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Understanding the Impact of Physical Functioning on the Experience, Desire, and Satisfaction of Physical, Emotional and Social Intimacies in Persons with Amyotrophic Lateral Sclerosis (ALS)

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Philadelphia College of Osteopathic Medicine

Department of Psychology

UNDERSTANDING THE IMPACT OF PHYSICAL FUNCTIONING ON THE
EXPERIENCE, DESIRE, AND SATISFACTION OF PHYSICAL, EMOTIONAL AND
SOCIAL INTIMACIES IN PERSONS WITH AMYOTROPHIC LATERAL
SCLEROSIS (ALS)

By Jamie Lee Rodriguez

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DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by Jamie L. Rodriguez on the 12th day of January, 2010, 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 understanding of intimate relationships in persons with amyotrophic lateral sclerosis (ALS) is not yet understood. A review of the current literature, including an overview of ALS and the development and maintenance of intimate relationships using psychological theory, is included. Comparisons to multiple sclerosis, acquired physical disability, and older adults are included to gain a greater understanding of how changes in physical functioning may impact an intimate relationship. This study used archival data, in which participants completed the following measures: ALS Functional Rating Scale–Revised, Personal Assessment of Intimacy in Relationships, and ALS Specific Quality of Life Measurement–Revised. Results suggest high levels of intimacy and that gender, age, time since symptom onset, and physical and bulbar functional ability are not predictors for experience of, desire for, and satisfaction with intimate relationships. Couples appeared to be resilient, and intimacy was maintained regardless of physical functioning. Potential explanations, limitations of the study, and implications of the research are also explored.

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Chapter 1

Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease affecting motor neurons in the spinal cord, brainstem, and motor cortex (Breier & Fletcher, 2004). It is characterized by progressive impairment of motor functions that results in muscular atrophy and is ultimately fatal. No cure exists for ALS at this time. Available treatments are limited to managing symptoms, sustaining independence, and improving overall quality of life (QOL) for the duration of survival. QOL has been a developing topic in ALS research, expanding from emphasis on physical functioning to include social, psychological, existential, and spiritual factors. Unfortunately, it appears that researchers have not yet adequately assessed the quality of intimate relationships in relation to overall QOL.

Intimate relationships are important to assess in persons with ALS, due to the inevitable physical and emotional reliance on loved ones as the disease progresses. Individuals in valued relationships feel accepted and appreciated when interacting with their spouse. However, when persons with ALS look to their spouse for overwhelming emotional and physical support, it is likely to influence the marital relationship. Emotionally, persons with ALS may feel depressed and anxious while coping with and trying to understand the ALS diagnosis. They may also be concerned with how ALS will affect their spouse and their relationship. Communication about concerns regarding the disease may be withheld to protect each other from additional burden or distress. In most instances, the marital dyad is a significant source of support; therefore, a reciprocal

interaction may occur. For instance, strain on the relationship may influence other components of QOL, and a decreased QOL may influence the intimate relationship.

Physically, persons with ALS undergo significant changes in a short period of time. Intimate relationships may encounter duress when the role of the spouse is to support and to fully care for the needs of the patient. The ability to effectively communicate is often impeded by changes in bulbar functioning, influencing the individual's speech quality and creating excessive saliva. Although treatments attempt to help individuals' maintain independence, as ALS progresses, the need for aid in toileting, dressing, and turning in bed is inevitable. Each is likely to influence the intimate quality of the marriage, as this role change is likely to alter perceptions, experience, and emotions of each individual. The caregiver or spouse of the person with ALS often acquires most of the responsibility to maintain needs of everyday living and the needs to accommodate his or her loved one. In assessing marital satisfaction, reciprocity appears to be an important component. As a result, it is inevitable that as roles change, satisfaction with intimacy may also change (Schmitt, Kliegel, & Shapiro, 2007).

Overview of Literature Review

The subsequent literature review provides insight into the physical components and psychological sequelae of an ALS diagnosis. Models of intimacy are explored to define physical, social, and emotional intimacy. The role of intimacy in marriage is further assessed by examining current literature regarding norms in individuals with and without healthy physical function. Due to the lack of literature regarding ALS and intimacy, literature from other physically challenged populations was used as a method to conceptualize biological, psychological, and social aspects of intimacy in ALS.

Relevance to Cognitive Behavioral Therapy

Research on ALS beyond the purely medically specific information on disease progression and symptomatology has increased in recent years, providing a greater understanding of the experience of persons with ALS. This desire and the ability to gain greater understanding of ALS have provided insight to practitioners involved in multidisciplinary care; however, elaboration in particular areas has been neglected. Intimacy is often an uncomfortable topic for many individuals to discuss and may often be overlooked to avoid potential embarrassment or hurt on the part of the clinician, patient, and spouse. It is possible that avoiding the discussion of intimate issues could affect the patient's overall treatment by avoiding underlying problems that may be pertinent to understanding the individual's current circumstances. The ability of the clinician to utilize acquired knowledge to address such issues in a professional, unbiased, and educated manner has the potential to decrease the ambivalence about discussing intimate issues, subsequently improving the QOL of the individual.

The ability to understand intimacy in persons with ALS would facilitate a comprehensive conceptualization of intimacy difficulties and appropriate treatment methodologies that may occur throughout the duration of the disease. In assessing intimacy in ALS utilizing the cognitive model, one's emotions and behaviors are influenced by the perceptions gathered from particular events (Beck, 1995). It is not the situation that elicits particular emotions, but how the event is construed. In coping with the diagnosis of ALS, one may desire and experience intimacy differently than it is perceived. This remains true as the disease progresses and reliance on the caregiver increases. As changes occur, persons with ALS may rely more heavily on certain types

of intimacy, whereas other intimacies become less satisfying. It is also possible that persons with ALS misconstrue emotions (Kilani, Micallef, Soubrouillard, Rey-Lardiller, Dematte, Dib, et al. 2004; Lulé, Kurt, Jürgens, Kassubek, Diekmann, Kraft, et al. 2005) of their spouses. Understanding these emotions in patients with ALS with guide interventions related to decreasing cognitive distortions and enhancing communication to facilitate a more intimate relationship as the end of life nears.

Purpose of the Study

Little is known about intimacy within the ALS population, an influential component of interpersonal functioning and marital satisfaction. The aim of this research was to understand the experience of, satisfaction with, and desire for physical, social, and emotional intimacy in persons with ALS. The ability to understand these concepts would provide a greater understanding toward the comprehensive maintenance and sustenance of QOL. Impairment in physical functioning is an inevitable experience of those with ALS; the effects should be examined as pertaining to intimacy. Specific to treatment efficacy, the aspects of physical functioning most salient to predicting satisfaction of intimate relationships were also identified to provide insight into potential areas of interest for clinicians working with this population.

Chapter 2

Literature Review

There are various levels of uncertainty when diagnosing ALS from clinical assessment alone. As a result, specific diagnostic guidelines have been set forth, and the most common method of determining an ALS diagnosis is through the use of El Escorial diagnostic criteria (EEDC). The most recently revised EEDC (2000) includes the presence of lower motor neuron (LMN) degeneration, upper motor neuron (UMN) degeneration, and progressive spread of symptoms or signs within a single region or to additional regions (Brooks, Miller, Swash, & Munsat, 2000). Due to the presence of symptoms that can mimic other disorders, the diagnosis of ALS is often difficult. As a result, comprehensive diagnostic testing is also implemented to rule out the presence of another disease process that may better explain the symptoms (Brooks et al., 2000).

The clinical types of ALS are: (a) clinically definite ALS, which includes the presence of UMN and LMN signs located in three spinal regions or the presence of UMN and LMN signs in the bulbar region and at least two spinal regions, (b) clinically probable ALS, in which UMN and LMN signs are seen in at least two regions, (c) possible ALS, in which UMN and LMN signs are located in only one region, and (d) suspected ALS, in which LMN signs manifest in two or more regions (Brooks et al., 2000). There are a number of ALS and ALS-like syndromes that are also recognized when addressing the clinical signs of progressive LMN and UMN degeneration. They can occur alone or without the presence of a preexisting disease (sporadic) or occur as a result of a genetic mutation (genetically determined) that is present in one or more familial generations. Signs may also include the presentation of ALS, but include

features of other neurological disease (ALS-plus syndromes), have laboratory abnormalities of uncertain significance, and similar symptoms not representative of any form of ALS (ALS-mimic syndromes) (Brooks et al., 2000).

The clinical presentation and progression of ALS have been well documented, and findings have been fairly consistent among researchers. In regards to clinical presentation, ALS affects each individual differently. In 33% to 39% of patients, patients first experience symptoms in the lower limbs and 29% to 39% experience their symptoms in the upper limbs (Chiò, Mora, Leone, Mazzini, Cocito, Giodana, et al., 2002; Kimura, Fujimura, Ishida, Nakajima, Furutama, Uehara, et al., 2006). Initial symptoms may include: (a) twitching or cramping of muscles in the hands or feet, (b) muscle weakness in arms, legs, hands or muscles of speech, salivation, and swallowing, (c) impairment in using arms or legs, and (d) difficulty projecting voice (ALS Association [ALSA], 2008b). Eighteen percent experience bulbar impairment at the time of diagnosis (Kimura et al., 2006). Bulbar deficits appear to be most prevalent in women (41%) in the progression of the disease and in those over the age of 69 at the time of diagnosis (Chiò et al., 2002; Kimura et al., 2006). The impairment of bulbar functioning involves flaccid and spastic movements of the muscles of the face, tongue, and throat, reduced saliva production, and an inability to adequately swallow the saliva produced, resulting in drooling (Simmons, 2005). Respiratory involvement is the least likely to be the symptom first experienced, but does occur from 1% to approximately 22% of the time (Chiò et al., 2002; Kimura et al., 2006). Due to the inability to breathe adequately, it is respiratory impairment that is ultimately fatal to persons with ALS (Kimura et al., 2006).

The time between the onset of symptoms to diagnosis is approximately 14.2 months (Kimura et al., 2006), with an average age at symptom onset of 62.8 years (Chiò et al., 2002). The way in which symptoms present initially can affect the immediacy of diagnosis. For example, significant bulbar impairment leads to a quicker diagnosis, around 8.6 months, whereas symptoms related to upper or lower extremity physical functioning result in a longer interval between symptom onset and diagnosis, averaging 13.5 months (Chiò et al., 2002). The approximate duration of survival from the onset of symptoms is 32 months and 17 to 19 months from the actual diagnosis (del Aguila, Longstreth, McGuire, Koepsell, & van Bell, 2003; Kimura et al., 2006). The average duration of survival for men at the onset of symptoms is 36 months and 23 months from the time of diagnosis, whereas women average 29 months from onset until death and 19 months from diagnosis (del Aguila et al., 2002). In consideration of all of these factors, the following risk factors have been identified as significant in considering the prognosis of an ALS diagnosis: bulbar features at onset, 65 years old or greater at diagnosis, shorter span of time from symptom onset to diagnosis, female gender, and marital status (del Aguila et al., 2003; Chiò et al., 2002).

There are currently no known cures for ALS, therefore, interventions to maintain and promote a comfortable QOL are provided until death. Persons with ALS may seek general care from various practitioners or go to specialized multidisciplinary clinics that provide persons with ALS a variety of services in one location. These services include: occupational therapy, physical therapy, speech therapy, respiratory management, diet and nutrition, and social services (Simmons, 2005). There is recent literature that suggests some advantage to multidisciplinary clinics. Van den Berg and colleagues (2005)

compared multidisciplinary treatment teams to general care in the ability to provide aid to persons with ALS. Findings suggest that those attending multidisciplinary ALS clinics had greater access to swallowing aids (94% versus 67%) and communication aids (87% versus 72%) and access to ambulation aids was nearly equal (96% versus 92%) (Van den Berg, Kalmijn, Lindeman, Veldink, de Visser, Van der Graaff, et al., 2005). Traynor et al. (2003) assessed if the difference in care influenced survival and found as much as 29% reduction in mortality at 12 and 24 months in those attending the multidisciplinary clinics. In the 4-year follow-up, 13% of multidisciplinary attendees still had lower mortality than those in general care (Traynor, Alexander, Corr, Frost, & Hardiman, 2003). Even with greater access to aids and evidence of greater survival in those who attended the multidisciplinary clinics, QOL was not indicated as any greater in comparing multidisciplinary settings and general care (Traynor et al., 2003).

Psychological Sequelae of ALS

The diagnosis of ALS is a lengthy process, due to the need to make certain that another disorder or disease is not responsible for the symptoms experienced. As a result of the process, persons with ALS may encounter relief that their impairment has been identified, and anguish when considering that they have been diagnosed with a terminal illness. The outcome of ALS is certain. While some struggle with psychological distress, such as depression, anxiety, thoughts of hastened death, and interpersonal strain, most persons with ALS ultimately experience a relatively high QOL (Nelson, Trail, Van, Appel, & Lai, 2003; Neudert, Wasner, & Borasio, 2004).

Depression.

It may be presumed that persons with ALS experience depression due to the psychological implications concordant with terminal illness; this does not appear to be true. In current research assessing the presence of depression in samples of persons with ALS, the percentage of patients with a diagnosis of depression is quite variable, ranging from 0 to 67% (Bungener, Piquard, Pradat, Salachas, Meininger, et al., 2005; Hammer, Häcker, Hautzinger, Meyer, & Kübler, 2008; Kübler, Winter, Ludolph, Hautzinger, & Birbaumer, 2005; Rabkin, Wagner, & DelBene, 2000; Ramirez, Piemonte, Callegaro, & DaSilva, 2008). Although there appears to be a presence of depressive symptoms among those living with ALS, a large percentage of the population does not experience these symptoms severely enough to warrant a clinical diagnosis. In most cases, depressive symptomatology was assessed through self-report measures. However, the use of structured interviews in a study to assess psychopathology according to criteria delineated in the Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (American Psychiatric Association [DSM-IV], 1994) for major depressive episodes and dysthymia found that no participant from the sample met any such criteria (Bungener et al., 2004).

Specific areas of physical functioning have been identified as significant in the presence of depressive symptomatology. Simmons (2005) suggests that the most devastating psychological and social consequences occur as a result of communication decline. Therefore, it is expected that bulbar functioning would be a predictor of psychological distress (Goldstein, Atkins, Landau, Brown, & Leigh, 2006a; Hillemacher, Gräbel, Tigges, Bleich, Neundörfer, Kornhuber, et al., 2004). Specifically, Hillemacher

and colleagues (2004) found that impairment of swallowing and breathing were the most significant when considering the presence of depression. There appears to be a consistent trend for the bulbar score to be related to the presence of depressive symptomatology, although it fails to reach a significant level (Hillemacher et al., 2004). It is possible that this presence of depression is due to the common fear that impairment of bulbar capacities will lead to choking to death. Neudert, Oliver, Wasner, and Borasio (2001) assessed this fear by assessing the actual cause of death in ALS patients and found that approximately 92% of patients died peacefully as a result of hypercapnic coma that arises as a result of respiratory weakness.

Fatigue is an inevitable experience in persons with ALS. The fatigue experienced is often in regard to physical fatigue and the reduction of physical activity, rather than overall fatigue encompassing mental fatigue and motivation (Lou, Reeves, Benice, & Sexton, 2003). Some discrepancy exists, however, in assessing nonphysical implications of fatigue. Lou and colleagues (2003) did not find that fatigue influenced mental processes and motivations, whereas Ramirez, Piemonte, Callegaro, and DaSilva (2008) have found that the experience of fatigue in persons with ALS has specific psychological consequences, such as a loss of patience and concentration. Some suggest that a younger age at onset and longer duration of the disease may have some impact on the experience of fatigue and depression due to the abrupt interruption of a more active life in a younger individual (Ramirez et al., 2008). These factors are present but have no impact on the presence or severity of depression (Ramirez et al., 2008).

In later stages of ALS, as physical functioning declines, pain is often indicated as a significant stressor (Rabkin et al., 2000). Unfortunately, pain is often poorly controlled

and can be severe and constant, especially in the final months (Ganzini, Johnston, & Silveira, 2002; Liao & Arnold, 2007). Ganzini and colleagues (2002) assessed the frequency and severity of pain in ALS patients in the final month of life. On a 6-point scale, ranging from 1, the patient had no physical pain, to 6, the patient had constant physical pain, the median pain frequency was 4. Severity of pain was also assessed using a 6-point scale in which 1 indicated the patient having no pain and 6 having severe physical pain. Thirty percent of the patients in this sample rated the pain as a 5 or a 6 (Ganzini et al., 2002).

Research assessing the presence of depressive symptomatology through the progression of the disease is consistent. Better functional level is correlated with higher experiences with life satisfaction and enjoyment (Rabkin et al., 2000). As persons with ALS experience physical decline, the presence of distressing symptoms does not indicate psychopathology or a significant decline in QOL (Nygren & Askmark, 2006; Simmons, Bremer, Robbins, Walsh, & Fischer, 2000). The experience of depressive symptomatology may have more to do with the perception of the illness and loss of independent functioning and inability to engage in previously favorable activities (Gauthier, Vignola, Calvo, Cavallo, Moglia, et al., 2007). This change from independent functioning to functional impairment may alter one's mood state and influence one's desire to engage with others socially, emotionally, and physically. The follow-up assessments of depressive symptomatology maintain that the depressive symptoms exist, but that they remain relatively stable and are not indicative of significant distress (Gauthier et al., 2007; Goldstein, Atkins, Landau, Brown, & Leigh, 2006b; Rabkin et al., 2000). Although this finding suggests insignificance of distress, assessing one's

depressive symptomatology as it relates to its impact on interpersonal relationships may have different implications.

Anxiety.

The presence of anxiety is another psychological consideration when coping with the diagnosis of a terminal illness and the forthcoming changes that occur with disease progression. Prior to assessing anxiety, it is important to understand that there are various dimensions of anxiety. There are those that are unique predispositions to respond to threatening situations developed over time, called trait anxiety, and those that are general reactions to environmental stimuli and may be displayed with tension and worry in reaction to a threat, called state anxiety (Spielberger, 1966). Researchers have explored both state and trait anxieties in persons with ALS and findings have been fairly consistent.

In the assessment of trait anxiety, ALS patients have slightly elevated levels of anxiety when compared to the healthy control group in which the measure to assess trait anxiety was normed (Rabkin et al., 2000; Vignola, Guzzo, Calvo, Moglia, Pessia, Cavallo, et al., 2008; Wicks, Abrahams, Masi, Hejda-Forde, Leigh, et al., 2007). In a sample assessed by Vignola and colleagues (2008), 50% of the participants fell within the low trait anxiety range, and 43% were in the medium range. These levels of trait anxiety suggest that patients with ALS experience somewhat higher anxiety than the regular population, but exude less anxiety than psychiatric patients (Rabkin et al., 2000; Wicks et al., 2007). Findings suggest that at diagnosis an individual's initial reaction and ability to cope with the diagnosis, will influence how they perceive and respond to other seemingly threatening events (Vignola et al., 2008). State anxiety, however, tended to be elevated

during the follow-up phase on the state subscale (Vignola et al., 2008). Forty-one percent of this sample had a medium level of state anxiety, often related to depression experienced by persons with ALS (Vignola et al., 2008).

Anxiety may also be specifically related to functional limitations caused by the physical decline of persons with ALS (Brenes, Guralnik, Williamson, Fried, Simpsom, et al., 2005). Persons with ALS will experience significant physical impairment in which performing many tasks will become obsolete. Brenes and colleagues (2005) were able to identify three particular factors associated with anxiety related to physical impairment: performance difficulty and activity limitations, inability to maintain independent function of activities of daily living (ADLs), and increased physical disability. The findings within this research suggest that anxiety was related to poorer physical performance and presence of depressive symptoms (Brenes et al., 2005). It does not appear that the presence of anxiety symptomatology is enough to warrant a clinical diagnosis because anxiety scores are not necessarily indicative of psychological distress (Clarke, Hickey, O'Boyle, & Hardiman, 2001). Furthermore, there has been no identified relationship between illness severity and levels of anxiety (Goldstein et al., 2006b).

In general, high levels of anxiety within a marital relationship often are indicative of marital discord and decreased marital satisfaction (Caughlin, Huston, & Houts, 2000), which would in turn affect the desire, experience, and satisfaction with marital intimacy of persons with ALS. The effect of anxious symptomatology and limited physical ability on dyadic relationships has not been examined.

Hastened death and assisted suicide.

There are significant factors to consider when assessing the wish for hastened death and assisted suicide. First, ALS is a disease characteristic of older adults, which significantly increases the risk for suicide (Conwell, Duberstein, & Caine, 2002). The National Institute of Mental Health identifies older Americans as accounting for 12% of the population and 16% of suicide deaths in 2004 (National Institute of Mental Health [NIMH], 2009). Second, the presence of a serious physical illness in any organ is independently associated with suicide (Waern, Rubenowitz, Runeson, Skoog, Wilhelmson, et al., 2002). When controlling for gender and the completion of suicide, men (65%) were more likely than women (44%) to complete (Waern et al., 2002). This statistic increases fourfold when physical illness is present (Waern et al., 2002). According to the ALS Association, the ALS CARE Database indicates that 60% of persons with ALS are male (ALSA, 2008c); this statistic may provide insight into the higher rate of suicide completion in males in the general population. Higher rates in men may also be due to the greater difficulty and embarrassment experienced when requiring greater support in previously independent activities (Gauthier et al., 2007; Schmitt, Kleigel, & Shapiro, 2007).

Kelly and colleagues (2003) studied the desire for hastened death in those with terminal illness and found 14% having a strong desire for hastened death. They report that 18% discussed the wish to die with a family member, 14% discussed it with a doctor, and 3% actually requested interventions to end their life. Specific to persons with ALS, psychological suffering, poor social support, and the distress of being a burden have been identified as factors associated with assisted suicide (Ganzini, Silveira, & Johnston, 2002;

Rabkin et al., 2005; Rabkin et al., 2000). Although other instances of terminal illness emphasize the impact of psychosocial stressors on the desire for hastened death, this is not always an accurate depiction of those suffering from ALS. Frequent insomnia and severe discomfort and pain have also been associated with a severe desire to end life (Ganzini et al., 2002; Rabkin et al., 2000). The degree of physical impairment has not been associated with suffering, hopelessness, or the desire for hastened death (Rabkin et al., 2000).

In an attempt to assess the beliefs regarding and acceptance of assisted suicide in persons with ALS, Achille and Ogloff (2003) found that 70% felt hastened death was acceptable and 60% felt that it should be legalized. Rabkin and colleagues (2000) asked patients if there were circumstances in which they would consider asking for medicine with the purpose of ending their life. Their findings indicate that 54% would not consider this as a method of ending their life, whereas 34% said they would. Taking into consideration the psychosocial and physical components of suffering in ALS, those who desire assisted suicide may not be in any more pain or suffering and may not experience any more depression than those who do not wish for hastened death (Averill, Kasarskis, & Segerstrom, 2007; Rabkin et al., 2000).

Interpersonal relationships.

The diagnosis of ALS is not solely the burden of the individual, but also affects the actual and perceived relationships with others, most often one's spouse. The challenge of a terminal illness is that it is constant and progressive in symptom severity and the individual and family are frequently adapting to roles and adjusting family structures to care for the ill individual (Newby, 1996; Rolland, 1987, 1994). In a study

assessing the choice of caregivers, approximately 92% of male and female patients with terminal illness choose his or her spouse to be a caregiver (Allen, Goldscheider, & Ciambrone, 1999). As a result, the spouse's role changes from intimate partner to also include caregiving responsibilities. Rolland (1987) describes the family process in terminal illness and suggests that progressive diseases allow the family time to prepare for anticipated changes and planning on the part of the patient and the family. Although the gradual nature of the disease may allow time for preparation, it may not prepare them for the actual decline in functioning and support that persons with ALS need.

Crisis phase.

In keeping with Rolland's (1989) phases of chronic illness, the crisis phase is considered to be prior to diagnosis and the initial period of adjustment and coping once the symptomatology experienced has been identified. Specific to ALS, the crisis phase may occur in persons who have just begun to experience symptoms, related to bulbar or limb dysfunction. During this time, persons with ALS are consulting with physicians and specialists and undergoing various diagnostic tests and clinical assessments to obtain an accurate diagnosis. This often includes the support and presence of the spouse. This phase can create high amounts of stress, due to the uncertainty and ambiguity experienced when attempting to understand the physical symptomatology experienced (Newby, 1996). Once the problematic symptoms have been labeled, persons with ALS and their spouses may find comfort in having an answer; however, they are quickly thrust into adjusting and coping with a terminal diagnosis.

Chronic phase.

The chronic phase is the time span between the initial diagnosis and when issues of death become more evident in the progress of the disease (Rolland, 1989). Thus, when a diagnosis has been made, the chronic phase begins, in which adjustments are made to adapt to the changes that occur as a result of the diagnosis and the expected progression of the disease (Rolland, 1989). This may be the longest phase experienced in persons with ALS and may be characterized by feelings of helplessness, being a burden, and emotional lability. Although the literature tends to focus on the negative impact of caregiving, research also supports that satisfaction, cohesion, and empowerment can also occur with caregiving (Andrén & Elmståhl, 2005; Ekwall & Hallberg, 2007; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998).

During this time, the progression of the disease is taking place and persons with ALS will endure a noticeable decline in functioning. The reliance on caregivers during this phase of ALS can create an emotional toll on the caregiver. For example, Cassells and Watt (2003) assessed caregiver emotions for individuals who needed assistance with toileting due to urinary and bowel incontinence. Their findings suggest that caregivers often feel embarrassed, frustrated, sad, and depressed due to the demands placed on them. Although many do not discount the need for assistance in maintaining activities of daily living (ADLs), relying on others to tend to physical needs can be considered an invasion of privacy or make someone feel vulnerable (Roe, Whattam, Young, & Dimond, 2001). Persons with ALS may feel isolated from others and embarrassed by these needs; it appears that these feelings remain stable over time (Gauthier et al., 2007). This stability

may suggest an acceptance of care needed to maintain their physical being during the span of their disease.

Caring for persons with ALS takes a tremendous amount of time, especially as ALS disability increases in severity. Chiò and colleagues (2006) found that an average of 9 hours daily was devoted to caregiving, with the most time spent on housekeeping (2.6 hours), feeding (1.6 hours), and toileting (1.3 hours). As a result of the time afforded to caring for those with terminal illness, it would not be unreasonable to appreciate that 23% of individuals with terminal illness report a severe sense of burden to others (Chochinov, Kristjanson, Hack, Hassard, McClement, et al., 2007). Chochinov and colleagues (2007) identified four variables predictive of perceived burden; hopelessness, current QOL, depression, and level of fatigue. In a systematic analysis of burden in end-of-life care, loss of autonomy, reliance on others for physical care, concern about emotional impact on others, and the inability to fulfill certain roles were identified as strong predictors of perceived burden (McPherson, Wilson, & Murray, 2007). While burden has been evidenced to interfere with many dynamics of interpersonal relationships, the influence of burden on intimacy in marital relationships has received little attention.

In contrast to the perceived burden by caregivers, carers may also experience great reward from caregiving. Often described in the literature is great satisfaction in seeing their loved one clean, comfortable, and well cared for and being the one to provide that care (Andrén & Elmståhl, 2005; Grant et al., 1998; Kuuppelomäki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004). Caregivers also report that they consider caring for their loved one an expression of love and that it has actually strengthened the relationship (Grant et al., 1998; Kuuppelomäki et al., 2004). In some instances, caregiving may also

be a personal fulfillment of being challenged, developing new skills, and feeling appreciated (Andrén & Elmståhl, 2005; Grant et al., 1998; Kuuppelomäki et al., 2004). Ekwall and Hallberg (2007) found that male caregivers especially found satisfaction in caring for their loved ones because they found it had helped them grow as persons and widened their horizons. It has been speculated that more satisfied caregivers endorse particular coping strategies when it comes to caregiving. These include: solution-trying, self-empowerment and self-control, and obtaining new insights (Ekwall & Hallberg, 2007). Experiencing great reward may also influence a dyads experience, desire, and satisfaction with different forms of intimacy.

As the disease progresses, more attention is needed to the care of persons with ALS. Persons with ALS may experience a loss of dignity, a will to live, and a desire for hastened death due to the significant physical impairment and need for others' physical assistance (Chochinov et al., 2007). As more time and care is devoted to caring for their spouse, Hecht and colleagues (2003) found that carers experienced significant burden. The carers did not endorse items that suggest that their spouses were an annoyance or burdensome. The difficulty for the carers was not the patient per se, but the personal and social restrictions and the physical and emotional problems that came with caring for them (Hecht, Graesel, Tigges, Hillemacher, Winterholler, Hilz, et al., 2003). At times there may be a miscommunication between spouses due the patient's perception of burden and the spouse's actual experience with burden. McPherson and colleagues (2007) found that patients experience a reluctance to discuss concerns and feelings pertaining to their illness with the fear that this discussion would create more burden. Therefore, it is no surprise that caregivers tend to underestimate the patient's QOL and

persons with ALS tend to overestimate the carers QOL (Trail, Nelson, Van, Appel, & Lai, 2003). The miscommunication and hesitance in expressing concerns or hardships can lead to faulty misperceptions from each person involved.

Recent literature provides evidence for some abnormalities in emotional perception impacting interpersonal relationships, QOL, and behavioral disturbance in persons with ALS. In the assessment of emotional response, Kilani and colleagues (2004) used films and Lulé and colleagues (2005) used stimuli in the form of pictures. Results in each study were consistent in finding that persons with ALS expressed more joy and high levels of pleasantness and arousal when presented with stimuli eliciting sadness, disgust, anger, scorn, calm, and surprise when compared to healthy controls (Kilani et al., 2004; Lulé et al., 2005). Those with bulbar onset have been found to experience difficulty recognizing emotional facial expressions, especially sadness, disgust, and surprise (Zimmerman, Eslinger, Simmons, & Barrett 2007). Physiologically, when presented with these stimuli, Lulé et al. (2005) found a delay in galvanic skin responses and strong reflex for unpleasant stimuli in persons with ALS when compared to healthy controls. There is additional evidence that persons with ALS may also experience impairment in attending to and recalling emotional words (Papps, Abrahams, Wicks, Leigh, & Goldstein, 2005). Overall, it appears that persons with ALS may experience a decline in emotional reactivity between month 0 and month 12 of ALS progression (Kilani et al., 2004). However, it is possible that these subtle changes may affect perception of emotional and social intimacy.

There are several theories for deficits in emotional perception. First, cognitively, ALS patients are expected to maintain baseline cognitive functioning throughout the

duration of the disease. There is some evidence that the cognitive abilities of nondemented persons with ALS are slightly impaired when compared to healthy controls (Irwin, Lippa, & Swearer, 2007; Kilani et al., 2004). Although these findings are not enough to yield clinical significance, these slight abnormalities may affect planning, attention, and verbal and nonverbal fluency (Irwin et al., 2007). It is possible that emotional perception can be a result of the persistent neurodegenerative process (Lulé et al., 2005). Second, some suggest that responses to emotional stimuli and changes in emotional processing may be due to psychological reactions to the changed situation or underlying depression (Lulé et al., 2005). Some evidence conflicts with this hypothesis, indicating that depression cannot account for the deficits in persons with ALS (Kilani et al., 2003).

Terminal phase.

Rolland's (1989) final stage, the terminal phase, is when death becomes evident and dominates family life. This phase includes issues surrounding separation, grief, mourning, and continuation of typical family life of surviving family members (Rolland, 1989). ALS is a terminal illness; therefore, the expectation of death is certain at diagnosis. In this particular phase, death is apparent due to the severe decline in functioning. Because of prevalence of home care in persons with ALS in order to maintain comfort, a vast majority of persons with ALS die at home with their family (Krivickas, Shockley, & Mitsumoto, 1997; Mitsumoto, Bromberg, Johnston, Tandan, Byock, Lyon, et al., 2005). Dealing with the death of a loved one can have significant implications, especially if the caregiving encompassed a great amount of time in the caregiver's life. This remains true even as a majority of spousal caregivers feel that

caregiving gives them meaning and helps them to appreciate life (Wolff, Dy, Frick, & Kasper, 2007). After the death, Martin and Turnbull (2001) found that spouses maintain interest in this disease. Twenty-two percent of spousal caregivers continued to attend support groups, and 67% had ongoing questions about the disease. In terms of emotional functioning, caregivers who devote a tremendous amount of time to caregiving experience greater difficulty after the death of their spouse, including isolation and depression (Burton, Haley, & Small, 2006). Specific to ALS, 37% reported coping poorly to very poorly, sometimes years after the patient's death (Martin & Turnbull, 2001).

Intimacy

Many theorists suggest the development of intimate interpersonal relationships is highly reliant on relationships from birth onward (Sullivan, 1953). Initially, it is the interaction with the mother that is most influential. The child is dependent on the mother for nutrition, tenderness, and nurturance, all of which have been identified as fundamental needs for the infant to grow physically, emotionally, and cognitively (Erikson, 1987; Hanley & Abell, 2002; Maslow, 1970; Sullivan, 1953). The mother, in particular, provides support throughout different stages of development and may have the greatest impact on the development of future intimate interpersonal relationships. The loss of a mother's love or unpleasant experiences with such love can lead to infantile depression (Erikson, 1959), fear or anxiety (Sullivan, 1953), and mistrust (Erikson, 1959; Maslow, 1970).

As children grow, the reliance on the mother lessens considerably (Mullahy, 1952; Sullivan, 1953). This propels the child to seek acceptance and intimate exchange

elsewhere. Maslow (1970) has identified belongingness, safety, respect, and love as those qualities sought through interactions with other family members, neighborhoods, and schools (Erikson, 1987; Sullivan, 1952). However, it is peers of similar age and gender who most frequently fulfill these needs for acceptance and intimacy during adolescence (Erikson, 1987; Maslow, 1970; Sullivan, 1953). Sullivan (1953) suggested that teens conduct a form of trial and error in the quest for acceptance by using peers to exchange ideas, information, and experiences (Mullahy, 1952). This also provides the opportunity to develop a sensitivity to others' affection and good will (Maslow, 1970). The ability to engage in relationships by being flexible and responsive to others creates collaboration and consensual validation (Goethals, 1976; Maslow, 1970; Mullahy, 1952; Sullivan, 1953). Positive and reciprocal relationships often increase the potential for inclusion, thus influencing positive emotions and happiness with having intimate relationships (Baumeister & Leary, 1995). Overall, it appears that first relationships foster growth and the ability to develop a mutually exclusive intimate relationship with another.

Development of Intimate Relationships

The development and satisfaction of identity has often been cited as a prerequisite to engaging in intimate relationships. *Identity* has been defined as a “firm and coherent definition of who you are, where you are going, and where you fit into society” (Sigelman & Rider, 2006 p. 300). Identity is first influenced by the experience of anxiety and discomfort early in life (Mullahy, 1952); however, it is the experience of exploration, manipulation, and choices (Maslow, 1970) throughout childhood that bring confidence and begin to unify differential aspects of being. Throughout childhood, dependence from

other persons and environmental stimuli for guidance is relied on. A healthy identity maximizes feelings of security and minimizes the experience of anxiety (Goethals, 1976; Mullahy, 1952). Maslow (1970) compares the full development of identity to the concept of being autonomous, such that the individual has the strength and power to engage in individuality of decisions, emotions. There is also a greater understanding of self and others (Maslow, 1970). At this particular point of identity development, the transition from engaging with same-sex peers to finding interest in those of the opposite sex begins (Sullivan, 1953). The formation of intimate partnerships is said to be due to the ability to fulfill personal potentialities and the maturity to acknowledge the interest of others and make sacrifices and compromises to fuse identity with another (Erikson, 1959, 1966, 1968; Goethals, 1976).

Concurrent with identity development is the presence of genital maturity and sexual desire, which Sullivan (1953) describes the peak of curiosity with those of the opposite sex. Depending on the theory of development, genital drives may begin in preadolescence (Sullivan, 1953) or young adulthood (Erikson, 1987) and continue throughout the lifespan. The awareness of genitalia and need for the satisfaction of sexual frustrations (Sullivan, 1953) are often evident prior to the formation of more encompassing interpersonal relations, involving both sexual gratification and emotional closeness. This may be due to the presence of new physical sensations experienced by the individual during this stage of development and the inability to truly understand the meaning. Goethals (1976) indicates that the motivation for sexual gratification and the motivation for intimacy are independent. Although biological impulses and interpersonal

strengths are considered independent, it is the combination of these factors that enhances communication and cooperation (Erikson, 1987).

The lust, or passion, component of intimate relationships may be the most powerful dynamic in interpersonal relationships (Sullivan, 1953). Anxiety, puzzlement, and embarrassment are components that Sullivan (1953) states may have influence over the sense of security. While Erikson (1959) suggests the loss of identity in the act of sexual intercourse or in sexual fantasies, it is the intensity of sexual and affectual sensations experienced in sexual engagements that causes a fusion of identity between the dyad (Erikson, 1959). One has little control over the arousal or passion experienced (Sternberg, 1986). Due to the functional deficits experienced in persons with ALS, unsatisfied sexual encounters are expected and may result in deficient or unsuccessful experiences (Maslow, 1970). Erikson (1959) suggests that the inability to connect physically may also result in an impairment of trust and security, causing possible withdrawal from and anxiety related to intimate encounters. The limited functional capacities experienced by persons with ALS are likely to contribute to the emotional response and perceptions of physically intimate encounters. Like thirst and sleep, sexual satisfaction may not be completely deficient if rewarding past experiences and present and future gratifications are expected (Maslow, 1970). For persons with ALS, future gratifications are functionally impossible.

The expression of sexual intimacy is preceded by one's ability to collaborate with another and observe and respect the individual as equally important (Goethals, 1976). Thus, the experience of passion, or sexual gratification, is highly and reciprocally interactive with emotional closeness and connectedness in a romantic relationship

(Sternberg, 1986). This implication is not new, as earlier theorists have made similar statements. Erikson (1963) believed sexual engagements should include orgasm with a partner of the opposite sex with whom one shares mutual trust and security. Due to current beliefs and understanding of sexuality, this early theory of Erikson (1963) may be expanded to encompass homosexuality and the experience of orgasm to include partners of the same sex. Additionally, Maslow (1970) and Sullivan (1953) suggested that the capacity of engaging in intimate relationships, involving both sexual and emotional components, requires personal security, mutual trust, and sense of belongingness and respect. The capacity that the relationship serves to meet particular needs can satisfy the quest to reduce loneliness (Sullivan, 1953) while enhancing unity with another (Maslow, 1970). The experience of healthy interpersonal relationships can influence the perception of reality, increase the acceptance of self and others, and enhance the richness of emotional expression (Maslow, 1970; Sullivan, 1953). This may be especially important while enduring the changes of a debilitating disease such as ALS. The strengths identified in healthy relationships may help persons cope with the knowledge of terminal illness by altering the perception of the disease and redefining healthy relationships to encompass the new physical, emotional, and social needs of the dyad.

According to Sternberg (1989), *intimacy*, or emotional connections, appears to be the core of most loving relationships. However, the pinnacle of satisfying relationships includes equal contributions of emotional closeness and connectedness, passion, and commitment (Sternberg, 1989, 1997). In persons with ALS, the contributions may become less balanced as some forms of physical affection become extinct. The amount of love one feels can vary considerably depending on whom one is referring to. Intimacy, in

regard to Sternberg's (1989) definition, takes the desire of fusing identities one step further and actively promotes the welfare of the loved one, seeks experiences of happiness, and places value on another's life. Persons with ALS and their spouses may often attempt to protect one another physically and emotionally in regard to the changes held within the relationship. As a result of literature suggesting miscommunication and an over- or underestimation of QOL when researching persons with ALS and their spouse caregivers (Trail et al., 2003), it should be no surprise that individuals often interpret situations in light of how the decision may impact interpersonal relationships (Baumeister & Leary, 1995). The satisfactions and security of the loved one are viewed as just as important as one's own (Mullahy, 1952), and the desire for a shared identity is present (Erikson, 1987). The need for intimacy at its highest manifestation, including physical, emotional, and social components can be considered love (Sullivan, 1953).

Love is also a term that varies in definition. Maslow (1970) considered love to be a need that needs nourishment and consistency to promote physical and psychological growth (Maslow, 1970). The theory of love is introduced because love often includes various aspects of intimacy, including physical, emotional, and social. Although Sternberg (1986) used different terms to describe the components of a dyadic relationship, love can be understood as a process that includes some amount of conscious control and physiological impulses. The beginning and maintenance of a relationship are heavily reliant on decisions and commitments made by those within the relationship. Often, passion plays a significant role; however, it may be quick to develop and quick to fade within a relationship. More durable relationships encompass passion with the emotional investment to sustain the closeness in the marital relationship (Sternberg,

1986). As the relationship continues, emotional investment may become ordinary and difficult to distinguish (Sternberg, 1986). Maslow (1970) would consider these individuals as healthy and possibly having been satiated in regards to love. The need for intimacy includes many components. It is these components that influence experience of, desire for, and satisfaction with physical, social, and emotion components in the marital relationship. It is important to understand these contributions to understanding intimacy when assessing marital relationships undergoing the strain of a terminal illness.

Function of Intimacy

Depending on the type of intimacy referred to, the function of intimacy may consist of a large number of concepts. Intimacy may be referred to as a method of expressing and enhancing a couple's love and commitment to one another (Gulledge, Gulledge, & Stabmann, 2003; Hinchliff & Gott, 2004). Hinchliff and Gott (2004) identified themes of sharing, trust, and love as integral components of sexual activity that enriched the marital relationship, providing further evidence of the interaction between physical, emotional, and social components in relationship satisfaction and maintenance.

Types of Intimacy

Physical intimacy.

Gulledge, Gulledge, and Stabmann (2003) define physical intimacy as "any touch intended to arouse feelings of life in the giver and/or the recipient" (p. 234). This definition encompasses a large range of affectionate behaviors that may or may not involve sexual intercourse. Although some define physical and sexual intimacy as one construct (Schaefer & Olson, 1981), others differentiate between physical expressions of affection and sexual intercourse. Physical expressions of affection may include

massages, caressing, cuddling, holding, kissing on lips and face, and holding hands (Ben-Ari & Lavee, 2007; Gullede et al., 2003), and sexual intimacy includes sexual intercourse, or genital penetration (Simmons et al., 2006). Despite the significant disability in persons with ALS, physical intimacy may still be experienced by forms of affection that do not require genital penetration but still promote physical closeness and sensuality also experienced in sexual intercourse.

Emotional intimacy.

Ben-Ari and Lavee (2007) identify three components of interpersonal relationships that contribute to the experience of emotional intimacy and appear to be consistent themes in assessing operational definitions of emotional intimacy or closeness. First, friendship provides unconditional support, understanding, appreciation, and mutual trust (Ben-Ari & Lavee, 2007; Schaefer & Olson, 1981). Sharing, the second component, involves meaningful conversations and disclosing thoughts and feelings to another (Ben-Ari & Lavee, 2007; Schaefer & Olson, 1981; Simmons, et al., 2006). Lastly, caring includes recognizing the partner's needs and providing for them (Ben-Ari & Lavee, 2007; Gaines et al., 1996).

Social intimacy.

Social intimacy is thought to be shared experiences or commonalities experienced within the marital dyad. This may include having common friends and similar social networks and similar interests in hobbies and participation in common activities for positive relational experiences (Ben-Ari & Lavee, 2007; Emmers-Sommer, 2004; Schaefer & Olson, 1981). Patrick, Sells, Giordano, and Tollerud (2007) identified

personality factors that may contribute to an individual's experience with social intimacy, such as personability and spontaneity.

Experience of Intimacy With Others

It is not uncommon to find physical, emotional, and social solace from others in addition to marital partners. Tower, Stanislav, and Darefsky (2002) examined the impact of marital closeness and found that approximately 33% of dyadic couples within their sample indicated someone other than their spouse as persons they can count on or find confidence from. There appear to be some gender differences, such that men are often more likely than women to name their spouse as someone they can depend on, whereas women are more diverse in who may provide support (Allen et al., 1999; Tower et al., 2002).

Older adults, especially men, often first receive support from their adult children (Allen et al., 1999; Van Valcom, 2006); women may seek more emotional support from friends and siblings. Van Valcom (2006) found sibling relationships to be one of the most enduring and accountable for higher morale and greater sense of control in older adults. It is argued that siblings remain close throughout life, regardless of the frequency of contact, due to shared experience, concern for each other, and enjoyment of the relationship. In a review of the literature, Van Valcom (2006) found that during times of crisis or need, one is just as likely to turn to a sibling for aid as they are to a spouse. In regard to friendships, Sternberg (1997) assessed ratings of intimacy with significant persons other than spouses and found that women's intimacy scores were higher for their best friend than their lover. Friendships have been found to deteriorate as romantic and spousal relationships begin to develop in early adulthood (Meeus, Branjje, van der Valk,

& de Wied, 2007). Friends who share similar cognitions and behaviors tend to remain close over time (Ledbetter, Griffin, & Sparks, 2007). Friendships may become more important in later adulthood as individuals face changes related to physical decline, disease, and widowhood.

Marital Satisfaction

Marital satisfaction is a global concept often used to describe those behaviors that allow for the fulfillment and satisfaction of physical, emotional, and social marital encounters. Lawrence et al. (2008) most recently identified five significant dyadic behaviors that account for marital satisfaction that were often identified as themes throughout their review of the literature: emotional closeness and intimacy, spousal support, sensuality and quality of the sexual relationship, and decision-making and relational control. It appears that differences in gender and length of marriage can influence marital satisfaction by placing more or less importance on any of the cited dyadic behaviors. Regardless of the emphasis on specific dyadic behaviors, marital satisfaction appears to decline consistently over time (Brock & Lawrence, 2008; Kouros, Papp, & Cummings, 2008; Kurdek, 2005; Lawrence, Pederson, Bunde, Barry, Fazio, et al., 2008), especially within the first 15 months of marriage (Brock & Lawrence, 2008). Steeper declines may be attributed to poorer dyadic skills at the beginning of the marriage (Lawrence et al., 2008).

Emotional Closeness and Intimacy

Emotional closeness and intimacy focus on the ability to create a mutual sense of closeness and intimacy within a marriage (Lawrence et al., 2008). This includes feeling close to one's spouse and the ability to communicate concerns freely without the

avoidance of topics. The ability to self-disclose with intimate safety can influence the ability to predict emotionally intimate behaviors (Laurenceau, Barrett, & Rovine, 2005) and the satisfaction one feels in engaging in such vulnerable disclosures (Cordova, Gee, & Warren, 2005). These factors also contribute to maintaining closeness and togetherness within a marital dyad by fostering the ability to connect and discuss issues of importance in comfort and privacy, especially when one partner has a terminal illness (Lemieux, Kaiser, Pereira, & Meadows, 2004). Difficulty communicating has been identified to influence marital satisfaction significantly, creating the potential for longitudinal marital distress (Bookwala, 2005; Cordova et al., 2005; Lawrence et al., 2008).

Mutual safety has been suggested to set the precedence for the process of emotional vulnerability in both men and women (Cordova et al., 2005). It appears that women rely more heavily on the communication of emotions and experience the greatest decline in marital satisfaction when poor communication is present (Lawrence et al., 2008). This emphasis suggests that women with ALS may experience the greatest difficulty coping with declines in bulbar functioning due to its impact on verbal communication. Women appear to be most influenced by their husbands' actual attention to their concerns and also by their partners' perception of and ability to share emotionally charged information (Lawrence et al., 2008). Mitchell, Castellani, Herrington, Joseph, Doss, and Snyder (2008) found that women felt the greatest intimacy when their husbands understood and validated their disclosure. Additionally, wives felt safe expressing vulnerability when their husbands had the capacity to identify and

communicate their own emotions, also influencing the woman's level of satisfaction within the marital relationship (Cordova et al., 2005).

Men have greater difficulty communicating (Cordova et al., 2005); however, they report greater levels of emotional intimacy when engaged in personal, factual, and emotional disclosure (Mitchell et al., 2006). It has also been found that men often value women's ability to identify emotions (Cordova et al., 2005), possibly as a method to initiate emotional discussions difficult for men to commence, influencing marital adjustment for both men and women. The emphasis on responsiveness and mutuality in discussing emotional closeness can lead to speculation that men value women's desire to feel and experience emotional closeness. As a result, satisfying the need of one's wife for emotional disclosure is enough to enhance the husband's levels of intimacy during self-disclosure (Cordova et al., 2005). Women and men have different needs for and methods of communicating emotions. The addition and complication of coping with physical and bulbar deficits can lead to faulty perceptions and marital distress within the marital dyad. Coping with any terminal illness is difficult; the ability to accurately identify and address duress in one's spouse may have a positive influence on their ability to communicate this distress, fostering the strength of the marital dyad.

Emotional connections are often placed at a higher value when compared to physical components because it is believed that physical intimacies involve the presence of emotional closeness for satisfaction (Ben-Ari & Lavee, 2007; Hinchliff & Gott, 2004). This is seen as an important source of validation for those enduring an illness that renders them unable to engage in physically intimate behaviors (Lemieux et al., 2004), and its emphasis should be heightened as functional disability becomes more incapacitating

(Mancini & Bonanno, 2006). Specifically in terms of ALS, those who had established communication styles and higher levels of marital satisfaction continued to make persons with ALS feel valued within the relationship throughout the duration of the illness (Goldstein et al., 2006b). Recent findings suggest that difficulties may be encountered when persons with ALS first demonstrate signs of bulbar impairment, affecting their clarity of speech (Duff, 2007). However, it appears that difficulties remit, as most are able to work through or adjust to the presented obstacles (Duff, 2007). Overall, the ability to effectively communicate influences marital health and satisfaction and the ability to cope with disease onset and also the capacity to engage in physical intimacy (Lemieux et al., 2004) and resolve conflicts (Mirgain & Cordova, 2007), which will be covered more in-depth later.

Spousal Support

Spousal support is the second identified dyadic behavior and includes the level of support and the type of support experienced. This includes behaviors exhibited when one partner is upset, such as talking about the problem, or even being able to identify when one's partner is feeling down or upset (Lawrence et al., 2008). Responsiveness of a partner plays a large role in intimacy and the satisfaction with the relationship (Laurenceau et al., 2005; Laurenceau, Troy, Carver, 2005). As a result, when one partner experiences emotional deficits, such as coping with terminal illness, it influences the adjustment to and satisfaction with intimate interactions in both the individuals (Cordova et al., 2005). The ability to identify emotions in oneself and others can be difficult and the inability to do so is often damaging in the early years of marriage when the relationship is most vulnerable (McCarthy, Ginsberg, & Cintron, 2008).

Differences identified in courtship or dating relationships when compared to a marital relationship suggest that individuals prefer that spouses recognize strengths and weaknesses (Swann, De La Ronde, & Hixon, 1994). Marriage is considered to be self-defining (Cutrona, 2004) and the need for self-verification helps to foster the pursuit of personal and mutual goals within a marital dyad. Verhofstadt, Buysee, Ickes, Davis, and Devoldre (2008) assessed emotional similarity and empathic accuracy in supportive interactions and found that self-verification may occur most often in emotionally similar spouses. The emotional similarity and the ability to accurately understand the needs of one's spouse may account for more effective and satisfying spousal support (Verhofstadt et al., 2008), contributing to marital satisfaction.

The presence of stress and demands that often accompany illness can influence one's experience with spousal support and significantly impact emotional, social, sexual, intellectual, and recreational intimacies (Harper, Schaaljie, & Sandberg, 2000). Bookwala (2005) found that the presence of more physical symptoms related to physical decline predicted greater disagreement and negative spousal behaviors. As would be expected, these findings suggest that more negative spousal behaviors are associated with declines in the quality of the marital relationship (Bookwala, 2005). The perception of unfairness related to demands and stressors can exacerbate marital conflict (Grote & Clark, 2001), thus emphasizing that the amount of support received is important for both men and women (Harper et al., 2000; Patrick et al., 2007). When someone becomes solely responsible for the complete care of their spouse, frustration and a perception of unfairness may ensue. The experience of stress and overwhelming demands has a

reciprocal effect on the marital dyad, such that one's experience with stressors can also significantly impact the partner's marital satisfaction (Grote & Clark, 2001).

It has been suggested that men often experience the greatest amount of role-specific demands that may result in steeper declines in marital satisfaction over time (Bookwala, 2005; Brock & Lawrence, 2008). Brock and Lawrence (2008) identified two particular roles: financial responsibility and physical strength. In persons with ALS, physical decline is inevitable, which also contributes to the spouse's ability to work and financially support one's family. As evidence to support the reciprocal relationship in regard to the experience of stress, the decline in the husbands' marital satisfaction is also associated with a decline with wives' satisfaction (Brock & Lawrence, 2008). These changes associated with ALS may be especially poignant for men with ALS and contribute to the marital dissatisfaction of the whole marital dyad. Women who have been diagnosed with ALS may experience the changes associated with ALS differently. When healthy wives experience the greatest amount of demands and stressors, they are more likely to report a favorable course of marital satisfaction when they receive adequate support from their husbands (Brock & Lawrence, 2008). Although women may also be physically and financially impaired, adequate emotional and instrumental support may act as a buffer when coping with a woman's diagnosis of ALS. In both men and women, spousal support through intimate interactions has been shown to reduce stress. This was evidenced by findings that suggest that those with moderate levels of intimacy and average daily hassles were quite satisfied with their marriage (Harper et al., 2000).

Sensuality and Quality of the Sexual Relationship

Sensuality and quality of the sexual relationship focus on the sexual and sensual aspects of the marriage and how satisfying and how frequent such engagements are within the relationship (Lawrence et al., 2008). McCarthy, Ginsberg, and Cintron (2008) suggest that 15% to 20% of the time, the role of intimacy and sexuality can enhance marital vitality and satisfaction. This is especially true in the beginning of the marital relationship, when partners seek affectionate behaviors (Gaines, 1996) and when procreation is most meaningful (Hinchliff & Gott, 2004). It appears that men are often less satisfied with their experience of sexual intimacy regardless of the stage of marriage (Greeff & Malherbe, 2001; Taleporos & McCabe, 2003). However, steeper declines in sexual satisfaction are experienced in long-term marriages (Lawrence et al., 2008).

Reciprocity appears to have a significant impact on the experience and initiation of sensual and sexual behavior (Schmitt et al., 2007). The tendency to have a reciprocal dynamic for physically intimate encounters can serve as reinforcement to continue to engage in such vulnerable behaviors (Cordova & Scott, 2001). Individuals engage in affectionate behaviors when their partners are also affectionate (Gaines, 1996). In regard to terminal illness, as health declines and caregivers provide more assistance, physically intimate behaviors may decrease in frequency (Svetliik, Dooley, Weiner, Williamson, & Walters, 2005). A greater need for assistance in caring for physical functioning can alter self-image and cause embarrassment. As a result, persons with ALS may feel rejected and unattractive (McCabe, McDonald, Deeks, Vowels, & Cobain, 1996; Schmidt, Hofmann, Niederwieser, Kapfhammer, & Bonelli, 2005). Thus, if reciprocity of physical

advances is not present, the likelihood of intimate safety is lessened, and the relationship is likely to suffer (Cordova & Scott, 2001).

Sexual intimacy may not be as significant in long-term marriages when compared to newlywed couples (Hinchliff & Gott, 2004), but there is evidence that physical intimacy continues to be important at the end of life (Lemieux et al., 2004). There are factors that contribute to the insignificance of sexual intimacy later in life. The most common change in older couples is the decrease in sexual intercourse and an increase in general physical contact (Hinchliff & Gott, 2004). This is often due to natural physical decline or the presence of a disease that influences physical ability. In terms of the effects of disease, Lemieux, Kaiser, Pereira, and Meadows (2004) emphasize the importance of emotional connectedness through sexual expression and nonintercourse forms of intimacy. Both men and women find holding hands, closeness of physical proximity, caressing, hugging, and kissing were also of importance in maintaining a strong, satisfying marriage (Gulledge, et al., 2003; Lemieux et al., 2004). Other adaptations to disease and physical decline include being more careful when engaging in physical affection and taking advantage of days when physical health is optimal (Hinchliff & Gott, 2004).

Decision-Making and Relational Control

The fourth dyadic behavior aims to identify balance in the relationship in terms of decision-making, for example money management, and relational control, or how the marital dyad communicates and manages conflict (Lawrence et al., 2008). More specifically, relational control includes addressing negative affect, using conflict resolution skills, and managing aggression. There are often specific decisions in which

gender determines the power in deciding. For example, Beach and Tesser (1993) identified where to live, how much free time to spend with spouse, large purchases, when to vacation, when to have sex, and how to have sex as specific decisions men make. Conversely, women have more power in deciding how many children to have, methods of disciplining children, when to have social contact with friends, and small purchases (Beach & Tesser, 1993). When a couple faces the challenges of terminal illness, decision-making may become the responsibility of one person.

Houlihan, Jackson, and Rogers (2001) conducted research on decision-making processes of satisfied and dissatisfied married couples. Although gender roles often determine which decisions are made and by whom, these findings indicate that more equality and proportional distributions of decisions result in more satisfying marriages (Houlihan et al., 2001). In terms of actual decision-making strategies, men often make decisions on the basis of the actual situation, regardless of the level of difficulty (Houlihan et al., 2001). Women rely on the actual situation when making a minimally difficult decision (Houlihan et al., 2001). However, when marital satisfaction was assessed, more satisfied husbands often made decisions based on the needs and benefits of their partner (Beach & Tesser, 1993; Houlihan et al., 2001). The wives' emphasis on the husbands' needs was not significant in the findings of this research, although, it appears that women often consider their husbands' wants when considering the importance of the decision. Wives will often agree to decisions if the situation appears important to their spouse, even in cases in which they have more decision power (Beach & Tesser, 1993). In persons with ALS, making decisions may become more complicated in regard to choosing responsibilities, plans of action, treatment procedures, and end-of-

life requests. As communication ability decreases, persons with ALS may become more reliant on their spouse to make decisions for them, which may influence the quality of their relationship.

In developing a model of primary prevention in the first 2 years of marriage, McCarthy, Ginsberg, and Cintron (2008) report that approximately 30% of marital problems are solvable, 55% are modifiable, and the remaining need to be accepted and coped with so that they do not weaken the relationship. High levels of positive appraisals are associated with higher levels of marital satisfaction (Kurdek, 2005), and more negative attributions increase the likelihood for negative behaviors toward one's spouse (Kirby, Baucom, & Peterman, 2005). These negative attributions can manifest themselves in the form of negative communications, such as criticizing and blaming, and negative nonverbal communications, such as leaving the room or slamming the door (Kirby et al., 2005); each associated with relationship distress (Epstein & Baucom, 2002). The challenges faced in the beginning years of marriage may prepare couples for how to deal with unexpected events throughout their marriage.

It has been found that frequent, smooth interactions (Emmers-Sommer, 2004; Kurdek, 2005) and more positive attributions and effective communication to meet intimacy needs resulted in greater relationship satisfaction (Kirby et al., 2005). Couples that relate in this manner may be better able to cope with the presence of a terminal illness and how the illness will impact the intimacy within the relationship. Those who indicate their spouse has total control and is critical and argumentative have more marital problems (Bookwala, 2005; Goodman, 1999; Schwarzwald, Koslowsky, & Izhak-Nir, 2008). Marital conflict can strengthen negative associations and influence one's

experience with psychological distress (Kouros, Papp, & Cummings, 2008). Kurdek (2005) found that high levels of psychological distress at the start of the marriage are linked to low average levels of marital satisfaction for both persons. As psychological distress continues to be experienced and the stress of ALS is added, the potential for low marital satisfaction is exacerbated (Kouros, Papp, & Cummings, 2008).

Conflict resolution can be related to physical affection (Gulledge et al., 2003), respect for autonomy, and emotional and social intimacies (Goodman, 1999). The ease with which conflict is resolved may be associated with the amount of physical affection given and received in a relationship, suggesting that these individuals may feel more loved and understood through physical closeness (Gulledge et al., 2003). Additional research suggests that allowing and accepting a spouse's decisions and viewpoints may also contribute to intimate experiences and conflict resolution through emotional understanding and respect (Goodman, 1999). Also, higher ratings on intimacy involving sharing problems, enjoyment and good times, and wanting to please the other were the most positive predictor of marital satisfaction (Goodman, 1999). The effect of conflict skills are so influential, so that even when controlling for spousal support, emotional intimacy, and decision making, conflict resolution behaviors remained a significant predictor of marital satisfaction (Lawrence et al., 2008). It may be beneficial to emphasize this in the early stages of ALS as a means of enhancing communication and intimacy so that these skills may continue throughout the progression of the disease.

ALS and Intimacy: A Biopsychosocial Perspective

The most comprehensive approach to understanding biological, psychological, and social interplay to conceptualize the full experience of disease is through the use of the *biopsychosocial* model (Engel, 1977). This term was coined in 1977, when medical professionals began to question the strict biomedical explanations for particular organic and psychiatric diseases. The strict medical models of understanding disease and illness neglected nonbiological circumstances of biological processes and excluded those that did not fit perfectly into biomedical principles (Engel, 1977, 1980). Evidence to support this holistic view of understanding disease is the behavioral, psychological, and social identification and diagnosis of medical processes. Those experiencing significant illness often exhibit behavioral changes, such as changes in appearance and functioning, psychological changes, such as negative feelings, and social changes, such as isolation or perception of relationships as unpleasant (Engel, 1977, 1980). Medicine, using the “body as a machine” mentality, does not include these factors in diagnostics but they are the exact thing in making a diagnosis (Engel, 1977, 1980).

Engel (1977) explains certain principles of the biopsychosocial model that emphasize the importance and implications of having a more holistic and comprehensive approach to treatment. Novack and colleagues (2007) emphasize that humans are composed of interconnected systems, and psychophysiological mechanisms contribute to the maintenance of health. These psychophysiological mechanisms can be compromised by social and environmental events or cognitive and emotional reactions to interact with existing somatic factors altering susceptibility and influencing time of onset, severity, and course of the disease (Engel, 1977; Novack, Cameron, Epel, Ader, Waldstein,

Levenstein, et al., 2007). While there is not evidence to suggest that social or psychological factors are responsible for the presence of ALS, these factors contribute to the patient's well-being as they endure the diagnosis, treatment, and progression of the illness. In addition, these components affect the perceptions of, experiences of, and desire for intimate interactions with others.

ALS is a medical disease; therefore, the biological components are apparent. In Engel's (1977) model, he suggested that often the physician takes the responsibility to decide if the presented disturbance would be best handled in a medical framework. However, diseases often do not exist in isolation, only affecting the physiology of the body, but most often have emotional and social implications. Engel's (1977, 1980) proposed model of biological, psychological, and social components of disease is bidirectional and can end or begin with biological processes, affecting each step in the hierarchy, which represents an "organized dynamic whole" (Engel, 1980 p. 536). When applying this model to the presence of ALS, it is the biological components within the model that would lead the hierarchy. The biological components evolve from the smallest, the molecule, to the largest component of physiology, the nervous system (Engel, 1980). The specific components that would exist within this process are the initial manifestation of the disease and then the noticeable symptoms experienced by the individual with ALS. Later, the progressive decrease in physical functioning, impairment in bulbar functioning, and respiratory difficulty would be components of the biological hierarchy, contributing to greater psychological impact on the individual.

Symptoms are experienced and reported by the individual. Furthermore, the individual's verbal account may express psychological and bodily disturbances, lending

information toward specific diagnoses (Weston, 2005). Biological awareness is often dependent on the incidence and verbalization of the person experiencing symptoms. It should be of no surprise that the center of this model is the person, separating biological and social components. One of the largest complaints about the biomedical model is the exclusion of the patient as a person and the personal attributes he or she may possess (Engel, 1980). It is likely that Engel (1980) wished to emphasize the person as the key component in allowing professionals, and others, to gain greater clarity regarding those physical symptoms and sensations experienced and how the physicality influences the self and others. It is necessary for physicians to understand the patient's experience as they do because physicians are expected to elicit and analyze correctly the patient's personal account and make an accurate diagnosis of the presented problem (Weston, 2005).

The hierarchical step identified as *person* involves psychological components, including both experience and behavior (Engel, 1980). In applying this model to persons with ALS, specifically those enduring the physical decline related to the disease, the experiences of depressive symptomatology (Gauthier et al., 2007; Goldstein et al., 2006b; Hillemaier et al., 2004; Rabkin et al., 2000), anxious symptomatology (Brenes et al., 2005; Rabkin et al., 2000; Wicks et al., 2007; Vignola et al., 2008), fatigue (Lou et al., 2003; Ramirez et al., 2008), and burden (Chochinov et al., 2007; McPherson, Wilson, & Murray, 2007; Roe et al., 2001) are likely. As a result of these experiences endured within the individual, components related to ALS may affect interpersonal relationships. Persons with ALS may feel embarrassment and a loss of dignity in regards to the capacity of functioning and the emotional experiences while coping with such changes. This is

especially true when considering interpersonal relationships and the individual's perception of the effect of illness on the spouse. As a result, persons with ALS may begin to isolate from social events or activities and seek out less emotional and physical intimacy to decrease perceptions of burden and embarrassment. In most severe cases, assisted suicide or hastened death may be sought out to relieve significant distress or perceptions of burden (Chochinov et al., 2007).

The next three systems identified in the hierarchy are two-person, family, and community (Engel, 1980). Emphasis will be placed upon the two-person system to represent the marital dynamic. Each of these systems pertains to the interpersonal interactions and relationships of persons with ALS and therefore will be discussed in tandem. Engel (1980) identifies several changes made within the two-person system, which include communication, engagement, and changing relationships. This is also a suitable model for persons with ALS that begin to change their interactions with others as a result of the psychological components. Communication may be limited due to impaired bulbar functioning, or may be a result of perceived or actual burden of care (McPherson et al., 2007). As previously discussed, miscommunication is often due to each individual's reluctance to discuss concerns that may cause more pain or hardship for the other, further influencing relationship satisfaction (Trail et al., 2003). Persons with ALS become more reliant on others for support. As a result, roles are often changed. Someone who was once a lover and emotional companion may become the caretaker involved in bathing, toileting, and maintaining ADLs. Although the same individual, interactions have changed. These changes may affect the ability to become physically,

socially, or emotionally intimate as a result of embarrassment, frustration, and sadness (Roe et al., 2001).

This model continues in the hierarchy to include other members of the family, community, and institutions and systems. Important persons outside the marital relationship have not been discussed in much detail throughout the literature; one cannot forget that ALS does also affect these relationships. In terms of the family and community systems, reactions to the changing individual and altered roles become pertinent to the relationship (Engel, 1980). These relationships include sibling, parent/child, friend, clergy, and with whomever persons with ALS seek support from or are interpersonally involved with.

Current Available Literature

Literature pertaining to emotional, social, and physical intimacy in persons with ALS is limited. In the review of the current literature, only one research study addresses intimate relationships with ALS patients and their caregivers. Goldstein, Atkins, Landau, Brown, and Leigh (2006b) compared pre-illness marital intimacy and present marital intimacy in persons with ALS in relation to self-esteem. Their findings suggest that those with poorer perceptions of the disease process may have more of an impact on the individual than the actual bulbar and physical impairments. Additionally, those with better pre-illness intimacy maintained superior intimacy during the illness (Goldstein et al., 2006b). To add depth to the understanding of intimacy in ALS, literature from other areas of functional impairment and decline has been evaluated by assessing other physically debilitating diseases, traumatic injury, and the natural progression of lifespan development.

Multiple Sclerosis

Multiple Sclerosis (MS) is a disease of the central nervous system that results in sensory, motor and cognitive impairment (Amato, Ponziani, Rossi, Liedl, Stefanile, et al., 2001; McCabe, 2002). Its typical onset is between the ages of 20 and 50 years (McCabe, 2002) and symptoms are remarkably variable (Courts, Newton, & McNeal, 2005). Similar to ALS, persons with MS experience symptomatology differently, regardless of similarities in the type of MS. The course of the illness is unpredictable and, like ALS, can be progressively debilitating. However, unlike ALS, symptoms of MS can remit and reoccur throughout the duration of the illness. Some common physical symptoms include impaired mobility, fatigue, difficulty communicating, blurred vision, and incontinence (Boeije, Duijnste, & Grypdonck, 2003). Cognitive abilities can also be affected. As a result of physical and cognitive limitations, there is often a loss of functional independence and community participation (Goverover, Chiaravalloti, Gaudino-Goering, Moore, & DeLuca, 2009). Additionally, the ability of persons with MS to perform activities of daily living is compromised by the disease (Goverover et al., 2009).

Physical intimacy.

Persons with MS are more likely to experience sexual dysfunction than those within the general population (McCabe, 2002). Researchers often classify sexual dysfunction into primary, secondary, and tertiary dysfunction according to the hierarchy of impact related to MS. Most common primary sexual symptoms are a direct effect of the disease and include decreased desire, altered genital sensation, decreased incidence or strength of orgasm, and decreased vaginal lubrication (McCabe et al., 1996; Schmidt et al., 2005). Secondary dysfunction related to specific physical changes includes fatigue,

muscle tightness, weakness, spasms, bowel and bladder incontinence, cognitive difficulty, decreased mobility, numbness, and pain (McCabe et al., 1996; Schmidt et al., 2005). Tertiary dysfunction is related to the psychological, social, and emotion aspects of MS and includes changes in self-image, mood, depression, anger, difficulty communicating with one's partner, fear of being rejected, and feeling less attractive (McCabe et al., 1996; Schmidt et al., 2005). As ALS progresses, it is likely patients will also experience primary, secondary, and tertiary dysfunction similar to those that occur in MS.

Physical intimacy has been considered a primary component of marital satisfaction in persons with MS (Perrone, Gordon, & Tschopp, 2006). McCabe and colleagues (1996) found that persons with MS experience less frequent sexual interactions after onset, with 67% experiencing sexual interactions once a month, 17% several times and week, and 16% once a week. Findings also suggest that approximately 53% of respondents viewed their sexual problems as not important or had few concerns about their sexual difficulties. As a result, accommodations for physical impairment and difficulty in sexual intercourse may promote additional forms of physical closeness, including kissing, embracing, holding hands, breast petting, body caressing, and manual genital contact (McCabe et al., 1996). Persons with ALS may also make adjustments to accommodate for their changing body. However, additional research suggests that it may not be the physical levels of disability that impact satisfaction but the quality and perception of the relationship (McCabe, 2002). Although some researchers suggest a large proportion of persons with MS can perform independent ADL maintenance, such as grooming, bowel control, and toilet use, which likely influences the desire and experience

with physical intimacy (Einarsson, Gottberg, Fredrikson, von Koch, & Holmqvist, 2006), ADL function has been identified as a unique predictor for sexual satisfaction (McCabe, 2002). Decreased ability to care for oneself may influence perceptions of attractiveness, embarrassment, and perceptions of burden; therefore, additional factors besides physical components may be prominent in physical intimacy. Persons with ALS should be educated about the changes that will be experienced and the multifaceted nature of physical intimacy as it relates to disease.

Emotional intimacy.

The perception of emotional closeness can influence emotional, social, and physical functioning in persons with MS, resulting in feelings of strength and encouragement (Krokavcova, van Dijk, Nagyova, Rosenberger, Gavelova, Middel, et al., 2008). Similar to ALS, MS involves significant emotional changes over time (McCabe, Stokes, & McDonald, 2009). The presence of emotional support during the time of coping and accepting MS allows for the reappraisal of values and negotiation of roles (Fong, Finlayson, & Peacock, 2006). Over time, persons with MS increase the level of emotional support, often from their spouse (McCabe et al., 2009). Harrison, Stuijbergen, Adachi, and Becker (2004) found that marital status influences the acceptance of MS over time, such that those persons with MS who are married had a higher acceptance of disability when compared to those who were single or divorced or separated after the MS diagnosis.

Accompanying MS are many obstacles to emotional closeness within the marital relationship. The presence of significant depression and anxiety symptoms with more severe, progressive, and longer duration of MS can significantly impact the marital

relationship (Benito-León, Morales, & Rivera-Navarro, 2002; Hakim, Bakheit, Bryant, Roberts, McIntosh-Michaelis et al., 2000). This is also true for those older patients who experience more severe physical disability (Krokavcova et al., 2008). Goverover and colleagues (2009) found that spouses may indicate more severe depression in the patient than the patient reports, indicating a decline of communication. An increased reliance on others for emotional, social, and physical assistance and role changes often are of great concern for persons with MS due to the impending threat of becoming a burden to their spouse or losing their spouse as a result of difficulties related to the disease (Courts et al., 2005; Edmonds, Vivat, Burman, Silber, & Higginson, 2007; Fong et al., 2006). Unfortunately, low levels of acceptance of disability and components comorbid with the disease increase the levels of marital distress and decrease overall marital satisfaction (Harrison et al., 2004).

Even with many complex considerations involved in the emotional relationships of a marital dyad, approximately 33% of persons with MS report an improvement in the quality of their relationship (McCabe et al., 1996). McCabe and colleagues (2009) found that, although persons with MS had low levels of QOL in many domains, they were more accepting of their situation and expected the situation to change. This, in combination with the willingness of the marital partner to talk openly about MS, can lead to more togetherness, collaboration, and positive coping (Krokavcova et al., 2008). Some couples show a strong commitment to overcoming problems together. Through openness and emotional exchange, caregivers learn how to deal with physical tending, and persons with MS learn how to make these tasks easier, in turn, supporting the caregiver (Boeije, Duijnste, & Gryndonck, 2003). In a qualitative interview of persons with MS, one

particular participant specified the desire and need for someone to allow this person to share dark feelings, to be honest about the difficulties she experienced, to ask about her, and to listen to her answers (Courts et al., 2005). Also, partners learned how to talk about boundaries and mourn and cry over their deterioration and the disease process (Boeije et al., 2003). Ultimately, marital loyalty influences the motivation and desire to provide care to their spouse with MS because they love their spouses (Boeije et al., 2003).

Social support and intimacy.

Einarsson, Gottberg, Fredrikson, von Koch, and Holmqvist (2006) found that 59% to 68% of their research sample reported a decrease in frequency of social and lifestyle activities that included gardening, housework, and walking outside. Fong, Finlayson, and Peacock (2006) found that persons with MS also gave up going to church, attending support groups, and visiting with family and friends. This is not uncommon for persons with MS, as withdrawal from social activities and a shrinking circle of friends are common, especially for those with severe disability (Hakim et al., 2000). Obstacles with inaccessible environments, uncertainty about and increasing loss of control with the course of the disease, and fear of bladder or bowel incontinence often result in weighing the worth of social outings when considering the energy to plan and the burden of asking for help (Fong et al., 2006). With similarities in physical disability among persons with ALS and MS, the need to plan for social activities and to manage symptoms may be essential in making social experiences more meaningful (Fong et al., 2006; Wilhite, Keller, Hodges, & Caldwell, 2004).

Physical impediments are not the only factors related to decreases in social activities. Ways in which persons with MS interpret and respond to their symptoms have

also been found to have a significant impact on their level of fatigue and social functioning (Skerrett & Moss-Morris, 2006). These include cognitive variables such as somatic attributions, catastrophizing, symptom focus, embarrassment, and avoidance (Skerrett & Moss-Morris, 2006). Depression has also been shown to impact the social adjustment of persons with MS (Amato et al., 2001; Hakim et al., 2000; Motl, McAuley, Snook, & Gliottoni, 2009; Skerrett & Moss-Morris, 2006). Those able to overcome psychological impediments and maintain some semblance of physical activity have been shown to exhibit lower levels of depression, fatigue, and pain and higher social support (Motl et al., 2009). Consequently, greater social support positively influences mental health, physical health, and social functioning (Krokavcova et al., 2008). These factors have also been indicated in person with ALS; however, maintaining physical activity in the late stages of the disease are not feasible.

Often the support from and opportunity for social interaction when married and living with one's spouse has been shown to enhance the QOL in persons with MS (Gulick, 1997). It is possible that this support is equally valuable to persons with ALS. Boeije, Duijnste, and Grypdonck (2003) indicated that couples hardly spend any leisure time outside their homes due to the extra efforts and costs for suitable accommodations. Similar to ALS, the capabilities in persons with MS change, but interests and the desire to engage in activities with one's spouse may persist. Marital dyads may preserve these values by changing their expectations and negotiating abilities when engaging in meaningful activities (Fong et al., 2006). Courts, Newton, and McNeal (2005) found that many caregivers try to maintain their partners' self-worth by promoting independence and encouraging more activities. Physical changes in persons with ALS can cause a great

deal of uncertainty and embarrassment. It is possible that persons in earlier stages of ALS may also benefit from the encouragement to participate in activities that are appropriate for their level of functioning.

Acquired Physical Disabilities

Physical disability (PD) is often used as a global term to include congenital abnormalities, amputation, arthritis, traumatic injuries, such as spinal cord injury (SCI), and neurological disabilities, such as MS. One major difference between PD and ALS is that some ambulation is often possible in persons with PD, whereas persons with ALS progressively lose all motor function ability. This is an important consideration when comparing PD with ALS, due to differences in the severity of functional disability. Although the progression of ALS may be similar to some PDs, persons with PD often live for extended periods of time, whereas persons with ALS face certain death in a short amount of time. These differences when comparing PD to ALS may involve different perceptions of functional ability and how PD influences intimate relationships.

Similar to ALS and other disorders with physical deficits, anxiety, depression, and negative self-esteem are highly correlated with the presence of functional disability (Mancini & Bonanno, 2006). Additionally, the presence of psychological sequelae has been found to be greater in those not involved in a romantic relationship (Taleporos & McCabe, 2003). In assessing marital status among individuals with PD compared to the general population, those with more severe disabilities were less likely to be married (Rokach, Lehcier-Kimel, & Safarov, 2006; Taleporos & McCabe, 2003). Single persons with PD may experience a greater amount of emotional distress, social inadequacy, and isolation (Rokach et al., 2006). Marriage, particularly marital closeness, can ameliorate

negative psychological effects of PD by decreasing the experience of psychological consequences and psychological distress (Mancini & Bonanno, 2006). Although these experiences may be ameliorated, one cannot discount the distress, inadequacy, and isolation that may be felt by persons with PD and ALS. These perceptions may influence interactions with one's partner, thus influencing the experience and satisfaction with intimacy and the desire to engage in intimate interactions.

Physical intimacy.

Similar to ALS patients, persons with PD may experience perceived and actual barriers to physically intimate interactions. PD has been shown to have a significant effect on perceived attractiveness (McCabe & Taleporos, 2003). Persons with PD often believe they are less attractive than able-bodied persons (Taleporos & McCabe, 2001). Lease, Cohen, and Dahlbek (2007) found that persons with an earlier age of disability onset had higher body and sexual esteem than persons with later onset. However, their findings are consistent with other literature, suggesting that persons with PD in general find themselves less attractive to others. Regardless of how confident persons with PD are with their own physical and sexual self, when compared to able-bodied individuals, negative perceptions persist for many. These perceptions may influence one's initiation of physically intimate interactions, due to negative evaluations of one's body and limited confidence.

Additionally, PD has been shown to have a significant effect on sexual satisfaction. In assessing physical independence, the decline in sexual satisfaction is evident when assistance to perform even one typically independent task is required (Lease et al., 2007; McCabe & Taleporos, 2003). Singh and Sharma (2005) indicated that 58% of their

participants experienced bladder or bowel problems while engaged in sexual activities. Such experiences may cause embarrassment, shame, and concerns about their partners' perceptions. The amount of assistance can also predict changes in satisfaction on the part of the spouse, often the person providing assistance. As the individual's health declines and spouses provide more assistance, the satisfaction with opportunities for physically intimate behavior decreases (Svetlik et al., 2005). From this literature, it appears that the need for assistance when previously independent can be damaging to spousal relationships. Some women report that their partners (42%) were never satisfied with sexual activity after their injury (Singh & Sharma, 2005), and others report that their husbands continued to compare the couple's lovemaking with how it had been before (Leibowitz & Stanton, 2007). This may further contribute to unsatisfying physical encounters. Additionally, the perception of incompetence, resentment, and guilt may lead to a lack of desire for sexual encounters, affecting arousal, sexual performance, and frequency of sexual contact (Ducharme, 2006).

When PD is present, it appears that many expand sexual intimacy to include other forms of physical closeness. Intimacy may become less purely physical and expand to also include mental, spiritual, and emotional aspects of sexuality (Leibowitz & Stanton, 2007). McCabe and Taleporos (2003) have found that the presence of other forms of physical intimacy besides sexual intercourse, including oral sex, nude cuddling, and viewing erotic imagery, have been associated with higher levels of satisfaction of physical intimacy in persons with PD. It is not surprising that ideas of physical intimacy change to include other important ingredients of sexuality to maintain activity and pleasure. It would be expected that persons with ALS would also shift their

understanding of sexual intercourse to become more globally known as physical intimacy and include other forms of physical closeness. Those who adapted their definition of sexuality have described a shift of erotic pleasure from the genitals to other areas of the body (Leibowitz & Stanton, 2007). In particular for SCI, a large percentage of women continue to be interested and engage in physical intimacies (Singh & Sharma, 2005).

While this encompassing idea of physical intimacy often takes place, spouses of persons facing PD may continue to hold their conceptualization of physical intimacy as strictly sexual intercourse. Those that hold rigid views on physical intimacy continue to experience a significant decline in satisfaction with affectionate physical contact at the onset of PD (Svetlik et al., 2005). Leibowitz and Stanton (2007) interviewed women with SCI and found that those who did not shift their definition of physical intimacy and focused more on genital intercourse after the SCI appeared to have greater difficulty enjoying physical affection. Couples dealing with the changes related to ALS may also have difficulty adjusting their experience of “normal” abilities to include other methods of physical closeness. Unfortunately, this is not uncommon, and relationship loss has been associated with the decline of physical intimacy in marital relationships where one person in the relationship experiences acquired PD (Svetlik et al., 2005).

Vansteenwegen, Jans, and Revell (2003) suggest that more education fosters a greater understanding and acceptance of physically intimate behaviors with PD. In conjunction with QOL care for ALS, professionals may help to enhance the understanding and presence of physical intimacy through education and guidance. In fostering such interventions, it is possible that increasing the levels of satisfaction can

greatly reduce psychological sequelae (McCabe & Taleporos, 2003) and enhance the marital relationship during the chronic phase of illness.

Emotional intimacy.

Emotional intimacy includes emotional connections, mutual trust, and meaningful conversations (Ben-Ari & Lavee, 2007; Schaefer & Olson, 1981). When PD is acquired through an accident or disease, the dynamic of the relationship often changes. In certain forms of PD, abnormalities may be present in regions associated with emotional processing, including the expression and learning of emotional feelings, psychophysiological expression, and the control of motivational behaviors (Nicotra, Critchley, Mathias, & Dolan, 2006). This biological component is important to consider when assessing emotionality and interpersonal relationships, as it may influence how persons with PD interact with their loved ones and how others perceive the individual as a result of impaired emotional processing and motivation. Similar changes may occur in persons with ALS due to recent findings that emotional identification may be impaired (Kilani et al., 2004; Lulé et al., 2005).

Persson and Rydén (2006) suggest that changes often include accepting the disability by arriving at an existential shift in values. The spouse may not know the appropriate response or the needs of the individual. Additionally, the spouse may have difficulty communicating how the change in physical capacity is influencing the relationship. Rather than focus on the physical aspects of a relationship or those activities that previously bonded the couple, persons with ALS and PD may better maintain the relationship through emotional connections (Persson & Rydén, 2006). The strength of the marital relationship may promote the exploration of despair and loss of

independence within both individuals. The quality of the relationship, mutual trust, and effective communication may facilitate a means of confidence in seeking not only instrumental support but also psychological support in persons who face physical decline as a result of accident or disease (Isaksson, Skär, & Lexell, 2005).

As an example, Isaksson and colleagues (2005) found that women who experienced SCI perceived themselves to be more humble and tolerant with others also coping with the changes. As a result, these women felt that relationships improved due to increased relationship investment, time availability, and emotional closeness brought upon by the incident (Bocarro & Sable, 2003; Isaksson et al., 2005). Additionally, these women sought to disclose their own emotionality in regards to their new situation so that others could understand how they wanted to be seen, fostering intimate relationships (Isaksson et al., 2005). Essentially, the women gave emotional support to family members and friends even though they faced a difficult situation (Isaksson et al., 2005).

Hirschberger, Florian, and Mikulincer (2005) identified gender differences in response to PD. It appears that women with PD may experience the most difficulty with their male counterparts. Unintentionally, it appears that men find PD aversive and often distance themselves emotionally, which may lend understanding to the average decline in perceptions of the caregivers' relationship quality when assessing happiness (Svetlik et al., 2005). Hwang, Johnson, and Smith (2007) report that persons with PD who experience anxieties within the marital relationship have less cohesion with their spouse. It is possible that similar gender differences occur in the presence of physical dysfunction in ALS. This reaction may be prevented by opening up to others about the changes experienced as a method of acceptance and understanding for PD's influence on the

marital relationship (Persson & Rydén, 2006). The emotional verification can make each partner feel good about themselves and may also promote emotional closeness within the dyad (Svetlik et al., 2005).

There are particular factors that may also influence emotional intimacy in persons with PD and the marital relationship. First, the duration of the disease has been found to relate to less daily emotional support (Fyrand, Moum, Finset, & Glennås, 2002). Those who have been receiving a tremendous amount of support from their spouse may have too much reliance on others, leaving persons with PD helpless and spouses frustrated and exhausted (Persson & Rydén, 2006). Second, personality traits such as extroversion and low neuroticism may improve the frequency and satisfaction of emotional support (Fyrand et al., 2002). These individuals may be more emotionally and instrumentally independent and pleasant to be around, thus fostering strengthened interpersonal relations and a positive response to continued emotional connections. Last, late onset disability or acquired disability may be influenced by the already formed marital bond and dyadic behaviors. Hwang and colleagues (2007) hypothesize that those who endure the immediate changes involved with traumatic PD and rehabilitation are already closer and more cohesive than other couples or they adapt. These individuals often had a positive perception of others, comfort with closeness, and reported a greater overall adjustment and cohesion with their spouse (Hwang et al., 2007).

Social support and intimacy.

Persons with PD experience a shrinking social world as old friends and acquaintances are uneasy or reluctant to continue relationships (Isaksson et al., 2005). Persons with acquired PD do not behave in ways that are considered socially acceptable.

As a result of an accident or disease, persons with PD may experience spasming, drooling, and loss of limb function (Taleporos & McCabe, 2005). Friends, family, and others within the community often do not know how to respond to such behaviors, especially when acquired from a disease or traumatic event. Often, the initial reaction to the disability is associated with a high degree of social support (Fyrand et al., 2002). However, it appears that more disabled persons have lower social companionship over time (Fyrand et al., 2002; Tak, Hong, & Kennedy, 2007). Similar to persons with ALS, their primary social support network is likely to be their spouse.

In regard to marital relationships, Bocarro and Sable (2003) found that the greatest disruption in the lives of persons with PD and their spouses was often the loss of shared activities that strengthened and maintained the relationship. Like ALS patients, persons with acquired PD need to make changes to accommodate new enjoyable activities. It does not appear that those interested in socializing with others prior to PD experience any less interest after the injury has taken place (Hwang et al., 2007; Tasiemski, Kennedy, Gardner, & Taylor, 2005). Hwang and colleagues (2007) hypothesize that those couples coping with the immediate changes involved with traumatic PD and rehabilitation together are more likely to adapt to the new “life” by including more solitary or couple-based activities as a means of replacing those interests that are not able to be continued. Those who engage in new interests often do not feel bitter about what has been lost due to the disability (Persson & Rydén, 2006). Those unable to adjust often report anxiety in the marital relationship and report fewer shared activities, whereas social integration has a positive influence on relationship satisfaction and the number of shared activities experienced. Although physical detriments are great

in the later stages of ALS, accommodations may be made to continue to engage in activities and may foster the satisfaction with socially intimate encounters.

Independent mobility has an impact on overall dyadic satisfaction and cohesion by increasing the opportunities for shared activities (Hwang et al., 2007). Perceptions of PD may influence self-esteem and confidence in engaging in activities. Persons with PD and progressing ALS may be ambivalent about engaging with others socially, due to their own coping with changes in physical functioning, loss of independence, and decrease in social opportunities. Tasiemski and colleagues (2005) conducted research on recreational activity of persons with SCI pre- and postinjury and found that watching television, listening to music, and reading were all activities highly endorsed. These are all solitary activities that do not require the participation of another person. It is possible that other activities, such as participating in sports, going to concerts, and traveling, are not as highly rated due to the infrequency of participation as a result of dependence on others. Additionally, Buunk, Zurriaga, Gonzalez, Terol, and Roig (2006) found that persons with PD often compare themselves on physical activities to those without health problems or physical impairment when experiencing high levels of stress. Taleporos and McCabe (2005) had similar findings, suggesting that persons with PD who perceived themselves to have severe disability had lower body esteem. This amplified as the need for assistance increased

This appears counterproductive to building confidence and may result in a perpetual cycle for those adjusting poorly to their injury, potentially influencing the desire and satisfaction with social encounters. The perception of incompetence by one's spouse may also decrease the desire for engage in social or recreational activities. If

recreation is fostered and marital partners continue to engage in activities together, evidence supports higher levels of life satisfaction and higher quality of social relationships (Tasiemski et al., 2005). This contributes to the overall efficacy, confidence, and acceptance of new limitations. Positive spousal support in learning and creatively developing compensatory techniques and aids, altering treatments, and changing the organization of daily living may influence overall perceptions and also facilitate active lifestyles (Persson & Rydén, 2006).

Older Adults

The aging process is one in which functional decline is inevitable as a result of the natural progression of human development (Mancini & Bonanno, 2006). Physical disability can create a number of negative outcomes, including loss of independence, institutionalization, and mortality (Mavandadi, Rook, & Newsom, 2007). Many suggest a bidirectional interaction between physical disability in older adults and the presence of anxiety and depression (Mancini & Bonanno, 2006). Likewise, older adults have a higher incidence of suicide attempts and completions than their younger counterparts (Lebret, Perret-Vaille, Mulliez, Gerbaud, & Jalenques, 2006). A protective effect from suffering higher levels of physical functioning has been identified in the emotional closeness experienced in marital relationships (Mancini & Bonanno, 2006).

Physical intimacy.

Sexuality and physical intimacy continue to be important at the end of life (Lemieux et al., 2004). Gott and Hinchliff (2003) assessed the importance of sexual relations in 44 persons over the age of 50, and a majority of participants rated sex as at least moderately important, with 10 rating sexual intercourse as very important and five

identifying it as extremely important (Gott & Hinchliff, 2003). Unfortunately, the likelihood of being sexually active steadily declines with age (Lindau et al., 2007). Lindau and colleagues (2007) conducted a study regarding sexuality and health in older adults and reported several important findings that aid in understanding sexuality in older age. They reported that 26% of those 75 to 85 years of age were sexually active, as compared to 73% of those 57 to 64 years of age. However, those in the older age group who were sexually active reported having sexual intercourse two to three times per week.

Second, Lindau et al. (2007) indicated that approximately half of female and male respondents reported at least one sexual difficulty. In order of prevalence, men most commonly experienced difficulty achieving and maintaining an erection, decreased libido, premature ejaculation, performance anxiety, and an inability to climax (Gott & Hinchliff, 2003; Lindau et al., 2007). Women experienced a decreased libido, difficulty with lubrication, inability to climax, finding intercourse unpleasurable, and pain (Gott & Hinchliff, 2003; Lindau et al., 2007). ALS often occurs in mid- to late adulthood; therefore, it is possible that persons with ALS are experiencing natural sexual dysfunction concurrent with the declines related to the disease. As a result of the similarities and potential overlap of symptoms, it would be important to conceptualize this in terms of biological, psychological, and social components. Bitzer, Plantano, Tschudin, and Adler (2007) developed a biopsychosocial treatment for elderly couples having difficulties in sexual experiences. The biological component includes medical concerns, hormonal changes associated with older age, affective disorders, and side effects of medicine. Negative perceptions, experiences of separation, and personality characteristics are included in psychological components of intimacy difficulties.

Finally, social components include media messages and unrealistic expectations regarding performance.

Those who claim sexual intercourse is not important to them often reported experiencing physical and psychological barriers due to age (Gott & Hinchliff, 2003). Consistent with the literature in other areas of physical decline, the expression of intimacy may take a different form. Sexual intercourse may be given a lower priority, and touching, holding, being close, caressing, and other physical forms of affection may become more prominent (Gott & Hinchliff, 2003; Lemieux et al., 2004). As a couple, balance needs to be found among individual needs, relationship needs, and the ability to cope with undiscovered aspects of their partner (Bitzer et al., 2007). Regardless, older adults emphasize the importance of maintaining physical intimacy, regardless of the possibility of engaging in sexual intercourse (Gott & Hinchliff, 2003).

Emotional intimacy.

Lemieux, Kaiser, Pereira, and Meadows (2004) identified many components of physical intimacy, but found that physical and sexual closeness were centered on emotional connectedness. As previously cited, emotional closeness to spousal partners can have a positive impact on functional disability, as well as on the presence of depression, anxiety, and low self-esteem (Mancini & Bonanno, 2006). Maintaining togetherness and QOL in older adults often revolves around the ability to find unconditional trust and mutual disclosure of important issues in comfort and in privacy (Lemieux et al., 2004).

Spousal care in older adults may become increasingly difficult when one partner needs care and the other is also suffering from physical impairment. As age increases, so

does the presence of physical disability and other health problems requiring medications (Bruce, Paley, Roberts, Underwood et al., 2005). Due to the age at which ALS occurs, the role shift from spouse to caregiver can be especially stressful on both parties of the marital dyad. However, factors such as love, dedication, and lifelong friendship have often influenced the ability to understand the condition as separate from the person, thus promoting the maintenance of emotional connectedness (Cassells & Watt, 2003).

Social support and intimacy.

After retirement, older adults often organize their life around their marital relationship by spending a great deal of time with their spouse (Trudel, Villeneuve, Anderson, & Pilon, 2008). This is a time in which partners participate in activities they enjoy together and sometimes become interdependent, due to the time investment that was not otherwise needed for child rearing, career, and so on. The presence of physical disability or other impairments may make engaging in social activities less desired. For example, those with more severe disability reported they were housebound and could not get out as often as they would like (Freyne, Koegh, & Wrigley, 2005). Another concern of some older adults is incontinence, which was discussed earlier as a part of how physical dysfunction may affect a marital relationship in persons with ALS. Those who experience incontinence often socially isolate to prevent embarrassment (Cassells & Watt, 2003). In social situations or environments other than their home, they are constantly attentive and assessing the unpredictable nature of incontinence. This can be emotionally draining to both the incontinent person and their spouse. Both persons are limited in social interactions if active together, and those left alone more frequently may be more likely to experience loneliness and depression (Freyne et al., 2005). If the

spouse is identified as caregiver, responsible for the incontinent spouse, a lapse in watchfulness could result in embarrassment, guilt, and more work for the caregiver (Cassells & Watt, 2003).

Although social isolation may be prevalent due to such concerns, those with less physical activity actually face a greater likelihood of physical limitations (Wu, McCrone, & Lai, 2008), which may increase mortality rates. Mancini and Bonanno (2006) found that persons with high levels of functional disability at baseline had an 82% greater increase in mortality over the 5-year study period when compared to study participants with low functional disability (Mancini & Bonanno, 2006). Survival can be enhanced by activities as simple as working on a hobby, engaging in regularly scheduled social activities, having frequent contact with friends (Wu et al., 2008), and regular positive interactions with others (Mavandadi et al., 2007).

Relevance to the Current Study

ALS afflicts older adults; the average age of onset is considered to be 62.8 (Chiò et al., 2002), and survival is often limited to 36 to 29 months from the time persons with ALS first begin to notice symptoms (del Aguila et al., 2003; Kimura et al., 2006).

Although intimacy has not been directly studied within the ALS population, there are many factors that are likely to contribute to the perception and experience of interpersonal relationships. The diagnosis of a terminal illness can be disheartening and anxiety provoking for many, and psychological components often ensue as a result. Additionally, the progressive loss of functioning and reliance on others for assistance can influence the satisfaction with, experience of, and desire to engage in intimate ways with

one's partner. The current literature does not provide information on how ALS impacts the marital relationship.

The comparison across different types of physical decline is necessary to understand the physical, emotional, and social implications of physical disability in intimate relationships, as research is limited in the ALS population. One purpose of this research is to gain a greater clarity regarding intimacy experience, desire, and satisfaction in persons with ALS and how physical functioning impacts marital relationships. Similar to persons with MS, acquired physical disability, and older adults, persons with ALS face extreme physical changes from previously "normal" functioning. Unique to persons with ALS, speech and the ability to verbalize are also impacted. It is likely that the unique features of ALS will cause different components of intimacy to be affected. With regard to physical intimacy, the decline in physical capabilities causes the definition of sexual intercourse and sexuality to be broadened to include other compassionate behaviors, such as holding hands, caressing, kissing, etc. Also, the frequency of physical affection may decline, but often the desire remains. Coping with ALS and relying on one's spouse for caregiving may affect emotional intimacy. As emotional expression is inhibited, the experience and satisfaction of emotional closeness may decrease, but the desire may persist or strengthen. Socially, persons with acquired physical disabilities become limited in their ability to engage in previously enjoyed activities with their spouse. Persons who have been living with impairments for a longer amount of time may have more time to adjust to and make accommodations for shared activities.

Overall, there are many factors that may contribute to the intimacy of persons with ALS. The second aim of this study is to identify specific predictors of intimacy that

may influence how physical, emotional, and social intimacy are experienced, satisfied, and desired. Some of these factors include: age, gender, onset of symptoms, and physical and bulbar impairment. With regard to understanding intimacy and treating this aspect of QOL in persons with ALS, it would be most beneficial to use data from ALS-specific populations, rather than attempt to understand it by comparing ALS to other disorders that are likely to have varying implications.

Chapter 3

Hypotheses

Overall Question:

This research project is guided by the following questions: (a) What is the experience of, satisfaction with, and desire for physical, social, and emotional intimacy in persons with ALS? (b) Is there a relationship between physical functioning and intimacy? and (c) Are there specific aspects of physical functioning that predict satisfaction with intimacy? Table 1 references each of the hypotheses dependent and predictor variables.

H₁: Gender, time since the onset of symptoms, and functional ability of cutting food, dressing and hygiene, and turning in bed according to the ALS Functional Rating Scale-Revised (ALSFRS-R) will predict the experience of emotional intimacy, as indicated by the ALS-Specific Quality of Life-Revised (ALSSQOL-R) (item 40).

Rationale: Women with ALS who have greater physical impairment are limited in their ability to physically show affection and maintain intimate interactions. Women rely more heavily on the communication of emotions (Lawrence et al., 2008). As a means to maintain intimacy and closeness in a marriage, personal and emotional closeness through verbal expression may replace the experience of sexual intercourse. Emotional closeness could potentially exist without sexual encounters; therefore, emotional intimacy is often held at a higher value than physical and social intimacy (Ben-Ari & Lavee, 2007). As a result of the barriers to physical and social intimacies, both patients and spouses may rely more on emotional connections.

H₂: Gender, age, time since the onset of symptoms, and severity of functional ability, as indicated by the total score of the ALSFRS–R, will predict the experience of physical intimacy, as indicated by the ALSSQOL–R (items 46 and 49).

Rationale: Those individuals who have been living with the symptoms of ALS for a longer period of time may experience greater impairment in physical functioning, due to the natural progression of the disease. Therefore, these individuals may not be physically able to provide physically intimate gestures such as kissing, hugging, and sexual intercourse. Additionally, the care needed to maintain the comfort of persons with ALS, especially those needed over 6 hours of care per day, may become burdensome to the spouse (Hecht et al., 2003). In combination with this impairment, gender and age may contribute to the experience of physical intimacy as a result of embarrassment and burden felt as a result of dependency placed upon the spouse.

H₃: Gender, time since the onset of symptoms, and bulbar functional ability, such as speech, salivation, and swallowing and physical functional ability, indicated by cutting food and dressing and hygiene, according to the ALSFRS–R will predict the experience of social contact, as indicated by the ALSSQOL–R (item 40).

Rationale: Persons with ALS who have bulbar and functional impairment are limited. Although they may maintain joy for hobbies, the ability to engage in them as they had previously done may no longer be reasonable. Social engagements are suggested to intensify marital satisfaction (Ben-Ari & Lavee, 2007; Cassells & Watt, 2003; Gauthier et al., 2007). The interest in social activity does not seem to vary according to gender; however, persons with ALS may experience physical and emotional discomfort in social settings, affecting the overall frequency in which social contact occurs.

H₄: Gender, age, and physical functional ability typically completed independently, specifically cutting food, dressing and hygienic needs, and turning in bed, according to the ALSFRS–R, will predict satisfaction with physical intimacy, as indicated by the ALSSQOL–R (items 47 and 50) and the Personal Assessment of Intimacy in Relationships (PAIR) (sexual intimacy subscale).

Rationale: The need for physical aid related to impairment and inability to attend to activities of daily living (ADLs) can influence vulnerability, autonomy, and privacy in persons with ALS (Roe et al., 2001). The idea of reciprocity and role assignment is not as important in older age, due to the natural decline in functioning; this is not so in middle-aged persons (Schmitt et al., 2007). The increase in physical disability and the overreliance on the spouse for physical support can be embarrassing, especially for previously independent and personal functions (Gauthier et al., 2007). The role reversal and dependence on the spouse for physical aid may contribute to feelings of inferiority and a loss of dignity, influencing the ability to be satisfied with physically intimate interactions. Gender may play a significant role, such that men may experience the most impact, possibly due to social standards of the expected male role.

H₅: Gender and bulbar functional ability in speech, salivation, and swallowing, according to the ALSFRS–R, will predict satisfaction with emotional intimacy, using the ALSSQOL–R (item 44) and the PAIR (emotional and intellectual intimacy subscales).

Rationale: Bulbar functioning involves the ability to verbally communicate with others and is considered a predictor of psychological distress (Goldstein et al., 2006b; Hillemacher et al., 2004). Because of its psychological implications and the reliance on bulbar functioning to communicate with others, greater bulbar impairment may be

expected to influence the individual's satisfaction with emotional intimacy. Women, specifically, felt greatest intimacy when their male partner was understanding and validated their disclosure (Mitchell et al., 2008). Therefore, the inability to verbally communicate may decrease satisfaction, due to the inability to communicate unmet needs (Kirby, Baucom, & Peterman, 2005). As a result, the individual with greater bulbar impairment will need to find other ways to share feelings and be emotionally close with others. Overall, the impairment of verbal communication may result in less satisfaction with emotional intimacy, due to the difficulty in verbal expression.

H₆: Gender, time since the onset of symptoms, and bulbar functional ability, indicated by speech, salivation, and swallowing, and physical functional ability, indicated by cutting food and dressing and hygiene, using the ALSFRS-R, will predict satisfaction with social contact, using the ALSSQOL-R (item 41), and social intimacy, using the PAIR (social and recreational intimacy subscales).

Rationale: Persons with ALS initially coping with and managing the changes experienced as a result of the progression of ALS often feel socially isolated and embarrassed. Over time, the sense of embarrassment does not increase, but remains stable (Gauthier et al., 2007). The initial presence of symptoms and need for assistance may be difficult to adjust to, especially when previously independent. Because of the novelty of the disease, those with slight impairment are likely to be less satisfied with social intimacy, due to the unfamiliarity, emotionality, and fatigue related to changes in functioning (Ramirez et al., 2008). It is possible that satisfaction is influenced by the gender of the persons afflicted by the illness, with males and females potentially weighing different factors as more or less important in regard to satisfaction.

H₇: Gender and physical functional ability, indicated by cutting food, dressing and hygiene, and turning in bed and adjusting bed clothes, according to the ALSFRS–R, will predict desire for physical intimacy, as indicated by the ALSSQOL–R (items 45 and 48).

Rationale: As previously indicated, persons with ALS demand a great deal of care, especially those with greater functional impairment (Hecht et al., 2003; Chiò et al., 2006). The desire for intimacy has been shown to persist over time, across gender and age; however, it is possible that the desire may differ between men and women. Additionally, due to the changes in role from spouse to caregiver, there may be discomfort in engaging in physically intimate behaviors. In conjunction with this ambivalence, McPherson et al. (2007) suggest that these concerns may not be communicated, due to the fear of adding to the burden of the caregiver or to the caregiver's fear of expressing distress to the individual with ALS.

H₈: Gender and bulbar functional ability, indicated as speech, salivation, and swallowing, according to the ALSFRS–R, will predict desire for emotional intimacy, as indicated by the ALSSQOL–R (item 42).

Rationale: Although research indicates a difference in preferences for intimate interactions, both men and women express a higher value and desire for emotional disclosures (Mitchell et al., 2008). As previously discussed, bulbar impairment affects the ability to verbally communicate with others. Due to the impact on verbal expression, impairment in speech, salivation, and swallowing may increase the desire for emotional intimacy due to the frustration of the difficulty in communicating personal and emotional expressions.

H₉: Gender, bulbar functional ability in speech, salivation, and swallowing, and physical functional ability in cutting food and dressing and hygiene, according to the ALSFRS-R, will predict the desire for social contact, as indicated by the ALSSQOL-R (item 39).

Rationale: In the assessment of marital satisfaction, men have indicated a greater interest in and desire for social intimacy, such as common interests and friends, etc. (Patrick et al., 2007). Women are also interested in socially intimate interactions, but may not value them as much as emotional and physical intimacy (Greeff & Malherbe, 2001). The inability to adequately engage verbally and through physical methods may increase the desire to engage in previously enjoyed social activities. Emotional reactions to their altered state, such as frustration, embarrassment, and dependency on the spouse to take care of menial tasks such as cutting food and maintaining hygiene, may also increase the desire for fruitful engagements.

Table 1

Hypotheses

	Gender	Age	Onset of symptoms	Bulbar function	Physical function	Total function
Hypothesis 1 (Exp-EI)	X		X		X	
Hypothesis 2 (Ex-PI)	X	X	X			X
Hypothesis 3 (Ex-SC)	X		X	X	X	
Hypothesis 4 (Sat-PI)	X	X			X	
Hypothesis 5 (Sat-EI)	X			X		
Hypothesis 6 (Sat-SC&SI)	X		X	X	X	
Hypothesis 7 (Des-PI)	X				X	
Hypothesis 8 (Des-EI)	X			X		
Hypothesis 9 (Des-SC)	X			X	X	

Note. Exp = experience; Sat = satisfaction; Des = desire; EI= emotional intimacy; PI = physical intimacy; SC = social contact; SI = social intimacy.

Chapter 4

Methods

Overview

This study utilized archival data that was previously gathered as part of a larger research study that included 11 multidisciplinary clinics. The aim of the parent study (Felgoise, Rodriguez, Stephens, Walsh, Bremer et al., 2008) was to validate a shorter version of an ALS-specific quality of life measure assessing the following factors: physical function, bulbar function, negative emotion, intimacy, interaction with people and the environment, and religiosity. Within this measure, there are 12 items addressing the experience of, satisfaction with, and desire for social contact, emotional intimacy, physical intimacy, and sexual intimacy. Although the topic of intimacy is a small component of the parent study (Felgoise et al., 2008), the particular questions addressed within this study are unique and emphasize the various aspects of intimate relationships. It also aims to explore the influence of specific components of physical functioning on intimacy. The use of archival data in this instance may lend a more comprehensive examination and understanding of the ALS population's physical, emotional, and social intimacy when assessing overall QOL.

Design and Design Justification

The parent study was a cross-sectional study using interview-administered, self-report questionnaires to collect the data. The benefit of cross-sectional studies is their ability to assess the data by making comparisons as they pertain to the population at a specific point in time (Kazdin, 2003). The capabilities and needs of those with ALS are varied. Therefore, the use of questionnaires is advantageous due to the ease and

standardization of administration. To involve patients of all functional levels, it is beneficial to conduct research in a manner that is not too strenuous or tedious to engage. Also in considering the special needs of the population, there is a potential for high attrition that may occur due to the progression of the disease or survival rates. To control for attrition and fatigue on the part of the patient, the participation occurred in single administration.

Participants

Participant data were gathered from a previously developed database by including patients who completed the appropriate measures needed for this particular research. Data within the provided database were collected from five multidisciplinary ALS treatment centers located in the following geographic regions of the United States: northeast, northwest, and southwest.

Inclusion and exclusion criteria

All subjects who met the following criteria were included for the parent study. The criteria included: (a) 18 years of age or older, (b) clinically definite, clinically probable, or clinically probable laboratory-supported ALS diagnosis according to the revised El Escorial criteria (Brooks et al., 2000), and (c) fluency in English of at least a sixth grade reading level. Participants were excluded if they failed to provide informed consent to participate in the current study, were identified by a physician or psychologist as having dementia or other cognitive deficits, or were without a current intimate partner. Excluded from the present study were persons who did not complete the Personal Assessment of Intimacy in Relationships (PAIR).

Recruitment

Participants within the parent study (Felgoise et al., 2008) were recruited by the neurologist or other personnel within the multidisciplinary team. Personnel at the clinic sites were given the option to send a letter explaining the study prior to clinic visits to inform the patient of the study being conducted, or subjects could be recruited by clinic personnel during the clinic visit.

Procedure

The parent study (Felgoise et al., 2008) collected data at 11 different multidisciplinary sites, each of which followed a delineated data collection process. At the beginning of the clinic day, the physician or another member of the staff would identify particular participants meeting the specified inclusion criteria and then introduce the study to the patient. After the study was explained and the patient decided he or she was interested, informed consent was obtained. The patient could either read or be read the contents of the informed consent, and signed the form. If the person was physically unable to sign, he or she could give verbal permission, as documented by the data collector and a witness in place of the signature.

The measures were administered in a particular order to maintain uniformity. Also included in the packet is a demographic sheet to obtain general information about the patient. The ALSFRS-R (Cedarbaum et al., 1999) could be obtained from the physician. Lastly, the data collector filled out the Data Collection Check List to ensure each step was completed and to also document if there were any problems in the administration.

The data for this current study (Felgoise et al., 2008) were accessed by reviewing the database created from the parent study from five sites. The data were extracted to include only those participants who completed the appropriate measures.

Measures

This current research study is derived from a larger parent study (Felgoise et al., 2008) that includes a variety of measures. The measures described below were used for the current research.

Demographic sheet. The demographic sheet collected the following information: gender, age in years, highest level of education, living arrangements, marital status, household income, racial background, current employment status, month and year when the participant first became symptomatic, and the month and date of the ALS diagnosis.

ALS-Specific Quality of Life–R (ALSSQOL–R). The ALSSQOL–R is the shorter, 46-item, self-report measure derived from a previously validated ALSSQOL, 59-item measure. Items are based on a Likert-type scale from 0, least desirable, to 10, most desirable. The goal of this measure is to encompass a comprehensive assessment of physical and nonphysical QOL factors: intimacy, religiosity, coping, social support, positive and negative affect, and physical function (Simmons et al., 2006). The original, 59-item, ALSSQOL has shown strong reliability and validity, and independent factors have strong internal consistency. Scores can range from 0 to 460. A high score obtained on the ALSSQOL–R indicates a higher QOL. The ALSSQOL–R is currently in the process of validation research and is expected to maintain its validity as a shorter and reliable measure of ALS-specific QOL.

Personal Assessment of Intimacy in Relationships (PAIR). The PAIR couple inventory is a 36-item, self-report inventory to assess perceived versus expected intimacy. The scores can range from 0 to 96 (Olson & Schaefer, 2000). It is based on a 5-point Likert scale and is intended to be administered twice, first to measure perception and second to determine expectation of intimacy (Schaefer & Olson, 1981). In this particular instance, the PAIR was administered only once to measure current perception of intimacy in various areas. The PAIR includes six scales, five of which assess different types of intimacy: emotional, social, sexual, intellectual, and recreational intimacy (Olson & Schaefer, 2000). The sixth scale controls for overly positive responses. This instrument yields strong reliability and validity for each scale. Normative scores were based on a pilot sample of individuals in community enrichment groups and undergraduate and graduate day classes, of whom half were married, and second sample of 192 nonclinical married couples enrolled in an enrichment program (Schaefer & Olson, 1981). The average score for perceived emotional, sexual, intellectual, and recreational intimacies is between 42 and 58, 61 is the average score for social intimacy, and 38 is the average score for conventionality (Olson & Schaefer, 2000). All scores are generated in a profile according to each type of intimacy; there is no total score for this measure (Schaefer & Olson, 1981).

ALS Functional Rating Scale–Revised (ALSFRS–R). ALSFRS–R is a measure used in many multidisciplinary ALS clinics to measure physical functioning of ALS patients as they progress through the disease. This measure includes 12 questions in which physicians rate the patient’s level of functional impairment in the following areas: fine motor, gross motor, respiratory, and bulbar function (Cedarbaum, Stambler, Malta,

Fuller, Hilt, Thurmond et al., 1999). The total score can range from 48, best physical functioning, to 0. The revision of the original ALSFRS added more specific respiratory ratings, which make it a stronger predictor in the outcome of the progression of ALS (Cedarbaum et al., 1999).

Procedures for Maintaining Confidentiality

The levels of maintaining confidentiality are systematic. First, at the time of data collection, patients were given a particular identification number to mask identification. The consent forms were separated from the patients' data and kept in separate locations. Patient names that may have been written on the battery of assessments were blackened out when filed to promote confidentiality. Second, the data and informed consents are maintained in a locked filing cabinet to preserve security. Third, the use of data for this particular aspect of the research is in the form of a database including only patient identification numbers with no other potential identifiers. As a result of these procedures, confidentiality was protected and access was restricted to those trained and involved in this particular research project.

Chapter 5

Statistical Analyses

To test the nine proposed hypotheses, Pearson product-moment correlations were used to measure and describe the relationship between the independent and dependent variables identified in each of the hypotheses. Next, hierarchical multiple regressions were conducted to provide more information about the relationship between several independent variables, in this case, gender, age, onset of symptoms, and functional ability and the dependent variable. The dependent variables for this particular study include experience of, desire for, and satisfaction with physical and emotional intimacy and social contact and intimacy. The use of hierarchical multiple regressions would control for and take into account the influence of different independent variables. Specific to this research, it was expected that gender, age, and onset of symptoms would have a natural effect on the dependent variables; therefore, it was believed that hierarchical regression analyses would be able to identify effects of physical functional ability over and beyond these effects.

Descriptive Statistics

Descriptive statistics were used to summarize and organize basic features of data collected in the sample (see Table 2 and Table 3). Means, medians, modes, and frequencies were used to describe key characteristics of the sample. Descriptive statistics were calculated for all participants within the overall sample ($N = 389$) and the intimacy subsample ($n = 81$). Specifically, the intimacy subsample included those participants who completed the PAIR measure to provide additive and more specific data on the satisfaction with intimacy.

Table 2

Descriptive Statistics

	Overall sample		Intimacy subsample	
	<i>M</i>	<i>SD</i>	<i>MS</i>	<i>D</i>
Age	60.85	11.36	60.68	11.62
Time in months from onset of symptoms to completion of questionnaire	39.69	39.25	34.85	30.15

Table 3

Demographic Data of the Sample

	Overall sample		Intimacy subsample	
	%	<i>n</i>	%	<i>n</i>
Gender				
Male	58.9	229	69.1	56
Female	41.1	160	30.9	25
Marital Status				
Never married	3.7	16	1.2	1
Currently married	78.0	301	95.1	77
Divorced	9.8	38	2.5	2
Separated	.8	3	1.2	1
Widowed	7.3	28	0.0	0

(continued)

	Overall sample		Intimacy subsample	
	%	<i>n</i>	%	<i>n</i>
Education				
No high school	1.0	4	2.5	2
Some high school	4.5	17	0.0	0
High school diploma	26.5	101	21.0	17
Some college	17.6	67	19.8	16
2-year college	5.2	20	4.9	4
4-year college	25.7	98	28.4	23
Graduate degree	16.8	64	22.2	18
Trade/technical school	2.6	10	1.2	1

(continued)

	Overall sample		Intimacy subsample	
	%	<i>n</i>	%	<i>n</i>
Living Arrangements				
Living alone	12.1	47	2.5	2
With significant other (spouse/partner)	77.0	298	92.6	75
With other relative	5.4	21	1.2	1
With friend or other	2.1	8	0.0	0
Long-term care facility	1.8	7	0.0	0
With significant other and other relative	1.6	6	3.7	3
Household Income				
Less than \$20,000	8.0	30	2.5	2
\$20,000 to \$39,999	23.2	87	13.6	11
\$40,000 to \$59,000	21.3	80	16.0	13
\$60,000 to \$79,000	14.7	55	16.0	13
\$80,000 or more	21.3	80	38.3	31
Prefer not to answer	11.5	43	13.6	11

(continued)

	Overall sample		Intimacy subsample	
	%	<i>n</i>	%	<i>n</i>
Race				
Caucasian	90.7	352	87.7	71
Hispanic	2.8	11	3.7	3
Black/African American	4.1	16	4.9	4
Oriental/Asian	.8	3	1.2	1
Pacific Islander				
Other	.8	3	1.2	1
Prefer not to answer	.8	3	1.2	1
Employment Status				
Part-time	7.5	28	11.7	9
Full-time	13.3	50	20.8	16
Retired	44.8	168	45.5	35
Unemployed	1.6	6	2.6	2
On disability	28.5	107	15.6	12
Not employed prior to ALS	3.7	14	3.9	3
Retired and on disability	.5	2	0.0	0

Functional Ability

The average functional ability for the overall sample ($N = 385$) is 33.11 ($SD = 7.9$), with a range of 6 to 48, and 32.82 ($SD = 8.8$) for the subsample, ranging from 6 to 47. The highest overall score that can be reached is 48, with higher the scores indicating higher level of functioning (Cedarbaum et al. 1999). In a study determining prognosis based on total scores, there was no significant difference among those patients with ALSFRS–R scores less than 38 or greater than or equal to 38 (Kimura et al., 2006). Due to the variability of ALS presentation, there are no definitive score ranges to determine consistent characteristics of a total ALSFRS–R score. However, an average total score of 33 may be considered moderate to high functional ability.

Correlations

Pearson product-moment correlations were conducted to measure the relationships among the dependent and independent variables chosen within the hypotheses. This was especially important due to the insignificant findings when conducting the hierarchical multiple regressions. The ALSSQOL–R intimacy subscale was used to measure desire and experience for emotional, physical, and social intimacy. Correlations were conducted to provide more understanding between the dependent variables and predictors chosen in the hypotheses to identify if there is a relationship.

The ALSSQOL–R and the PAIR were used to measure the satisfaction with emotional, physical, and social intimacy, as the PAIR is a measure of perceived satisfaction. As shown in Table 4, the ALSSQOL–R intimacy subscale correlated moderately with social intimacy ($r = .409, p < 0.01$), intellectual intimacy ($r = .391,$

$p < 0.01$), recreational intimacy ($r = .376, p < 0.01$), and emotional intimacy ($r = .310, p < 0.01$) on the PAIR. The largest correlation occurred between the ALSSQOL–R intimacy subscale and the PAIR sexual intimacy ($r = .521, p < 0.01$). Moderate rather than large correlations could be due to the general approach of the ALSSQOL–R versus the narrower focus on satisfaction in the PAIR. Stepwise regression analyses further confirmed sexual intimacy’s role in the intimacy construct.

Table 4

Correlations between the ALSSQOL–R Intimacy Subscale and PAIR Subscales

	PAIR social	PAIR intellectual	PAIR recreational	PAIR emotional	PAIR sexual
ALSSQOL–R Intimacy	.409*	.391*	.376*	.310*	.521*

Note. * $p < 0.01$

Experience

Social contact.

Correlational analyses for the experience of social contact (see Appendix A) looked at ALSSQOL–R item 40, Family and friends have visited me, with demographic information (age, sex, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the

ALSFERS–R total score. There was no correlation between the experience of social contact and any of these variables.

Emotional intimacy.

Correlational analyses for the experience of emotional intimacy (see Table 5) using ALSSQOL–R item 43, I have shared emotional intimacy with others, with demographic information (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score found no relationships between any variables.

Physical intimacy.

Correlational analyses for the experience of physical intimacy (see Table 5) examined ALSSQOL–R item 46, I have shared physical intimacy with others, and item 49, I have shared sexual intercourse with others, with demographic information (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. The experience for physical intimacy, such as hugging, kissing, and touching, identified no correlational significance with any of the variables. The experience for sexual intimacy, or sexual intercourse, demonstrated a small correlational relationship with age ($r = -.226, p < 0.01$), suggesting that as age increases, the experience of sexual intimacy decreases.

Table 5

Correlations Between the Experience of Social Contact (SC), Emotional Intimacy (EI), Physical Intimacy (PI) and Social Sexual Intimacy (SI) and Predictor Variables

	Age	Gender	Time with symptoms	Speech	Salivation	Swallowing	Cutting/ utensils	Dressing/ hygiene	Turning/ adjusting	ALSFRS-R total
SC	0.42	.040	-.057	-.001	-.022	.023	.029	.003	-.022	.010
EI	-.041	.050	-.075	0.17	.026	.014	-.029	-.066	-.081	-.045
PI	.042	-.009	-.034	.020	.015	.008	.017	-.030	-.023	.000
SI	-.226**	-.083	-.065	.042	0.24	.133**	.083	.053	.066	.119*

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

Satisfaction**Social Contact and social intimacy.**

Correlational analyses for satisfaction of social contact (see Table 6) examined ALSSQOL–R item 41, Visits from family and friends have been satisfying, and the social and recreational intimacy scales of the PAIR for social intimacy with demographic information (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. No correlations were statistically significant between satisfaction with social contact and the independent variables. Items in the social intimacy scale include: We enjoy spending time with other couples, We usually ‘keep to ourselves, We have very few friends in common, Having time together with friends is an important part of our shared activities, Many of my partner’s closest friends are also my closest friends, and My partner disapproves of some of my friends. There was a small correlation between social intimacy and the ALSFRS–R total score, $r = .222$ ($p < 0.05$). Items in the recreational intimacy scale include: We enjoy the same recreational activities, I share in few of my partner’s interests, We like playing and having fun together, We enjoy out-of-doors together, We seldom find time to do fun things together, We share few of the same interests. There was a small relationship between recreational intimacy and salivation, $r = .226$ ($p < 0.05$).

Emotional intimacy.

Correlational analyses for satisfaction with emotional intimacy (see Table 6) examined ALSSQOL–R item 44, Emotional intimacy with others has been satisfying,

Table 6

Correlations Between the Satisfaction of Social Contact (SC), Social Intimacy-PAIR (SI-P), Recreational Intimacy-PAIR (RI-P), Emotional Intimacy (EI), Intellectual Intimacy-PAIR, (II-P), Physical Intimacy (PI), Sexual Intimacy (SI), and Sexual Intimacy-PAIR (SI-P) and Predictor Variables

	Age	Gender	Time with symptoms	Speech	Salivation	Swallowing	Cutting/ utensils	Dressing/ hygiene	Turning/ adjusting	ALSFRS-R total
SC	.005	.064	-.038	.067	.041	.056	-.029	-.058	-.013	.020
SI-P	-.012	.087	-.033		.107	.136	.111	.202	.140	.222*
RI-P	.012	.161	-.077		.226*	.071	.068	.182	.114	.135
EI	-.046	.022	-.054	.066	.063	.088	-.007	.016	.028	.052
II-P	-.069	-.046	-.044		.158	.097	.002	.133	.111	.085
PI	-.006	.051	-.103	-.013	.005	-.006	.036	.058	.093	.075
SI	-.186*	-.057	.019	.125	.067	.129	.013	.110	.157	.094
SI-P	-.137	.051	-.037		.054	.061	.220	.253*	.236*	.238**

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

and the emotional and intellectual intimacy scales of the PAIR with demographic information (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. There was not a significant relationship between satisfaction with emotional intimacy using the ALSSQOL–R item 44 and any of the demographic variables. The PAIR emotional intimacy scale includes the following questions: My partner listens to me when I need someone to talk to, I can state my feelings without him/her getting defensive, I often feel distant from my partner, My partner can really understand my hurts and joys, I feel neglected at time by my partner, I sometimes feel lonely when we're together. The PAIR emotional scale is not correlated with any of the demographic variables. The PAIR intellectual intimacy scale includes the following questions: My partner helps me clarify my thoughts, When having a serious discussion, it seems we have little in common, I feel 'put-down' in a serious conversation with my partner, I feel it is useless to discuss some things with my partner, My partner seldom tries to change my ideas, We have an endless number of things to talk about. There was no relationship between the PAIR intellectual scale and any of the independent variables.

Physical intimacy.

Correlational analyses for satisfaction with physical intimacy (see Table 6) included ALSSQOL–R item 47, Physical intimacy with others has been satisfying, and ALSSQOL–R item 50, My sexual relationship has been satisfying, and the sexual intimacy scales of the PAIR with demographic information (age, gender, time since onset

of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. No correlations relationships were founded between ALSSQOL–R item 47 and the other variables. ALSSQOL–R item 50 showed a small correlation with age ($r = -.186, p < 0.05$). The PAIR sexual intimacy scale items include the following: I am satisfied with the level of affection in our relationship, I feel our level of affection is just routine, I am able to tell my partner when I want sexual intimacy, Because of my partner’s lack of caring, I “hold back” my sexual interest, Sexual expression is an essential part of our relationship, My partner seems disinterested in sex. The PAIR sexual intimacy scale showed small but significant correlations with dressing and hygiene ($r = .253, p < 0.05$), ALSFRS–R total score ($r = .238, p < 0.05$), and turning in bed and adjusting bed clothes ($r = .236, p < 0.05$).

Desire

Social contact.

Correlational analyses for the desire for social contact (see Table 7), ALSSQOL–R item 39, My desire for social contact has been strong, with demographic (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. A small correlation existed between the desire for social contact and gender, $r = .137$ ($p < 0.01$) and swallowing, $r = .109$ ($p < 0.05$).

Table 7

Correlations Between the Desire for Social Contact (SC), Emotional Intimacy (EI), Physical Intimacy (PI), and Sexual Intimacy (SI) and Predictor Variables

	Age	Gender	Time with symptoms	Speech	Salivation	Swallowing	Cutting/ utensils	Dressing/ hygiene	Turning/ adjusting	ALSFRS-R total
SC	.019	.137**	.026	.048	.087	.109*	.027	-.007	-.021	.019
EI	-.033	.007	-.099	.050	.023	.056	-.075	.108*	-.083	-.039
PI	-.017	-.102*	-.053	.037	.022	.055	.000	-.022	.003	.004
SI	-.274**	-.305**	-.008	.032	.078	.122*	-.032	-.055	.022	.018

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

Emotional intimacy.

Correlational analyses were conducted between ALSSQOL–R item 42, My desire for emotional intimacy has been strong, and demographic (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score (see Table 7). A small correlation existed between the desire for emotional intimacy and dressing and hygiene, $r = -.108$ ($p < 0.05$).

Physical intimacy.

Correlational analyses for the experience of physical intimacy (see Table 7) examined ALSSQOL–R item 46, My desire for physical intimacy has been strong, and item 48, My desire for sexual intercourse has been strong, with demographic (age, gender, time since onset of symptoms), bulbar functional ability (speech, salivation, and swallowing), physical functional ability (cutting food and handling utensils, dressing and hygiene, and turning in bed and adjusting bed clothes), and the ALSFRS–R total score. There was a small correlational relationship between the desire for physical intimacy (hugging, kissing, touching) and gender, $r = .102$ ($p < 0.01$). The desire for sexual intimacy (sexual intercourse) was correlated with gender ($r = -.305$, $p < 0.01$), age ($r = -.274$, $p < 0.01$), and swallowing ($r = .122$, $p < 0.05$).

Variability

The variability of a distribution is another method of describing a particular sample. Due to the lack of significant findings, the variability of the measures used for

this study was analyzed (see Table 8). The ALSSQOL–R intimacy subscale in the overall sample ($N = 392$) has a minimum score of 1 and a maximum of 10, with $M = 5.85$, $SD = 2.0$. The analysis of the score distribution shows a majority of participants scoring between 4 and 5 ($n = 121$). A more detailed analysis revealed a symmetrical distribution, with a majority of participants ($N=16$) scoring 4.85. The symmetrical distribution suggests that the ALSSQOL–R intimacy subscale is an unbiased measure of understanding intimacy.

The range of scores for the PAIR measure is 0 to 96, with the normative average score of emotional, sexual, recreational, and intellectual intimacy between 42 and 58 and a higher normative average of 61 for social intimacy (Olson & Schaefer, 2000). Higher scores on this measure indicate a higher level of perceived intimacy. Table 8 illustrates the data for the subsample ($n = 82$) in this study, the means for the different intimacy constructs were as follows: Emotional intimacy, $M = 78.34$ ($n = 82$, $SD = 18.69$); Sexual Intimacy, $M = 65.87$ ($n = 76$, $SD = 23.03$); Recreational Intimacy, $M = 66.39$ ($n = 82$, $SD = 20.6$); Intellectual Intimacy, $M=69.43$ ($n = 81$, $SD = 17.63$); Social Intimacy, $M = 71.75$ ($n = 81$; $SD = 18.04$). The average normative score for conventionality was somewhat lower, with 38 as the average; and means equal to or higher than 55 are very high and may be considered “faking good.” The mean within this sample was 71.65 ($n = 81$, $SD = 20.2$). This sample appears to have a significantly higher level of perceived intimacy than the populations in which the PAIR was normed, but may tend to idealize their relationship.

Further analysis of the PAIR intimacy constructs shows negatively skewed distributions. Although there was some variability in the scores, the negative skew

suggests participants have a higher average score and were endorsing items favorably. A large percentage of participants had a total score of 96 within each of the different constructs: approximately 71% of participants for emotional intimacy ($n = 82$), 46% for social intimacy ($n = 81$), 38% for sexual intimacy ($n = 76$), 43% for intellectual intimacy ($n = 81$). The frequency data gathered for recreational intimacy ($n = 82$) was a bit more dispersed, but still negatively skewed, with 29% of participants having a score of 96, 28% having a score of 88, and 22% having a total score of 80.

Table 8

Variability of the ALSSQOL-R and PAIR

	<i>M</i>	<i>SD</i>	<i>n</i>
ALSSQOL-R	5.85	2.0	392
Emotional Intimacy	78.34	18.69	82
Sexual Intimacy	65.87	23.03	76
Recreational Intimacy	66.39	20.6	82
Intellectual Intimacy	69.43	17.63	81
Social Intimacy	71.75	18.04	81
Conventionality	71.65	20.2	81

Hypothesis Testing

Regression analyses could not be conducted because there were non significant correlations between the predictor and criterion variables to warrant this analysis.

Post Hoc Analysis

In an attempt to better understand this study's findings and the construct of intimacy in this population, post hoc analysis examined the relationships between the intimacy subscales of the ALSSQOL-R and the Center for Epidemiological Studies depression scale (Radloff, 1973) administered in another arm of the parent study. The purpose was to determine if depression symptoms may be related to intimacy and, therefore, could have affected reporting of desire, experience, and satisfaction. The correlation between these variables was $r = -.388$, $p < .001$ ($n = 73$), which suggests there was an inverse relationship. However, the depression measure was not completed by the subset of the sample that completed additional intimacy measures. The relationships between intimacy and other variables could be moderated by depression.

Chapter 6

Discussion

Overall Description of the Sample

As a whole, the sample used in this study is largely representative of the national demographic of ALS patients with regard to age, gender, and race (ALSA, 2008c). The participants in this study were most often married and living with their spouse or romantic partner. With regard to education, a majority had a high school diploma or a 4-year college degree and were currently on disability. The intimacy subsample's average years of education were higher, with a majority of these individuals having a 4-year college degree or a graduate degree and being retired at the time of participation. On average, they had been experiencing symptoms of ALS for approximately 3 years and were fairly high functioning in regard to functional ability.

This research suggests persons with ALS experience moderate to high levels of physical, emotional, and social intimacy. The ALSSQOL-R and PAIR were used to assess intimacy. The ALSSQOL-R assessed the experience of, desire for, and satisfaction with and the PAIR specifically assessed the perception or experience of different forms of intimacy. The ALSSQOL-R was the more global measure and showed good variability of responses; it suggested that persons with ALS were somewhat satisfied with their experience and feelings related to intimacy. When specifically targeting perception of intimate interactions by looking at the PAIR, participants appeared to have a high degree of satisfaction with their intimate relationships, with a majority of the results above the average scores of 42 through 58, for emotional, sexual,

recreational, and intellectual intimacy and 61 for social intimacy obtained from a married and unmarried nonpatient sample (Olson & Schaefer, 2000).

Discussion of the Hypotheses

The goal of this research was to understand the experience of, satisfaction with, and desire for physical, social, and emotional intimacy in persons with ALS and to identify if a relationship exists between functional ability and intimacy, and if so, among which specific aspects of functional ability. Nine hypotheses were developed in regard to experience of, satisfaction with, and desire for these three forms of intimacy. None of the proposed hypotheses were supported.

In this particular study, it was expected that age and gender would have an impact on the dependent variables (experience, desire, and satisfaction). The length of time persons with ALS live with symptoms and the functional implications of the disease over time were hypothesized to contribute to how persons with ALS desire, experience, and perceive their intimate relationships. Greater impairment influences vulnerability, autonomy, and privacy and can have a large impact on relationships (Roe et al., 2001). For example, physical impairment increases dependence on caregivers to devote a large portion of time (Hecht et al., 2003) to providing assistance with everyday tasks, such as cutting food, dressing, and hygiene. When men face these changes, social norms are challenged and roles are reversed (Gauthier et al., 2007). Bulbar impairment places constraints on verbal communication, highly valued by both men and women, and may inhibit emotional disclosures that contribute to intimacy. Due to limited research on intimacy in ALS, ALS was compared to intimacy in other populations with physical decline. It may have been inappropriate to compare these populations, due to the

variability of symptoms and experience. Additionally, these findings are inconsistent with the current literature. This sample has a high level of intimacy, and it does not appear that physical functioning has any impact on intimacy variables.

Correlations

As a result of the proposed hypotheses being unsupported, Pearson product-moment correlations were conducted to gain a greater understanding of the relationships between the different variables and forms of intimacy. In accordance with previous writings, intimacy is a novel subject of research within the ALS population.

Physical intimacy.

The experience of, desire for, and satisfaction with sexual intimacy, specifically sexual intercourse, decreases with age in persons with ALS. This finding is consistent with the current literature on older adults and other physically impaired populations (Hinchliff & Gott, 2004; Lawrence et al., 2003; Lindau et al., 2007). The findings also suggest some difference in gender, suggesting that women may have a greater desire for sexual intimacy. It is possible that women experience a greater psychological impact of disability, including embarrassment and lower body esteem. As a result of this psychological barrier to engaging in sexual intercourse, women may have greater desire for it. No additional gender differences related to sexual intimacy were evident. This is interesting, considering men are often less satisfied with their experience of sexual intimacy, regardless of their stage of marriage and level of physical impairment (Greeff & Malherbe, 2001, Taleporos & McCabe, 2003).

The literature has shown that greater health decline influences the frequency with which sexually intimate behaviors occur (Svetlik et al., 2005). This is likely due to the

altered self-image and embarrassment associated with dependence on others to maintain ADLs (McCabe et al., 1996; Schmidt et al., 2005). With regard to persons with ALS, this research found a relationship between high levels of overall functioning, specifically dressing and hygiene and turning in bed and adjusting bed clothes, and the satisfaction of sexual intimacy. Chochinov and colleagues (2002) and Hack and colleagues (2004) suggest that changes in health status and physical appearance, sense of being a burden to others, increased dependency, and pain are associated with loss of dignity. This finding, in conjunction with literature in other populations, could account for the suggestion that greater impairment, especially in ADL functions, has the potential to significantly influence satisfaction with intimacy, and more specifically with sexual encounters.

Gross bodily function is not the only area of significance, but swallowing was also related to the desire for sexual intimacy. Impairment of swallowing has been associated with the presence of depression in persons with ALS (Hillemacher et al., 2004), suggesting that this aspect of ALS can be particularly detrimental. It is possible that the reaction to and perception of swallowing impairment could lead to changes in self-confidence and desirability. Difficulty with swallowing can lead to excessive saliva buildup, resulting in manual removal or drooling if not addressed in time. As a result of the physical presentation and aid needed to remove the saliva, sexual desire is likely impacted.

As sexual intimacy declines with the age of the ALS population, it appears that physical intimacy increases and continues to be important at the end of life (Lemieux et al., 2004). Physical intimacy includes holding hands, kissing, caressing, etc. It is common for older adults to emphasize the importance of maintaining physical levels of

intimacy (Gott & Hinchliff, 2003) and place sexual intimacy at a lower priority (Lemieux et al., 2004). It is possible that emphasis on physical intimacy is a result of changed views of intimacy and accommodations needed to adapt to new limitations. Leibowitz and Stanton (2007) found that persons with physical disability expand sexual intimacy to include other forms of physical closeness. Similarly, research in MS shows that often, accommodations are made for physical impairment, and physical closeness becomes just as significant as sexual intercourse (McCabe et al., 2006). Given the available data and the heightened value of physical intimacy in this population, it is likely that couples facing ALS also develop methods of adaptation to maintain levels of closeness.

Emotional intimacy.

Emotional intimacy has little relationship with the variables chosen within this research. A small relationship was identified between the desire for emotional intimacy and dressing and hygiene, but it does not appear that any of the other demographic or functional ability variables are related to the desire for, satisfaction with, and experience of emotional intimacy. It is possible that persons with ALS have a greater desire for emotional intimacy as their functional ability begins to decline. Although not correlated with the other functional variables, it is possible that dressing and hygiene are the most fundamental and unmistakable sign that ALS is causing significant impairment. Goldstein et al. (2006b) suggest that the perceptions of the impairments, rather than the actual impairment itself, may cause the greatest distress. This is also supported by literature suggesting a strengthening of a dyad's emotional bond, due to the level of commitment and care displayed with caregiving (Andrén & Elmstahl, 2005; Grant et al., 1998; Kuuppelomäki et al., 2004). The strength of the relationship during the loss of

functioning may help to examine the despair and dependence experienced. Isakson, Skär, and Lexell (2005) found that emotional components of trust and effective communication offered support during the process of physical decline in PD and this may also be effective when coping with ALS.

Goldstein et al. (2006a) and Hillemacher et al. (2004) found bulbar functioning, specifically swallowing and breathing, to be an important factor in determining psychological distress and influencing emotional intimacy with one's spouse. It is somewhat surprising that significant correlations were not found among these factors. There may have been reluctance in discussing concerns and feelings related to ALS (McPherson et al., 2007; Trail et al., 2003), burden of physical impairments (Bookwala, 2005), and emotional miscommunications that cause frustration (Kilani et al., 2004; Trail et al., 2003). It is possible that these individuals had established communication styles prior to the ALS diagnosis and their experience of, desire for, and satisfaction with emotionally intimate encounters were maintained or adapted to in the progression of the disease. Goldstein et al. (2006b) found that open communication can heighten a person's sense of worth and values in a relationship as their abilities become more impaired.

Social intimacy.

The personal and social restrictions that physical impairments generate are difficult for a couple as a whole (Hecht et al., 2003). Physical changes can cause uncertainty and embarrassment and may be experienced and perceived differently for men and women. As a result, persons with ALS may begin to isolate from social events (Chochinov et al., 2007; Gauthier et al., 2007). It was originally hypothesized that functional ability and the length of time persons with ALS have lived with their

symptoms would influence social encounters, due to their perception of the illness and the extra costs and efforts involved to obtain adequate resources (Boeije et al., 2003). It appears that the frequency with which social contact is experienced is not related to gender, the onset of symptoms, or functional ability.

It may be beneficial to examine the relationship of the persons involved and the quality of the social contact, rather than the quantity of encounters. The literature in other forms of illness involving physical deficits reports a high degree of support and social interactions initially (Taleporos & McCabe, 2005), which then declines as the illness continues and disability ensues (Hakim et al., 2000; Isaksson et al., 2005). Although the restrictions and impediments become greater, it is not uncommon for couples to adapt to these changes to help maintain interest and shared activity. Such adaptations have the potential to significantly influence the quality of social encounters and may have little to do with demographic or functional factors (Persson & Rydén, 2006).

Although the frequency of social encounters may not be influenced by such factors, it does appear that functional ability may have a role in the perception of social contact and intimacy. In fact, there was a small correlation between the satisfaction with social intimacy and the overall ALSFRS-R score, suggesting greater social satisfaction with more functional ability. This is not surprising given the social implications of physical impairments, especially decades of little to no functional impairment. When focusing on the specific physical components of ALS, salivation ability was also significantly associated with social satisfaction. Areas of decreased bulbar functioning, such as salivation, may decrease satisfaction with social interactions, due to the verbal

communication difficulty it presents (Duff, 2007) and the importance of physical appearance in social interactions.

Naturally, it is expected that each gender differs in their desire to engage in social contact. It is alleged that both men and women place value on social interactions (Greeff & Malherbe, 2001; Patrick et al., 2007), and the interest is believed to remain even after limitations persist (Boeije et al., 2003; Hwang et al., 2007; Tasiemski et al., 2005). However, the data from the current study suggest that men with ALS may have more desire for social contact. Men have been shown to experience greater difficulty coping and embarrassment (Gauthier et al., 2007; Schmitt et al., 2007) related to the loss of physical functioning. Given this information, it may be men who tend to withdraw and isolate from the couple's activities of prior interest, especially when unable to contribute to role-specific demands (Bookwala, 2005; Brock & Lawrence, 2008). The presence of physical obstacles combined with social expectations of the male gender may influence the desire for social intimacy.

The data from this study shows that intimacy ratings are fairly high, regardless of their level of functioning, leaving much to be desired. If age, gender, duration of symptoms, and functional ability do not predict various aspects of intimacy in persons with ALS, what does? It appears that persons with ALS are resilient to those things most others would consider natural obstacles to having intimate relationships. One could argue that intimacy requires certain levels of physical functioning, but for persons with ALS, intimacy is maintained regardless of physical functioning. It is possible that the focus is more on the population of ALS as having a disability, therefore impacting intimacy, rather than a marital couple's intimate relationship when faced with

functionally related obstacles. In other words, persons with ALS should not be looked at as disabled. Instead, it is their marriage that should be the focus and not be influenced by the fact, that one individual in the dyad has ALS.

Individual and Dyadic Coping

To understand resilience, it is important to understand how individuals cope with stressful situations. ALS creates a different dynamic in a marital relationship, one that many are not expecting. Persons who were once lovers and emotional companions are now taking care of the patient's personal needs. Healthy relationships that involve equal contributions of emotional closeness, connectedness, passion, and commitment (Sternberg, 1989, 1997) now face unbalanced interactions, significantly affecting intimacy (Roe et al., 2001). Physical impairment results in unsatisfied intimate encounters and influences the perception of self, the marital relationship, and the ability for the couple to function as they once had (Erikson, 1959; Maslow, 1970). When a disease as significant as ALS is encountered, dyads are faced with managing their own stress, attending to instrumental tasks, and addressing the emotional needs and presence of each other (Coyne & Smith, 1994).

Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands” (p. 141) ultimately above what an individual can normally handle. It is not often the situation itself but the perception of the situation that determines one's emotions and behaviors (Beck, 1995). Therefore, coping occurs through a process of evaluating what might be thought or done in a particular situation, referred to as *appraisals*. Lazarus and Folkman have identified three basic forms of appraisals that determine the level of stress and the

coping strategy to apply to the situation. *Primary appraisals* are the initial assessments of the situation to determine if the encounter is irrelevant, benign, positive, or stressful. *Secondary appraisals* involve a complete evaluation process, and persons may begin brainstorming the actions they wish to take. This includes an evaluation of coping methods and the likelihood of its success. Last, *reappraisal* occurs when new information is provided or changes occur within the person or the environment (Lazarus & Folkman, 1984).

The appraisal and reappraisal of particular encounters is actually quite complex, considering they are highly influenced by the commitments and beliefs of the appraiser. Commitments underlie the choices people make, and the greater the strength of the commitment, the greater psychological vulnerability is experienced (Lazarus & Folkman, 1984). For persons with ALS, commitment often involves their loved ones and how ALS will affect them through the disease and ultimately after their death. In a study assessing important considerations at the end of life, of high importance were concerns regarding symptoms and personal care, such as being kept clean, having personal touch, and freedom from pain and anxiety. Even more important were those aspects that influenced their family and loved ones, such as having financial affairs in order, having funeral arrangements planned, believing that the family is prepared for their death, and not being a burden to family (Steinhauser, Christakis, Clipp, McNeilly, McIntyre et al., 2000).

Beliefs play a role in shaping individuals' perceptions and often go unnoticed because they are fundamental to the person, often forming beginning in childhood and strengthened through life's experience (Beck, 1995). Often when experiencing a life-threatening change, like a terminal diagnosis, persons with ALS and their spouses may

gradually change the way in which they appraise their relationship with themselves, others, and the world. For example some may assume that the enduring and chronic stress of ALS could wear someone down physically and mentally. While the mental and physical components are apparent, the predictability and certainty of death in persons with ALS may actually facilitate habituation and acceptance because the threat is diminished and the meaning of the situation has changed. Persons with ALS could not control the presence of the disease and cannot control its progression; however, they can control how they cope with and adjust with its existence. Even the smallest amount of perceived control over an uncontrollable situation can significantly impact adjustment and marital relationships (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993). This information, combined with past beliefs and the formation of new beliefs, allows appraisals to become more of a conscious process (Lazarus & Folkman, 1984).

Coping is a self-generated process (Lazarus & Folkman, 1991) driven by purpose and effort, often facilitated by the cascade of emotion that follows appraisals. To cope, one must have purpose and effort to manage the stressful demands, regardless of the outcome and long-term effects. It is the cognitive coping that can significantly impact internal understanding, environmental modification, and the adaptability to environmental components (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) delineate two specific methods of coping: emotion-focused coping, used when there is little control over a threatening condition, and problem-focused coping, an objective process directly involving the environment. Emotion-focused coping is directed at lessening emotional distress but can be negative, such as avoidance, or positive, such as

changing the way the event is construed, thus causing reappraisal (Lazarus & Folkman, 1984). Problem-focused coping involves defining the problem, generating solutions, weighing costs and benefits, and engaging in a process of trial and error (Lazarus & Folkman, 1984). Problem-focused strategies appear to be related to better adjustment with other chronic physical illnesses but are less often endorsed (McCabe, McKern, & McDonald, 2004; Pakenham, 1999; Pakenham, Stewart, & Rogers, 1997). Emotion-focused strategies appear to be the most widely endorsed but often include avoidance and other negative methods (McCabe et al., 2004), causing greater emotional distress and poorer adjustment (Pakenham, 1999; Pakenham et al., 1997).

The ongoing threat and stressful experiences brought upon by ALS may foster different methods of coping for each person involved. This includes methods of coping internally with the meaning and implications of the illness, seeking resources and developing modifications to aid with the limitations and changes, and accepting that the disease cannot be controlled. Emotionally avoiding their diagnosis may be impossible, due to the unrelenting nature of the illness, forcing the couple to cope adaptively. Likewise, problem-solving methods must be employed to maintain a particular quality of living, especially toward the end of life. Although each method of coping is particularly pertinent to persons with ALS and their spousal caregivers individually, it is the coping of the marital dyad that is of interest within this research.

Relationship-focused coping.

Following Lazarus and Folkman's Coping Model (1984, 1991), Coyne and Smith (1991) added relationship-focused coping to the theory. This is defined as "cognitive and behavioral efforts to manage and sustain social relationships during stressful episodes"

(O'Brien, DeLongis, Pomaki, Puterman, & Zwicker, 2009, p.18) and is used when there is great concern and implications for the well-being of a loved one (Coyne & Smith, 1994; O'Brien et al., 2009). Wunderer and Schneewind (2008) found that relationship quality, relationship stability, and ability to communicate strongly influence dyadic coping. The original model of coping did not adequately address the coping of a marital dyad; instead, it focused more on the individual. The addition of relationship-focused coping emphasized the impact that illness and coping ability and style have on each other and the marital relationship.

There is abundant literature on marriage and chronic or terminal illness that emphasizes the impact the marital partnership has on resilience and the ability to cope with illness. The commitment and love experienced in the relationship can significantly influence perceptions of physical impairments and serve as a buffer to negative psychological effects and distress (Cassells & Watt, 2003; Mancini & Bonanno, 2006). This is likely due to the collaborative effort many married couples demonstrate to overcome problems (Krokavcova et al., 2008) and the desire to protect one another emotionally. The support of each partner and strength of the marital relationship has been shown to help partners explore emotions and changes in independence (Isaksson et al., 2005). As a result, they are often more accepting of their illness and subsequent changes when compared to their single counterparts (Harrison et al., 2004; Hwang et al., 2007; McCabe et al., 2009). Relationships that involve avoidance and ambivalence may experience more anxieties when attempting to cope with ALS (Gaine & LaGuardia, 2009; Hwang et al., 2007). Given the findings within this research, it may be reasonable to assume that these individuals are not only committed to their relationship, but also are

enduring the illness as a dyad. This is important because successful coping involves problem solving, emotional management, and the maintenance of relationships during periods of stress, especially when coping as a unit (Coyne & Smith, 1991). Effectiveness of such coping has the potential to reduce stress, enhance well-being, and strengthen a sense of “we-ness” in partners (Wunderer & Schneewind, 2008).

The ability to cope as a couple involves many individual factors, such as coping similarities and the personality of each individual. There is a natural difference in the way each individual interprets an event. Each person’s reaction varies according to their level of sensitivity and vulnerability (Lazarus & Folkman, 1984), but congruence of coping styles within a dyad can significantly contribute to how they react to and cope with ALS (Revenson, 1994). Revenson (1994) found that illness can cause disorganization within the family unit, but similar coping styles shared within a couple make it easier to deal with new stressors because they are coordinated and reinforcing to the couple. These complementary strategies may offer a wealth of and broader methods of coping (Revenson, 1994), increasing the collaboration of the couple to help adapt to new ways of dealing with the illness and subsequently maintaining their level of intimacy (Hwang et al., 2007; Ptacek & Dodge, 1995).

Additionally, cohesion and adaptability are significant factors, including the function of the relationship and the personality factors involved. The Circumplex Model of Marital and Family Systems (Levitt, 1986) found that healthy couples have workable boundaries, flexibility in leadership, are open to suggestion, and able to negotiate and share roles and feelings. Those that close themselves off to experience and are rigid and disagreeable will experience more negative affect (Gaine & LaGuardia, 2009),

significantly impacting how couples interact with each other after being diagnosed with ALS and dealing with the physical impairments as they occur. Conversely, sociability, creativity, flexibility, altruism, and helpfulness have been found to directly influence styles of coping, and it is these persons who are more likely to engage in relationship-focused coping (Lee-Baggley, Preece, & DeLongis, 2005).

ALS adds significant pressure to the marital relationship, and commitment and investment in the relationship are important. Those who wish to be in the relationship experience greater commitment, satisfaction, intimacy, and vitality (Gaine & LaGuardia, 2009). The presence of a terminal illness will significantly impact and challenge the relationship; however, couples have a way of working together, and supportive behaviors can impact vulnerabilities (Wunderer & Schneewind, 2008).

Limitations of the Study

Limitations of the study include the selection of the sample, methodology, and factors related to data collection. Although the sample is largely representative of ALS patients, specific characteristics of the sample gathered for this research study may not be an accurate representation. For instance, 90% of this sample identified themselves as White. Although this is largely representative of those with ALS in the United States (ALSA, 2008c), it may be difficult to generalize to other racial populations and cultural differences. Albert, Wasner, Tider, Drory, and Borasio (2007) found cross-cultural variations in physical and emotional experiences of persons with ALS in Israel, Germany, and the United States. Germans have been found to be less physically disabled in speech, leg movement, and the need for tube feeding, and Americans appear to experience the least emotional distress related to ALS when compared to other cultures (Albert et al.,

2007). These variations are important to consider when considering how ALS impacts persons of different cultures. The cultural variation of the experience, desire, and satisfaction of intimate relationships could impact clinical understanding and intervention.

Additionally, persons with ALS who participated in this research study were recruited from multidisciplinary treatment settings, which may be considered a specialized sample of persons with ALS. Resources to aid in physical and bulbar impairment are more accessible in multidisciplinary ALS clinics (Van den Berg et al., 2005). This availability and support could significantly impact how the experience of impairment affects the experience of, desire for, and satisfaction with interpersonal relationships. It is also possible that particular participants were approached based on characteristics other than those indicated within the inclusion and exclusion criteria. When assessing functional ability, a large portion of the participants were highly functional. Staff may have been more ready to engage higher functioning and cooperative patients, creating a selection bias. Although functional ability's influence on intimacy was unfounded, there is no way of knowing if the results would be different given a lower level of functional ability on the ALSFRS-R. It is possible that those endorsing greater impairment may have a different outlook on how their functional ability impacts intimacy.

In addition to the selection bias, the administration and selection of measures chosen to assess intimacy may have created additional limitations. All sites were expected to follow a standardized method of collecting data. However, due to the number of sites involved in this study, it is unknown if this protocol was followed

consistently for each participant. With regard to the measures, the ALSSQOL–R is a valid measure for assessing QOL in persons with ALS; however, only a small portion of the measure was used for the purposes of the research. The intimacy subscale of the ALSSQOL–R consists of items on emotional intimacy, physical intimacy, and sexual intimacy. Social contact is part of a different construct, but was included for the purposes of this research. When testing the hypotheses the intimacy subscale was evaluated by looking at each question individually to gain a greater understanding of the experience of, desire for, and satisfaction with intimacy in persons with ALS. Unfortunately, the separation into separate items may have altered the reliability and validity of the subscale.

Using the PAIR raises some question with regard to the altered method by which it was administered. The PAIR is expected to be administered once to assess perceived intimacy and then an additional time to assess expected intimacy (Olson & Schaefer, 2000). Olson and Schaefer (2000) identify the difference between perceived and expected scores as how satisfied one is with his/her relationship. Although the use of perceived intimacy shows how much intimacy is in the relationship and is likely to provide more information than assessing expectations, using only this portion may alter the understanding of satisfaction because the expected intimacy data was unable to be obtained. One may argue that adding the expected intimacy portion would be a better measure; however, for the purpose of examining of other ALS variables, this measure was appropriate.

Second, assessing only one partner within the dyad may influence the data when comparing it to data that could have potentially been acquired from both partners within the dyad. Traditionally, both individuals fill out the PAIR to provide data on their

perceptions of intimacy in the relationship (Schaefer & Olson, 1981). Collecting information from each partner assesses the similarity and discrepancy in their perceptions of intimacy (Olson & Schaefer, 2000) and is a more comprehensive way of understanding the dyad. Unfortunately, from the data obtained for the conventionality scale, it appears that participants within this sample may have idealized their relationship and may not be entirely truthful when answering the questions. The PAIR manual (Olson & Schaefer, 2000) states that the average score for conventionality is 38, and scores above 55 are considered very high. Those with conventionality scores in the very high range may idealize their relationship and may not be answering the questions truthfully. In this study, the range of PAIR scores for conventionality was from 8 to 96, with a mean of 71.7. This suggests that those reporting on their intimate relationship may not have portrayed an accurate account of how they perceive their relationship and may minimize problematic aspects of their relationship. The literature suggests that this is not uncommon and that both men and women are unrealistically optimistic when reporting on their expectations of and satisfaction with their marital relationship (Lin & Raghubir, 2005; Sanderson & Cantor, 2001).

When using a particular measure to make statements about a population within a study, the normative sample to which scores are compared must be considered. The ALSSQOL–R is a measure developed specifically for persons with ALS. Although its validity is currently being examined for the revised version, the concurrent, convergent, and discriminant validity of the ALSSQOL are strong. The PAIR was developed using a pilot sample from a university sample of couples in community enrichment groups, undergraduate day classes, and postgraduate class and then validated on 192 nonclinical

couples interested in couple enrichment (Schaefer & Olson, 1981). This measure has been used in the development of couple enrichment programs (Kouneski & Olson, 2004), assessment of marital satisfaction (Kenny & Acitelli, 1994; Quitter, Espelage, Opiari, Carter, Eid, & Eigen, 1998), examination of relationship beliefs (Sinclair & Nelson, 1998), and identification of marital role strain (Quitter et al., 1998). With regard to marriage and chronic illness, the PAIR has more recently been used in assessing how relationship factors may contribute to diabetes control and adherence (Trief, Britton, Wade, & Weinstock, 2002; Trief, Orendorff, Himes, & Weinstock, 2001; Trief, Ploutz-Snyder, Britton, & Weinstock, 2004). Although norms for the PAIR do not include persons with chronic or terminal illness, it has been used in this population. It is important to consider how scores for this sample of participants compare to the healthy, nonpatient samples the normative scores were based upon.

Other measures that may be beneficial in gathering more information with this population may focus more on intimacy and marital relationships. The Dyadic Adjustment Scale (DAS; Spanier, 1976) is a 32-item rating measure of marital adjustment commonly used in a variety of settings and research. It was designed to measure relationship adjustment in married, cohabitating, and same sex-couples (Spanier, 1989). This measure allows clinicians to obtain different views of the marital relationship within the dyad. It is brief and widely used on a variety of clinical and nonclinical populations, including medical populations such as those with multiple sclerosis, diabetes mellitus, and rheumatoid arthritis. Although criticisms have been made of the difficulty in generalizing the original normative data, recent research has shown the DAS to be reliably sound (Budd & Heilman, 2004; Carey, Spector, Lantinga,

& Krauss, 1993). The Marital Satisfaction Inventory–Revised (MSI-R; Snyder, 1979) is a 150-item, true and false measure, derived from the 280-item Marital Satisfaction Inventory (MSI; Locke & Wallace, 1959). This measure has been validated as culturally sensitive in a number of populations (Means-Christensen, Snyder, & Negy, 2007; Negy & Snyder, 1997; Scheer & Snyder, 1984; Snyder, Wills, & Keiser, 1981). Unfortunately, this assessment is quite lengthy, would be difficult for persons with ALS to complete, and is not efficient for research. Most often, this measure is used in a clinical context for diagnosis, goal-setting, communication enhancement, and rapport building (Bernt, 2004)

It is not uncommon for participants who are knowledgeable about the hypothesis of an experiment to respond to questions in a manner that supports the hypothesis (Nichols & Maner, 2008; Rosnow, 2002). The role of the parent study was to assess the QOL of persons with ALS. Given the emotional investment of the population having this disease, their willingness to participate in the research, and the self-report interview format, it is possible that participants wanted to depict themselves as highly functional in many aspects of their life, regardless of their functional ability. This could be especially true when providing information about something as sensitive as their interpersonal and intimate relationships. The desire to perform as a “good subject” is especially evident if the examiner is likeable or a person of authority (Blass, 1991; Nichols & Maner, 2008). In all instances, participants were recruited by persons they knew in the multidisciplinary clinic and may have also been interviewed by familiar persons, significantly contributing to how they responded. Additionally, they were within a setting in which they received all of their care, which can be quite influential in the participant wanting to be the “good subject.”

Based on the discussion and consideration of the literature, other variables should be included for future research. Since demographic variables and physical functional ability are not predictive of intimacy in persons with ALS, it would be important to explore other factors that may influence the experience of, desire for, and satisfaction with intimacy. Such factors were addressed within the literature and have been found significant in other populations when examining marital relationship and intimacy. These include: self-confidence, embarrassment, body-esteem, loss of dignity. Most importantly, it would be essential to assess the marital relationship and the emotional connection of the dyad.

Implications of the Research

Although the hypotheses of this research study were not supported, it provides very valuable information regarding the understanding of intimacy in persons with ALS, specifically their experience of, desire for, and satisfaction with intimacy. As with QOL (Simmons et al., 2006), there is more to persons with ALS than their functional ability when assessing aspects of their intimate relationships. The implications we, as clinicians, assume as a result of loss of functioning may not be as detrimental as we predict. Rather than focus on the physical aspects of persons with ALS, it may be more important to focus on the marital relationship as a whole and how the loss of ability can impact certain areas of the relationship and various ways to cope and adapt to the changes as a couple.

In many regards, ALS is different from other chronic diseases, due to the terminal prognosis and progressive, unrelenting muscle weakness and impairment. As a result, the method of diagnosis and treatment is also different. Many times, treatment providers specifically deal with and address the patient and patient's concerns. McCluskey,

Casarett, and Siderowf (2004) suggest otherwise for persons with ALS. Specifically, they recommend involving the patient's support network in the process of diagnosis, coping, and planning for the future. Although generally focusing on the medical model and specifically interested in the physical implications of the disease, the model of involving spouses can also enhance communication, support, and coping as it relates to diagnosis, planning for changes, engaging openly about concerns regarding changes, and dealing with end-of-life care. Each aspect of ALS contributes to the appraisals and reactions from each party, undoubtedly influencing their intimate interactions. As a result, it is important to deal with the couple as a unit, first, because the spouse is equality involved and implicated by ALS (Coyne & Fiske, 1992), and second, couples have the tendency to accommodate each other's coping efforts and work together, especially in times of crisis (Coyne & Smith, 1994).

This is a new endeavor in the focus on ALS, as much of the focus is often placed upon physical care and resources to help with comfort at the end of life. Newer research has begun to explore QOL, and future research may seek to explore different aspects of intimacy and factors that may impact relationships. A major limitation of this study was that spousal data were not collected or included on this construct, as it was not the purpose of the parent study. It would be important to collect data per dyad to examine each individual's perceptions of ALS's impact on their relationship. Future research may also design a protocol for preparing couples faced with ALS for barriers and obstacles they may encounter, such as role changes, communication barriers, and feelings related to personal hygiene assistance. As the illness progresses and persons with ALS become more dependent, satisfaction, empowerment, and cohesion may be experienced as a result

of the caregiving experience (Andrén & Elmståhl, 2005; Ekwall & Hallberg, 2007; Grant et al., 1998), but guilt, shame, and reluctance to discuss these emotions may also occur (Hecht et al., 2003). As a result, persons with ALS and their spouses may withdraw and not discuss their concerns and feelings pertaining to the illness for fear that this would create more burden (McPherson et al., 2007).

A number of programs have been developed to assist couples in dealing with significant stressors, such as terminal illness. Although brevity would be preferred due to the enduring progression of ALS, modified versions of developed programs may be appropriate to help couples enhance their communication, appraisals, and support throughout the illness and end of life. Although persons with ALS report high levels of intimacy within the marital relationship, it may be further enhanced by helping the couples work on the same goals. For example, Sanderson and Cantor (2001) found that a dyad with strong goals related to intimacy engaged in patterns of communication, activity, interdependence, and social support. While persons with ALS are facing significant functional impairments, the intimacy of the relationship may be less of a priority than the more instrumental implications of such experiences. This is when skills and ideals acquired through a modified program may help the couple to find ways to maintain their intimacy while also integrating new instrumental challenges to their life.

The Couples Coping Enhancement Training (CCET; Bodenman & Shantinath, 2004; Bodenman, Pihet, Shantinath, Cina, & Widmer, 2006) is a program that goes beyond teaching couples communication skills and also integrates the enhancement of individual and dyadic coping. The goal is to reduce the negative impact that stress can have on an intimate relationship, which can often lead to isolation or a lack of awareness

and involvement in each other. The goals of the training include improving one's own stress, enhancing the ability to cope as a couple, fostering sensitivity to issues of mutual fairness and respect, and improving problem-solving abilities of the dyad (Bodenman & Shantinath, 2004). Since ALS couples are older due to the typical age of onset, it is possible that these couples have longer histories. The ability to draw upon well-established and shared understanding and routines may work to their benefit in dealing with ALS (Coyne & Fiske, 1992).

The CCET is typically six different, structured modules delivered over a certain period of time. With regards to persons with ALS, the time points may be modified by combining some of the modules, since survival is approximately 17 to 19 months from the time of diagnosis (Kimura et al., 2006). This is not to discredit the CCET program because there have been significant strengths and positive outcomes in 1- to 2-year follow-up data (Bodenman et al., 2006), but because ALS is a progressive illness that occurs and debilitates quite quickly. The CCET has been shown to improve constructive and mutual problem-solving, influencing life satisfaction, psychological and physical well-being and overall marital quality (Bodenman et al., 2006; Pihet, Bodenmann, Cina, Widmer, & Shantinath, 2007).

Initially, persons with ALS and their spouses may be introduced to the first goal, education on types of stress, and goal two, improving the ability to cope with individual stressors (Bodenman et al., 2006). This is especially important early in the diagnosis, as impairments are becoming more evident and stressors begin to increase as responsibility and role changes begin to take form. Bodenman and Shantinath (2004) recommend

introducing the idea that each situation can trigger appraisals and specific stress emotions, and these are different for each person (Lazarus & Folkman, 1984).

When stress is high, it is not uncommon to focus on one's own stressors and overlook those of our counterpart. The ability to recognize and understand the partner's stress is the premise of the third module (Bodenmann et al., 2006; Bodenman & Shantinath, 2004). This goal involves taking into consideration and enhancing the understanding of the partner's stress and enhancing stress-related communication and overall dyadic coping (Bodenman et al., 2006; Bodenman & Shantinath, 2004).

Although one person within the dyad has ALS, both persons are significantly impacted. Spouses of persons with ALS may not verbalize concerns or emotional distress because of guilt over their reaction. Again, persons with ALS in this study did endorse higher levels of intimacy function and satisfaction. This may be different if gathering the spouse's perspective.

A method of facilitating positive dyadic coping is to enhance equality and to be sensitive to each other's needs (Bodenman et al., 2006; Bodenman & Shantinath, 2004), the fourth goal of the CCET model. Toward the end stages of life, persons with ALS are significantly limited, and the spouses often bear the brunt of the responsibility. In conjunction with the fourth module, the fifth, improving communication skills, and sixth, strengthening problem-solving skills, would also be appropriate to introduce (Bodenman et al., 2006; Bodenman & Shantinath, 2004). Earlier in the disease, the couple could work together to maintain equality and shared responsibility until this would no longer be possible. Enhancing communication and dyadic coping may aid in developing a plan of how to handle emotions and stress as persons with ALS become more dependent. It

would also be beneficial to discuss how the patient's death may also impact the spouse, emotionally and instrumentally.

The benefit of developing a program for marital couples facing ALS is to acknowledge that although one person has ALS, the other is also significantly impacted by the disease. It also shows that clinicians and practitioners are aware of and familiar with particular issues within the family and are identifying the patient as a dynamic person and not as an ALS patient. Intimacy is a sensitive topic and should not be overlooked. The recognition of this and normalization of feelings related to guilt, anxiety, sadness, helplessness can encourage communication and allow marital dyads to maintain their level of intimacy throughout the patient's life. The commitment of clinicians to provide resources to and workshops for persons with ALS and their spouses shows their dedication to enhancing communication, support, and coping as it relates to diagnosis, planning for changes, engaging openly about concerns regarding changes, and dealing with end-of-life care.

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