study to correlate with the desire to hasten death. This finding highlights the difference between the desire to hasten death, and the consideration of suicide. Although previous research has linked poor problem-solving skills with suicide, it is evident in this study that there is no relationship between problem-solving ability and the desire to hasten death. As opposed to suicide, the desire to hasten death does not appear to be an impulsive or careless decision. This decision, rather, appears to be one that is a result of careful and thoughtful consideration of the positive and negative aspects of this outcome. This information is valuable to healthcare professionals because it speaks to the contemplation and careful deliberation that ALS patients must go

through when thinking about this outcome. Overall, it is important that the factors identified in this study as contributing to the desire to hasten death be carefully explored and addressed with ALS patients. It is important that these desires not be avoided or dismissed, but rather addressed directly in order to uncover any underlying concerns or worries on the patient's part that may be contributing to this desire. Although this desire may be uncomfortable for family members, and some healthcare professionals to address directly, it appears that not addressing these desires could serve to worsen the experiences of ALS patients because they may feel as though their concerns are not being heard or taken seriously. By being aware of the various aspects of a patient's experience that could contribute to the desire to shorten one's life, healthcare professionals, family members, and caregivers will be better equipped to respond to and address these desires in a more effective manner.

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