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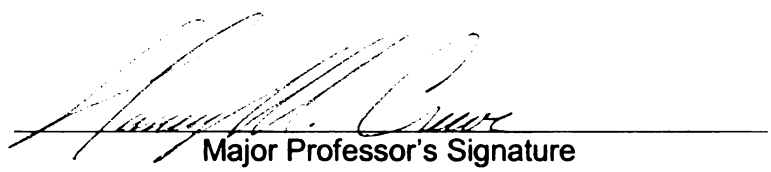

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LIFE SATISFACTION AMONG PEOPLE WITH PROGRESSIVE DISABILITIES

By

Roy Kuan-Yu Chen

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ABSTRACT

LIFE SATISFACTION AMONG PEOPLE WITH PROGRESSIVE DISABILITIES

By

Roy Kuan-Yu Chen

People with congenital disabilities do not necessarily react the same way to disability as people with acquired disabilities (Smart, 2001). Despite the known importance in rehabilitation outcomes, research on life satisfaction among people with progressive disabilities remains minimal. The purpose of the present study was to provide rehabilitation professionals with a better understanding of the impact of progressive disability on the adjustment to disability and life satisfaction. Specifically, the study investigated the relationships among life satisfaction, self-acceptance of disability, future time orientation, hope, and spiritual well-being in people with neuromuscular and neurological diseases. A total of 228 individuals were recruited through the Muscular Dystrophy Association and the National Multiple Sclerosis Society across the United States. They completed questionnaires containing several scales measuring predictor and outcome variables, as well as two open-ended reflective questions.

A series of regression analyses and an adapted phenomenological study were performed to analyze quantitative and qualitative data, respectively. The combination of future time orientation, spiritual well-being, hope, importance of religion, and acceptance of disability explained 42% of the variance in life satisfaction. Likewise, hope, spiritual well-being, levels of physical functioning, importance of religion, and future time orientation explained 42% of the variance in self-acceptance of disability. Additionally,

the results revealed that life satisfaction was positively correlated with spiritual well-being, hope, and self-acceptance of disability. Moreover, participants with higher levels of hope also reported having higher spiritual well-being and self-acceptance of disability. Although there was no relationship between future time orientation and life satisfaction, future time orientation was negatively correlated with hope and self-acceptance of disability. Interestingly, respondents with multiple sclerosis had higher scores on future time orientation and were more future-oriented than those with muscular dystrophy. Several important themes emerging from the qualitative study included fear of uncertainties, lack of accessible transportation, hereditary diseases, and a here-and-now mentality. Furthermore, participants reported a hindrance to establishing and maintaining intimate relationships. The limitations to the study and implications for rehabilitation practices and further research concerning progressive disabilities are discussed.

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Lastly, I dedicate this dissertation to my paternal and maternal grandparents, for it was their love and guidance that allowed me to pursue my dream under very difficult circumstances. In their memory, I carry the inspiration to be a decent-hearted and faithful servant to Lord Jesus Christ. Thank you and I love you all.

TABLE OF CONTENTS

LIST OF TABLE

LIST OF FIGURE

CHAPTER 1

INTRODUCTION

"Are you satisfied with your life?" is an uncomplicated question that nevertheless conceivably entails an infinite number of answers. At first glance an individual's response to this seemingly simple question might fall into the dichotomy of yes or no. However, as we attempt to understand what life satisfaction means to people through their own lens, we soon realize that no two people in the world would define it in the same way, because life satisfaction has temporal, cultural, psychosocial, spiritual, philosophical, contextual, and self-referential properties. For instance, suicide is perhaps the most drastic and tragic form of expressing dissatisfaction in life. Nonetheless, most people suffering from varying magnitudes of depression and unhappiness still go on with their lives. This raises a pondering point: Is life satisfaction determined by expectations or by experience? (Carr, Gibson, & Robinson, 2003).

Bioethicists and disability rights activists are known to hold divergent views toward such disability-related issues as eugenics, reproduction rights, and stem-cell research, which at times require legal interpretations from the judicial system to mediate their differences (Reinders, 2000; Wendell, 1996; Wolbring, 2003). One controversial bifurcating point pitting both camps against each other is their stance on the perseverance of life against the will of the afflicted individual. Conflict in the ideologies of fundamentalists and liberals can and has escalated to a full-scale legal battle. The stark contrast lies in the argument as to who is entitled to decide when a life may be terminated prematurely—God or the individual. In April, 1999, Dr. Jack Kevorkian was sentenced in

Michigan to two concurrent terms of imprisonment for his infamous role in abetting a 52-year-old man who had amyotrophic lateral sclerosis (ALS, a neurodegenerative condition better known as Lou Gehrig's disease) to take his own life. This case attracts extensive monitoring from both domestic and international news media in part because of the public's bitter split on its opinion of voluntary euthanasia and assisted suicide. However, amid the debate over Dr. Jack Kevorkian's fate, no one seems to be able provide a cogent and irrefutable definition of quality of life pertaining to people with disabilities, terminal illnesses, or chronic ailments.

The subject of disability in American culture has become a field of theoretical, clinical and policy interest. Regarded as a taboo subject until recent years, disability now engages a growing interest among human rights activists, academics, rehabilitation professionals, and those responsible for the organization and delivery of rehabilitation services. The conceptual and practical difficulties involved in assessing life satisfaction among people with progressive disabilities have resulted in inadequate research into this important area. The effects of inevitable physical and cognitive changes in the course of life span make it even more difficult to interpret the changing status in quality of life. Schou and Hewison (1999) criticize much of the life satisfaction research for retaining a biomedical focus on behavioral change, and for its exclusion of vital features of the experience of disability and chronic illness that are interwoven in the social, psychological, spiritual, and institutional contexts of patients.

What exactly construes disability is also a hotly contested point that threatens the unity of the disabled community. Deaf culture has always adopted the view that hearing impairment and deafness are not deficits per se. Rather, deaf culture sees sign language as

another form of communication. It is the failure on society's part that hinders the full participation in society by people with hearing impairment. *Sound and Fury*, which received a 2001 academy award nomination for best documentary feature, depicts the bitter division among three generations of both hearing and deaf family members over the use of cochlear implants.

In an interview with the Australian Broadcasting Corporation, Christopher Reeve, a staunch proponent of the use of embryonic stem cells and of therapeutic cloning, revealed his immense unhappiness with spending his life in a wheelchair (Goggin & Newell, 2004). It is a bewilderment to many wheelchair users why someone of his status who has the access to abundant resources including money, media attention, social support, strong family ties, and the most advanced medical treatments has little satisfaction with his life.

Study of life satisfaction is a formal attempt to include the rehabilitation services clients as well as the rehabilitation services providers in an effort to affect greater rehabilitation outcomes. Variables that have been linked to higher life satisfaction include age (Mehnert, Krauss, Nadler, & Boyd, 1990), employment status (Aquino, Russell, Cutrona, & Altmaier, 1996; Mehnert et al., 1990; Viemero & Krause, 1998), income (Boschen, 1996; Mehnert et al., 1990; Viemero & Krause, 1998), marital status (Mehnert et al., 1990), future time orientation (Prenda & Lachman, 2001), age at onset of disability (Mehnert et al., 1990). People with congenital disabilities do not necessarily react the same way to disability as do people with acquired disabilities (Smart, 2001). In recent years the survival rates for disabilities such as traumatic brain injury and spinal cord injury have improved markedly due to rapid advances in treatment technology and

pharmaceutics. Despite its known importance to rehabilitation outcomes, research on life satisfaction among people with incurable progressive disabilities such as muscular dystrophy (MD), multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS) remains minimal.

Very few studies have examined the association between future time orientation and acceptance of disability. "Future time orientation is inherent in a person's need and motive system" (Gjesme, 1979). An understanding of how people with disabilities envision their present and future may provide rehabilitation counselors and their disabled clients with a sound basis for developing effective strategies for achieving desirable employment goals. The conception of the future influences an individual's selection and pursuit of goals (Fung & Carstensen, 2004; Karniol & Ross, 1996; Zimbardo & Boyd, 1999). Psychologists have called for more research on time perception, which is an integral part of human motivation (Carstensen, Issacowitz, & Charles, 1999). It is unknown how time perception affects people whose outlooks on life are affected by incurable progressive disabilities.

Statement of the Problem

A substantial amount of research has been conducted on the correlates of life satisfaction among people with disabilities (Boschen, 1996; Boswell, Dawson, & Heininger, 1998; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Coyle, Lesnik-Emas, Kinney; 1994; Heckman, 2003; Hinckley, 2002; Nosek, Fuhrer, & Potter, 1995). However, thus far relatively few psychological studies have been carried out that focus specifically on the progressive disabilities group. Low incidence rates of neuromuscular diseases and neurological disorders, compared with more common developmental

disabilities, mental health illness, and HIV, contribute to the scant attention they receive from rehabilitation researchers and practitioners (Chen, 2001). Psychology literature is also replete with studies using hope theory to examine people's inner strength and their outlook on life (Chang, 2003; Chang & DeSimone, 2001; Danoff-Burg, Prelow, & Swenson, 2004; Horton & Wallander, 2001; Kwon, 2000; Snyder, Lopez, Shorey, Rand, & Feldman, 2003; Snyder, Shorey, Cheavens, Pulvers, Adams III, & Wiklund, 2002). None of these studies involve participants with progressive disabilities either.

Purpose of the Study

The purpose of the present study is to test a theoretically based multidimensional model of life satisfaction. The model addresses ways in which cognitive, physical, spiritual, and psychological variables mediate acceptance of disability and employment status.

In this proposed model of life satisfaction, constructs believed to have influences on a person's level of perceived satisfaction in life include hope, acceptance of disability, future time orientation, level of physical functioning, importance of religion, and spiritual well-being.

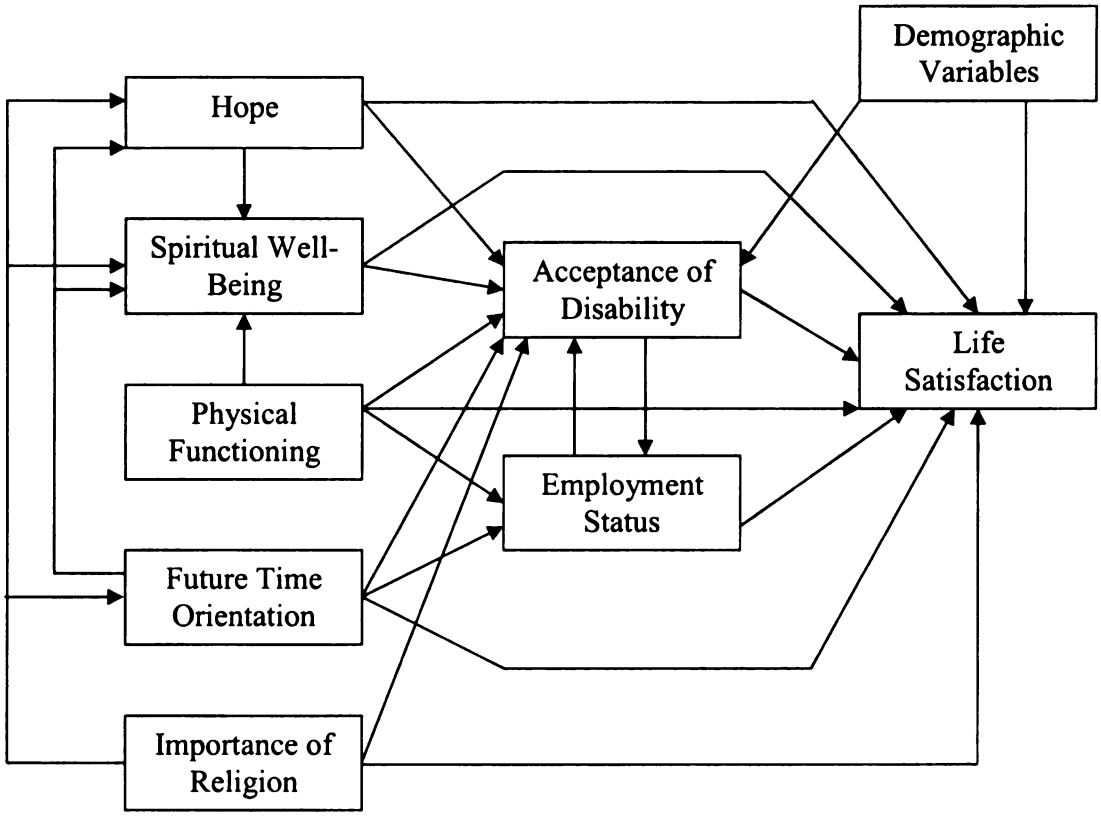

Figure 1. A model of acceptance of disability and employment status as mediators of the relations among hope, level of physical functioning, spiritual well-being, future time orientation, importance of religion and life satisfaction.

Research Questions

The following are the primary inquiry areas.

1. Which demographic and background characteristics (i.e., age, sex, marital status, educational attainment, race, type of disability, employment status, level of physical functioning, and duration of knowledge of disability) are predictive of future time orientation, acceptance of disability, and life satisfaction?
2. Are future time orientation, spiritual well-being, hope, importance of religion, and acceptance of disability predictive of life satisfaction?
3. Does acceptance of disability or employment status mediate the relationship between future time orientation and life satisfaction?
4. Can acceptance of disability be predicted by hope, spiritual well-being, level of physical functioning, importance of religion, and future time orientation?

Qualitative inquisition of the study is guided by the two open-ended questions in the demographic questionnaire.

1. In what ways does progressive disability affect the pursuit of personal goals such as employment and romantic relationships?
2. How does the uncertainty of progressive disability influence life perspectives?

Definition of Terms

Progressive Disability: Types of disabilities which are characterized by their unpredictable course of gradual loss of physical function and/or cognitive function. Some prominent examples are MD, MS, and ALS.

Acceptance of Disability: The extent to which a person accepts his or her inability to perform certain activities of daily living resulting from the loss of the use of his or her physiological and cognitive function.

Physical Function: The physiological function within a human body that enables a person to perform activities of daily living such as walking, lifting, standing, and squatting.

Hope: Positive expectations for goal attainments. Hopeful thinking requires the perceived ability to envision feasible ways to accomplish predetermined objectives, sustained by will power.

Future Time Orientation: The cognitive construct that impacts an individual's propensity to work for a distant goal (Gjesme, 1983a; Nuttin, 1985).

Religiosity: Transcendence in views toward life through the belief in God or a religion.

Employment Status: The category that describes the type of an individual's remunerative work, e.g. full-time, part-time, unemployed, retired, and volunteer.

Life Satisfaction: An individual's subjective appraisal of his or her own position in life with respect to domains such as social, health, spiritual, and financial status.

Delimitations

There are many types of progressive disabilities. For the scope of the present study, prospective participants will only include individuals with MD, MS, and ALS who are at least eighteen years of age.

Significance of the Study

This study will provide rehabilitation counselors with a better understanding of the impact of progressive disability on the adjustment to disability and life satisfaction. The findings from this study may help identify and dispel the stereotypes that society has in regard to individuals with disabilities that it has toward people of color and same gender sexual orientation. By confronting these issues, researchers and service providers in the field of rehabilitation can acquire the insight necessary to improve knowledge of disability.

The next chapter includes a discussion of the literature bearing on conceptual and methodological issues related to this study. Although disability is an individualized experience, this study will generate ideas to help rehabilitation professionals and their clients with disabilities in increasing life satisfaction.

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter provides an overview of literature relevant to the present study, focusing specifically on the four research questions stated in the previous chapter. Themes presented will include (a) life satisfaction, (b) acceptance of disability, (c) future time orientation, (d) spirituality, and (e) hope.

Life Satisfaction

Life satisfaction is a key construct that has been frequently employed in psychosocial, medical, and theological studies to evaluate an individual's perceived well-being. Standards for happiness and quality of life vary in the contexts of culture, health, spirituality, and wealth accumulation. The considerably higher prevalence of suicide rates in developed nations illustrates the complexity and limitation of understanding life satisfaction from one single perspective. Pavot and Diener (1993) posit that the affective and cognitive components of subjective well-being form the basis of evaluative criteria for people to compare their own happiness to that of other people. Life satisfaction thus involves a judgmental process because people assign different weights to the aforementioned contexts.

Individuals must also demonstrate long-term stability in their global assessment of their own life circumstances in order for their life satisfaction to be meaningfully measured. There is an assumption that people choose relevant and salient information from their lives to make meaning of a new situation (Diener & Lucas, 1999). Often people repeatedly rely on memories of past emotional experiences such as work, social

relationships, and academic performance to form successive life satisfaction judgments (Schimmack, Diener, & Oishi, 2002). The result of this cognitive regurgitation of pertinent information is a self-perceived well-being that remains quite stable.

In a cross-sectional study of 75 patients two years or more after a severe traumatic brain injury, Mailhan, Azouvi, and Dazord (2005) found no linear relationships between life satisfaction and severity of disability. The reported subjective quality of life in participants with severe disabilities did not differ significantly from those with less severe disabilities. A similar study of 45 individuals with a variety of physical disabilities who were receiving services from independent living centers also corroborates that disability may not be the only determinant that influences one's perceived well-being (Nosek, Fuhrer, & Potter, 1995).

Informed Desire Theory

Philosophers have debated whether the nature of human well-being is subjective or objective (Varelius, 2004). It is helpful to use the informed desire theory to analyze what the connotations of well-being are to a person. Griffin (1986) contends that enhancement of well-being is contingent upon satisfying the goals that informed people would desire to pursue. In other words, one ranks preferences of a set of goals to attain. Another facet of the informed desire theory is that one's sensibility is funneled through a vast store of practical information that exists ubiquitously in daily life. The subjective well-being of a person who uses a wheelchair is likely to be more affirmative if he or she engages in a leisure activity that does not preclude his or her full participation, such as playing musical instruments, instead of sulking in self-pity for not being able to scale the highest peak in the world.

According to De Ruyter's (2004) interpretation of personal flourishing, humans will burgeon into a state of holistic metamorphosis if they truly feel they are flourishing. Put simply, human thriving occurs only if people believe they are actually flourishing. A person's mental states are attributable to how well off he or she is. For instance, a novice music student's own acknowledgement of well-being elevates as his or her mastery of musical instruments increases. But this raises the question of how appropriate hedonism is as an indication of a high level of well-being. Tiberius (2004) suggests that humans possess moral capacities to reason out a cogent, logical, moral approach to making clear distinctions between pleasant and unpleasant contentment. The nature of well-being is thus objective rather than subjective because it is completely up to that person to delineate the premise of life satisfaction. This is in contrast to Griffin's viewpoint of informed goal seeking.

Religion and Spirituality

Sigmund Freud and Albert Ellis are two prominent psychologists who denounced the use of religion and spirituality for the purpose of research. Lack of concurrence on the definitions on religion and spirituality makes it hard to use them as quantifiable, operational constructs. In order to facilitate the scientific study of religion, Koenig, McCullough, and Larson (2001) selected several criteria to distinguish religion from spirituality.

"Spirituality is about a person's beliefs, values, and behavior, while religiousness is about the person's involvement with a religious tradition and institution." (Spilka, Hood, Hunsberger, & Gorsuch, 2003, p. 9). The terms religion and spirituality have become increasingly synonymous in recent years. Religion plays a functional role in the

study of human behavior as it unveils how faith operates in an individual's world (Spilka, et al., 2003). Scientific comprehension of the impact of religion on cognition and perception departs from the way traditional hermeneutic analysis of religious doctrines makes meanings out of life events.

Religion As an Asset and As a Liability

Wulff (1996) describes the paradoxical nature of religion using the study of religion to interpret how and why human beings act and conduct themselves in certain ways. He asserts that religion is both an asset and a liability in orienting oneself toward other people and the universe. As an asset, religion inspires, provides insights to self-actualization, fosters the growth of hope and wisdom, and transforms narcissism into the pursuit of perfection. On the other hand, religion is a liability that inhibits the infinite potentialities in people. Traditional religious values have throughout history acted to strictly control and determine the norms in society by reinforcing desired behaviors. The Oedipus complex, according to Freud, is the root of human being's eternal search for the father-child bond with a ubiquitous higher being when facing unpredictable situations. Some psychologists and social scientists deem this mystical psychological phenomenon as irrational and pathological and thus not worthy of scientific research.

Implications for Bifurcation of Religion and Spirituality

Researchers have in recent years used religion and spirituality to link to mental and physical health (Faull, Hills, Cochrane, Gray, Hunt, McKenzie, & Winter, 2004; Kim, Heinemann, Bode, Sliwa, & King, 2000; Powell, Shahabi, & Thoresen, 2003). But the rapid growth of such studies has created confusion in the conceptualization and measurement of religion and spirituality (Hill & Pargament, 2003). The increasing use of

the terms *religion* and *spirituality* as interchangeable by some researchers is drawing criticism from others who attribute separate and distinct meanings to each term (Makros & McCabe, 2003). *Religion* is now routinely used to refer to a belief system of organized religious practices (Wulff, 1996) whereas *spirituality* encapsulates the personal, emotional, and subjective expressions of religiousness (Koenig et al., 2001). Leading scholars in theology research have spoken out about the dangers of polarizing religion and spirituality. Pargament (2002) argues that bifurcation of these two highly correlated constructs could lead to the possibility that the helpful and harmful effects of each on an individual's well-being might be overlooked. Moreover, findings based on interviews, surveys, and questionnaires may be subjected to important concerns about whether the responses are generated within spiritual or religious contexts because most people untrained in theology, sociology, and psychology are unable to distinguish clearly between these phenomena (Marler & Hadaway, 2002).

Notably, between 67 to 74 percent of American Christians consider themselves as both religious and spiritual persons (Scott, 2001; Zinnbauer, Pargament, Cole, Rye, Butter, Belavich, Hipp, Scott, & Kadar, 1997). From researchers' perspectives, time and effort spent on needless duplication in concepts and measures of religion and spirituality could be better directed to other research interests (Hill & Pargament, 2003). In an attempt to be more inclusive of these two terms, Thoresen and Harris (2002) coin the term *Religious/Spiritual Measures* to denote measurement of these two constructs co-concurrently.

Theory of Religious Coping

In his much-quoted book *The Psychology of Religion and Coping*, Kenneth Pargament (1997) provides several theoretical approaches to explicating the role of faith in relation to coping behavior. The process of coping with a negative life event begins by mobilizing an orientation system to appraise a circumstance-specific meaning. This orientation system, comprising religious beliefs and practices, serves as a useful resource for people in distress to counter stressful situations. A person with an acute spinal cord injury may at the onset ask what the unanticipated accident means to himself or herself. Whether the incident is interpreted as a threat or an opportunity for personal growth depends on the individual's existential schema. In the next step of the coping process the individual prays to God to be restored to his or her premorbid health. However, some researchers warn that prayer can be dysfunctional if the individual waits passively for a miraculous healing instead of resorting to immediate medical help (Spilka, et al. (2003).

Pargament (1997) posits that people deploy problem-focused coping when an adverse situation is deemed changeable and emotion-focused coping when it is not modifiable. A sense of the situation's significance and a composite of values, beliefs, and feelings determine which coping mechanism is appropriate to activate. Disability, whether congenital or acquired, invokes mysticism as it drapes over the life of the afflicted individual. Although genetic counseling, biopsy, magnetic resonance image, etc. can help determine the etiology of a disease or disorder, they cannot explain the question why one is *selected* to become the victim of tragedy while another is not. The coping function of religion allows people who are facing a difficult situation to make sense out of it. Pargament further asserts that comprehending a tragic event through religion gives

meaning and helps regulate emotion to facilitate successful coping and adjustment. He delineates three categories of religious coping styles: (a) the self-directing approach, (b) the deferring approach, and (c) the collaborative approach. In essence, the first approach seeks to resolve problems without God; the second approach waits for Divine intervention; and the third approach combines the efforts of the individual and God to work out crises.

Spiritual Well-Being

Ellison (1983) suggests that spiritual well-being has both a religious component and a psychosocial component. In other words, there is a sense of comfort in connection with God as well as an experiential understanding of life purpose and life satisfaction. In a study of 120 college students, personal spirituality was correlated positively to satisfaction with life (Fabricatore, Handal, & Fenzel, 2000). Finding a sense of life's meaning reverses the shame often firmly internalized by people with disabilities. Once the stigma that shackles self-worthiness is broken by forging a new self-identity, the individual with a disability is no longer bogged down by humiliating looks and fear of rejection. More importantly, transcendence over limits on bodily functions, mental deficits, and cognitive impairments leads to inner peace, a quintessential property of spiritual well-being.

God has always been viewed as a source of both comfort and resentment for people whose lives are struck by tragedy. No consensus on whether God is merciful or cruel will ever be reached among the Jewish survivors of the Auschwitz concentration camps or the victims of the Indian Ocean tsunamis. Nevertheless, spirituality as a coping method is frequently deployed by people with disabilities and chronic illness to help them

look to a brighter future. To test the hypothesis that strong religious and spiritual beliefs are positively correlated with both cognitive and affective perceptions of subjective well-being, Daaleman (1999) administered the Spiritual Well-Being Scale to 80 outpatients at a university-based family-practice center. His findings support the notion that patients who are apt at constructing an existential meaning for life usually have a proclivity to incorporate the concept of a loving God in their schema.

Acceptance of Disability

Disability acceptance is an ongoing experiential phenomenon people with disabilities undergo in their lives. Adjustment to disability has been linked to the individual's perception of disability, and is shaped by personal beliefs, family support (Alston, McCowan, & Turner, 1994; Elliot, Shewchuk, & Richards, 1999), perceived social attitude (Li & Moore, 1998; Prince & Prince, 2002), cultural values (Chen, Jo, & Donnell, 2004), religious orientation (Alston, McCowan, & Turner, 1994), and spirituality. Persons with disabilities and their non-disabled counterparts differ greatly on what constitutes a disability. In a study to assess the attitude toward individuals with disabilities in the workforce, Popovich, Scherbaum, Scherbaum, and Polinko (2003) discovered substantial differences in non-disabled workers' beliefs about what constitutes a disability and the definition of disability as per the Americans with Disabilities Act (ADA). Although the participants were accepting of mobility and sensory disabilities, they clearly did not believe alcoholism and schizophrenia are disabilities when in fact they are recognized to be disabilities by the ADA.

In general, a person is said to have come to terms with his or her new disability identity after activating both acknowledgement of and adjustment to the disability (Martz,

Livneh, & Turpin, 2000). In a sample of 1,266 people with a variety of disabilities, Li and Moore (1998) correlated the nature and manifestation of disability with disability acceptance. Participants with congenital disabilities are more likely to be accepting of their own disabilities than are participants with acquired disabilities. Facing stigma and discrimination, people with less visible disabilities are under tremendous social pressures to "pass" as individuals without disabilities.

Hahn (1988) disagrees with the prevalent belief that acceptance of disability is achieved solely through an internal process. He argues that while the internal locus of control might play an important role in motivating an individual to overcome the challenges accompanied by a disability, rehabilitation professionals sometimes fail to see how both functional limitations and social attitudes could stall the reconfiguration process of a new self-concept. Martz et al. (2000) surveyed individuals with disabilities to determine if differences in disability acceptance existed between individuals with internal and external loci of control. They found better adjustment to disabilities among those with an internal locus of control than among those with an external locus of control. Confusion by rehabilitation professionals and their clients with disabilities over what contributes to satisfactory adaptation is compounded by an inundation of contradictory studies on acceptance of disability. For instance, there are positive correlations between acceptance of disability in people with acquired brain injuries and their quality of life (Snead & Davis, 2002). Disability acceptance is also reported to be negatively associated with perceived discrimination (Li & Moore, 2001), which in turn increases illicit drug use and practice (Moore & Li, 1998).

An unrelenting focus on the loss of physical function and on a sense of worthlessness is not unusual for persons with disabilities. Developing a positive image of self presents a rather difficult psychological goal to attain for many people with disabilities. Ayrault (1997) notes a widely mistaken approach in attempting to counsel individuals with disabilities to readily accept their disability status. In contrast to traditional rehabilitation psychology literature, denial of disability has proven to be an effective coping strategy (Olney, Kennedy, Brockelman, & Newsom, 2004). Those who accept their disabilities report more mental health problems than do those who reject their disability status. Moreover, recent research also indicates conflicting findings (e.g. Li & Moore, 2001) with regard to gender in reaction to disability. Women with disabilities appear to have a lower level of disability acceptance compared to their male counterparts (Hampton & Crystal, 1999).

Somatopsychology

In their classical writing on psychosocial adjustment to disability, Dembo, Leviton, and Wright (1956) liken acceptance of disability to acceptance of loss. The degree of acceptance of loss is contingent upon a process of value changes. They suggest the following behaviors as indicative of a desirable adaptation to disability: (a) focus on the residual abilities and strengths rather on the deficits, (b) undertake personal responsibility in mapping out one's life course and establish preferred goals, (c) recognize any personal achievement accomplished, (d) avoid expatiating on negative life experiences and downbeat thoughts, (e) decrease the scope of restrictions in the physical and social environments, and (f) partake of and take pleasure in cherished activities.

Building on the earlier writing of Dembo et al., Wright (1983) further posits four value changes to militate devaluation of self and to broaden acceptance of loss, which include (a) enlargement of the scope of values, (b) subordination of physique relative to the other values, (c) containment of disability effects, and (d) transformation of comparative-status values into asset values. She regards shifting away from the mourning of a presumed loss of physical function as critical to finding new meanings in life during the phase of enlargement of the scope of values. The lessening emphasis on body image permits the person with a disability to construct a heightened self-concept by augmenting the relative weight of certain values such as intelligence, charisma, and confidence over other values like dexterity and athleticism. Containing disability effects alludes to delimiting the spread effects of functioning losses. In other words, the impacted area (e.g., amputation of an arm) and the unaffected area (e.g., friendliness) must not be frivolously lumped together. Disability should be seen as a possession of rather than as a characteristic of an individual. For example, the semiotic descriptor of "a learning disabled person" is problematic in the sense that an individual's difficulty in processing information has become a characteristic and the descriptor fails to appreciate the wholeness of a person. A deleterious outcome of allowing learning disability to be portrayed as the central and sole characteristic of that person is that it selectively overlooks the familial, vocational, and social roles he or she may assume.

According to Davis (1997), the application of statistical science in the form of political arithmetic during the late nineteenth century gave an impetus to the growing hegemony of normalcy. Implicitly, this myth precludes any variant from the ideal body image. Thus, a person of a short stature is assigned to an inferior comparative-status

compared to a person of a tall frame. When the worthiness of an individual is arbitrarily devalued by preconceived norms, the process of adaptation to the disability is made more difficult. Reframing disability requires the transformation of comparative-status values into asset values (Wright, 1983). Put simply, the person is perceived in a more positive way only when appraisal of asset values shifts its focuses to what one can do instead of what one cannot do.

Stigma Incorporation Theory

DeLoach and Greer (1981) draw on psychodynamics stigma incorporation to link the relationship between self-concept and disability acceptance. Stigma is the social disgrace rendered onto an individual who is considered to have deviated from the norm, be it behaviorally, aesthetically, culturally, etc. The stigma incorporation theory purports that adjustment to a disability will take place only after a lucid self-state, comprising appraisal of one's own and others' perception of the disability, has been conceived. This theory has three components: (a) stigma isolation, (b) stigma recognition, and (c) stigma incorporation (DeLoach & Greer, 1981). People in general prefer to be in control of their own lives. The onset of a disability, regardless of its severity, can arouse tremendous anxiety and stress in individuals as they are forced to figure out how to best cope with the unexpected. The process of stigma isolation revolves around the continued manifestations of denial and repression. By isolating the stigma from the self-state, one is presumably able to abate the occurrence of frequent and intense disability-related stress. As one enters the phase of stigma recognition, one first comes to grasp the implications of having physical limitations and then surveys task-oriented strategies to resolve new life challenges. To reach the stage of stigma incorporation, one must discern both the positive

and negative aspects of living with a disability. The disability no longer looms in the foreground of a person's life as the perceived stigmatizing conditions subside concomitantly with one's new self-concept (Ososkie & Schultz, 2003).

Disability Transcendence Theory

Acceptance of disability requires embarking on a lifelong process of acknowledging disability. This process is affected by one's continued personal, cultural, spiritual, physical, intellectual, and emotional revolution (Vash, 1994; 1981). Disability Transcendence Theory (Vash, 1981) puts forward a model that embraces disability as an opportunity for psychological development and spiritual growth. Transcending disability implies tapping into the innermost consciousness to move beyond disability-related constraints imposed by functional abilities, societal expectations, personal perspectives, and emotional reactions. Vash explains that the growth experience is catalyzed by three levels of acknowledgement of disability: (a) recognition of the facts, (b) acceptance of the implications, and (c) embracing the experience. At the first level the individual recognizes the inherent negative valence in disability. However tragic the disability might look, one must learn to live with it to move on with life. At the second level of disability acknowledgment, the individual views disability as an inconvenience of neutral valence that can be overcome. The metamorphosis of a new self emerges as bitter brooding resulting from the sense of loss of physiological function starts to subside. As a consequence, the implications of the disability are imbued with a chosen way of life. The individual operating from the third level embraces disability as a chance to attain self-actualization. Disability, regarded as a positive valence, motivates the individual to extract a new meaning in life by turning potential adversity into potential opportunity.

Philosophy of Existentialism

Viktor Frankl, a Vienna born psychiatrist who survived the Nazi concentration camps, is credited with applying existentialism to searching for meaning and purpose in life, especially in one who is in dire and despondent circumstances (Corey, 1996; Ososkie, 1998; Ososkie & Schultz, 2003). Neurotic reminiscence of the before injury lifestyle and obsessive contemplation of the etiological origin of a hereditary genetic defect are the antithesis of existential thinking. The constantly evolving nature of the existential approach requires the individual to accept the responsibility for the consequences of a choice made. One's destiny takes the path of the chosen options. As Corey (1996) puts it, "facing existential anxiety involves viewing life as an adventure, rather than hiding behind securities that seem to offer protection" (p. 179). Refusal to change for the better, arising from making poor excuses and blaming others, impedes the formation of a new self-identity. Instead of posing the question of why a tragic event has befallen oneself, an existentialist would try to construe a sense of meaning out of the present predicament. From a rehabilitation counseling perspective, people with disabilities are to be encouraged to explore deep human experiences so that the conception of a meaningful existence in relation to a world that highly stigmatizes disability is feasible.

The development of a person's capability to cope with physical suffering and mental anguish culminates in a successful search for a new meaning in life (Frankl, 1984). Contentedness and happiness will come to an individual who seeks them. The central tasks of change fall squarely on the shoulders of persons with disabilities. As

such, finding meaning in life with a disability lays the foundation for disability acceptance from an existential standpoint.

Livneh's Unified Approach to Adaptation Process

In an attempt to synthesize a multitude of disability acceptance theories, Livneh (1991) carried out an extensive literature review of over 40 reaction to disability models and presents a unified model for conceptualizing the process of adjustment to physical disability. This non-static adaptation process consists of five interwoven temporal stages: (a) initial impact, (b) defense mobilization, (c) initial realization, (d) retaliation, and (e) reintegration; it is deemed a prerequisite for a successful transition from non-disabled status to a new disability identity. The initial impact stage is characterized by feelings of shock and anxiety. Presumably, the individual suffers from severe shock following the occurrence of a traumatic situation or a life-threatening situation. Uncertainty about what changes an unfamiliar physical or functional impairment might entail often trigger such acute emotional symptoms as confused thinking and cognitive flooding (Livneh & Antonak, 1997) which lead to enormous anxiety. The main feature of the defense mobilization stage is refusing to acknowledge the disability and its impact. To cope with the initial strain of disbelief, the affected individual mobilizes psychological defenses in hope of bringing some sense of orderliness to a world that is seemingly spinning out of control. In this phase of the adaptation process, the person with a disability might first find himself or herself trying to bargain with God or a higher spiritual being to seek a second chance in life. The promise to adhere to high moral standards is made in anticipation for an exchange for a reversal to the previous able-bodied physical state.

When the much-expected immediate recovery fails to materialize, denial of disability soon replaces bargaining.

Denial of disability involves a string of long-term suppressions of the altered body image as well as the reduced physical functioning. It implies a subconscious yet futile attempt to block any reminder of the reality. The malleable human mind is usually very cognizant of the self and its surrounding. In the third phase of the adaptation process, the person with a disability starts gradually to sort out information regarding what awaits in the future. Typically, the mourning of a lost physical function is accompanied by a bout of depression that is either brief or deep depending on the individual's personality, network of support, and severity of the disability. Self-directed resentment is another phenomenon frequently observed in the stage of initial realization. For example, a person with spinal cord injury may internalize the guilt for his or her indulgence in high-risk behaviors such as skydiving and bungee jumping. In the fourth stage, retaliation, a person with a disability replaces self-blame with outward hostility. The feelings of antagonism for the onset of a physical impairment are directed at external events, objects, and people. For instance, a blind person may attribute the loss of sight as a punishment by God for his or her parents' transgression or as an injustice done at the hands of the enemies in war. Put simply, the disabled individual is inculpable of the personal tragedy.

To complete the final phase of the adaptation process, reintegration, one must journey through three cognitive substages, i.e. acknowledgment, acceptance, and adjustment. Acknowledgement takes place only when the individual recognizes the economic, vocational, personal, familial, social, and physical ramifications of the disability (Livneh, 1991). This reorganization of schema is critical to assist with the

acceptance of a changed body image, which engenders the creation of an entirely new disability identity. Healthy adjustment to a disability is feasible only if the person concentrates on the repertoire of his or her remaining skills and strengths, rather than focusing on the deficit areas.

Although disability acceptance theories can shed light on the mental turmoil persons with disabilities may have to endure, several caveats should be noted when applying these theories to the rehabilitation practices. People with disabilities whose recoveries do not proceed in accordance with the clinically hypothesized stages are oftentimes labeled as pathological or deviant (Vash, 1994). Olkin (1999) criticizes the adjustment theories used by psychologists and rehabilitation professionals for failing to evaluate the progress within the sociocultural milieu of their clients with disabilities. She points out several theoretical and empirical flaws embedded within the framework of stage models of response to disability. First, the human mind is extraordinarily complex and it is highly improbable for two persons to adapt to a disability in the same fashion. Likewise, the assumption that an individual ought to go through a sequential series of steps to reach the goals of successful adjustment is both erroneous and overly simplistic. Second, findings drawn from small samples of participants in the hospital and in rehabilitation settings might not withstand stringent validity tests. Researchers cannot remain objective observers if they hold a pathogenic view of their subjects, and values and beliefs of people with disabilities are not taken into consideration. Third, the variations in the psychological states among people who experience depression and anger make it nearly impossible to quantify an appropriate length of this stage. Lastly, stage models of response to disability do not elucidate why some people with disabilities

display positive outlooks on life despite bypassing certain phases in the adaptation process.

Future Time Orientation

The exact origins of the concept of time is an issue that has drawn research interest among anthropologists, scientists, theologians, and historians, but they have yet to arrive at a consensus as to when and how time is quantified. The first indication of tasks being performed in a loosely structured time frame can be seen in primitive nomadic men who hunt and gather during the day and rest at night. The Biblical notion of a God who creates the world and rests on the seventh day further demonstrates that people have both cyclical and linear views of time. One might argue that human beings are not the only specie in the animal kingdom that has the ability to perceive time. The migration of caribous across the tundra and the hiatus of polar bears in wintry months appear to reflect a sense of time. But human beings are set apart from animals by time orientation, which requires complex cognitive skills to think in abstract forms of past, presence, and future.

The human brain is a work of wonder. It can store, retrieve, disseminate, and synthesize plethora of information with marvelous ease. Cognizance of time orientation takes place when either an actual or an imagined incident is being processed in reference to a time frame (Cottle & Klineberg, 1974). To illustrate this point, let us consider two possible reactions of a person who has just been diagnosed with degenerative retinitis. Jogging down memory lane to reflect on his or her sighted days is a reaction that is in the mode of past time perspective. Projecting a new self-image of being blind in the near future is in the mode of future time perspective. Time orientation thus confers a sense of

reality upon an event. To deal with uncertainty, persons with progressive disabilities envisage their future based on what they would experience if they actually found themselves in those uncertain scenarios.

Models of Time Orientation

Seeking a new meaning is actually future-oriented (Ososkie, 1998). The confusion in defining time orientation is evident in the proliferation of divergent models proposed by researchers and scientists. Boris (1994) conceives a model of time orientation based in the discipline of psychiatry. He posits that time has no dimension and therefore cannot be measured. Stated differently, if time existed, it might move in various unpredictable ways like arrows because we cannot tell whether the psychological state of mind and the physical state of being are framed by time or vice versa. Time seems to drag its feet when college students must sit through a boring 90-minute lecture that hardly keeps their interest and excitement. On the other hand, the time spent watching an entertaining 90-minute movie with a boyfriend or girlfriend may appear to fly by in light speed.

Gjesme (1979; 1983a; 1983b) defines future time orientation (FTO) as an aptitude for anticipating and organizing future events. People with high FTO are usually more adept at making plans and solving problems. The capacity for thinking about a personal future is critical to the successful vocational rehabilitation of people with progressive disabilities because they need to be able to foresee what awaits them in their lives as their physical condition continues to deteriorate. Three factors that shape an individual's development of FTO include (a) the motives, (b) the delay of gratification, and (c) the ability to conceptualize the future. Culture, age, gender, anticipation of death, and

disability are some of other factors that have been attributed to variations of time orientations (Martz, 2003; Martz & Livneh, 2003; Teahan & Kastenbaum, 1970).

Using J. W. Atkinson's achievement motivation theory, Gjesme (1983b, 1979) explains that the strength of a person's FTO is determined by two intrinsic and differing motives: the desire to approach success and the desire to avoid failure. Put simply, motives direct people towards future achievements, in the form of both pleasure seeking and pain avoidance. One distinction between the two types of motives needs to be made. Awaiting the positive oftentimes harbors a longer FTO than does attempting to steer clear of the negative. The lucrative potential earnings of physicians and attorneys, for example, definitely have an impact on a student's decision to spend more time studying and less partying in order to gain admission into professional schools.

Future time oriented people usually think farther out in time about their future, whereas present time oriented people appear to pay less attention to possible consequences in regard to their own choices and have a propensity to engage in risk-taking behaviors such as reckless driving and unsafe sex. Developmental psychologists theorize that children and adolescents are more inclined to seek instant gratification if they have failed to form a bond with their primary caregivers (Teahan & Kastenbaum, 1970). Their need to seek immediate gratification is a result of their failure to develop the ability to conceptualize the possibility of future gains.

Using socioemotional selectivity theory, Fung, Carstensen, and Lutz (1999) caution that goal selection must be examined in the temporal context. The relative importance of a specific goal changes as a function of time (Fung & Carstensen, 2004). Perhaps goal-oriented individuals recognize the contingency of their future outcomes and

their current actions (Rothspan & Read, 1996). In their study of sex behaviors among heterosexual college students, Rothspan and Read found that those who were less sexually experienced and who tended to have fewer sexual partners were also high in FTO. In contrast, the responses of those participants low in fear of HIV and high in the number of sexual partners were higher in present time orientation. Gender also has an influence on a person's time perspective. Females are more future time oriented and report possessing fewer dangerous driving habits (e.g. speeding, tailgating). Males, on the other hand, are more present time oriented and do not anticipate themselves being involved in accidents (Zimbardo, Keough, & Boyd, 1997).

What is so remarkable about the conception of FTO is that it is clearly evident at an early age. Past studies have demonstrated that schoolchildren high in internal control are more future time oriented because they have a higher capacity to delay gratification from forthcoming rewards (Klineberg, 1968, 1967; Lessing, 1972, 1968). But empirical results correlating intelligence and individuals' future time perspective in regard to gender remain inclusive. Although men and women are of equal intelligence, Siegman (1971) speculates that boys are indoctrinated by social learning from a young age to set ambitious goals which usually take many years to materialize.

Although a definite answer is lacking as to how long it takes for a person with an acquired disability to adapt, an optimistic outlook on life may be explained by time perspective. In their study on death anxiety as a predictor of FTO among 317 individuals with spinal cord injuries, Martz and Livneh (2003) found a relationship between disability-generated depression and FTO. Participants who dwell in the past are less apt to move forward with life and as a result remain unmotivated. It is possible that people

with disabilities might deploy temporal displacement as a defense mechanism to deny their loss of physical function. They savor what they could do in the past rather than acknowledge what they are no longer able to do after the onset of disability.

The relationship between future time orientation and desirable employment outcomes can be located in a line of several previous inquiries (Feather & Bond, 1994; Feather & Bond, 1983; Martz, 2003; Teahan & Kastenbaum, 1970). Feeling disoriented in their sense of time is commonly observed among people who have been out of the labor force. Furthermore, individuals who predict an earlier death are less likely to be employed than their counterparts who believe they would have a longer lifespan. If the preconceived views towards life in the distant future are overtly bleak, then it is not surprising to find that people whose minds are trapped in the state of hopelessness and helplessness choose to relinquish any goals. Hence it is interesting to notice that future time oriented people with a high level of hope report having had more satisfying lives. A recursive self-fulfilling prophecy seems to dictate one's cognition to either a positive path of thought or a negative path of thought.

CHAPTER 3

METHODOLOGY

This study examined life satisfaction among people with progressive disabilities. Its specific purpose was to investigate, in people with neuromuscular and neurological diseases, the effects of hope, acceptance of disability, physical function, spirituality, and future time orientation on life satisfaction. Another of its purposes was to learn if acceptance of disability is related to hope, physical function, spirituality, and future time orientation. The investigator looked into whether employment status can significantly add to the prediction of life satisfaction after controlling for the aforementioned factors.

Design

The nature of this study was non-experimental, i.e. no attempt was made to manipulate the variables. Research participants were not assigned to treatment and control groups. Survey is the most common type of descriptive research used in rehabilitation (Bellini & Rumrill, 1999). For this quantitative research, the investigator used descriptive studies (e.g. surveys and questionnaires) to gather information. Relationship analyses (e.g. multiple correlations, path analysis, and structural equation modeling) were used to test the relationships of predictor variables (independent variables) to criterion variables (dependent variables).

Participants

Men and women aged 18 and older who have progressive disabilities were invited to participate in this study. A power analysis using an independent sample t-test at the .05 level (Bausell & Li, 2002) indicated that 64 participants per group would result in an 80%

chance of obtaining statistical significance for the effect size of .50. Cohen (1988) suggests that a multiple regression model with six predictor variables and one outcome variable, at an α level of .05 with power = .80 requires a sample size of 97.

Instruments

Spiritual Well-Being Scale (SWBS: Paloutzian & Ellison, 1991). The SWBS is a self-report instrument designed to assess the subjective quality of life. It is comprised of two 10-item subscales, the Religious Well-Being (RWB) and the Existential Well-Being (EWB) scales, to gauge the construct of spiritual well-being. Each item uses a 6-point Likert-type scale ranging from 6 (strongly agree) to 1 (strongly disagree) to indicate the extent of agreement. Stronger agreement represents a higher level of well-being. The RWB (odd numbered items) and the EWB (even numbered items) subscale scores measure well-being expressed in relation to God and in the notion of life satisfaction and life purpose respectively. Negatively worded items (numbers 1, 2, 5, 6, 9, 12, 13, 16, 18) are reverse scored. The total possible score for SWBS ranges from 20 to 120. The original scale was standardized on a normative sample of 206 students attending four colleges, three in California and one in Idaho (Paloutzian & Ellison, 1982). The authors estimate SWBS has an internal consistency of .89 to .94 and a test-retest reliability of .82 to .99. The validity of this scale is evidenced by its positive correlation with life purpose and its negative correlation with loneliness.

Acceptance of Disability Scale-Revised (AD-R: Groomes & Linkowski, in press). The AD-R is a 32-item self-reporting measure of adjustment to disability among people with disabilities. Each statement is rated on a 4-point Likert-type scale ranging from 1 (strongly disagree) to 4 (strongly agree). Possible scores on the AD-R range from 32 to

128. A low score reflects a low level of acceptance of the disability. The AD-R was adapted and modified from the original 50-item Acceptance of Disability (AD) Scale, constructed by Linkowski (1971). The AD Scale is a widely used instrument and has been translated to other languages. Its high level of internal consistency in measuring degree of adjustment among people with disabilities is evidenced by its Cronbach's α values varying from .79 (Li & Moore, 1998) to .95 in the Swedish version (Nordstrom & Lutzen, 1995).

Satisfaction With Life Scale (SWLS: Diener, Emmons, Larsen, & Griffin, 1985). The SWLS is a 5-item self-reporting positive emotion scale that requires participants to indicate how intensely they are experiencing global life satisfaction. Each item of the instrument is measured on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Adding up all the items derives the total score, which ranges from a low satisfaction of 5 to a high satisfaction of 35. According to Diener and his colleagues (1985), the SWLS has an average score of 23.5 with a standard deviation of 6.43. The original 48-item SWLS was constructed with a convenience sample of 176 undergraduates at a research-oriented university in the Midwest. Factor analysis and elimination of redundancies reduced the current scale to a group of 5 items (Pavot & Diener, 1993). Diener, et al, (1985) found that the two-month test-retest correlation coefficient and the Cronbach's α coefficient were .82 and .87 respectively. Internal consistency for another study to predict life satisfaction in black college students coping with race-related stress was .80 (Danoff-Burg, Prelow, & Swenson, 2004). Lucas, Diener, and Larsen (2003) assert that short scales with four or five items measuring positive

emotions often exhibit strong reliability similar to that seen in long scales with over one hundred items. The SWLS is in the public domain and not copyrighted.

Hope Scale (HS: Snyder, Harris, Anderson, Holleran, Irving, et al., 1991). The HS is a 12-item self-referent multidimensional cognitive appraisal designed to reflect the relative level of hope pertaining to goal-related activities. The HS has two subscales and four filler items. Among the 12 items of the questionnaire, four items assess pathways (numbers 1, 4, 6, 8), four items gauge agency (numbers 2, 9, 8, 12), and four items serve as a distracter (numbers 3, 5, 7, 11) to make the intent of the survey less apparent. They are not used for scoring. The individual completing the instrument rates each response on a 4-point Likert-type scale ranging from 1 (definitely false) to 4 (definitely true). The psychometric properties of the HS have been shown to be both internally consistent--Cronbach's α coefficients of .82 to .84, (Chang & DeSimone, 2001; Danoff-Burg et al., 2004) and stable, test-retest reliability of .85 after intervals of several weeks, (Snyder, 1995). Its concurrent validity demonstrates that hope correlates positively with optimism and inversely with depression (Snyder, Shorey, Cheavens, Pulvers, et al., 2002). Adding the 8 items, with a possible range from 8 to 32, derives the total score. Higher scores on the HS correspond with greater hope.

Future Time Orientation Scale (FTOS: Gjesme, 1979). The FTOS is a 14-item self-assessing instrument that measures the ability to cognitively organize and anticipate future events. Gjesme refined the FTOS by adding eight items from Heimberg's Future Time Perspective Inventory (1963) to an earlier version of his 6-item FTO instrument. Responses to these test items use a 4-point Likert format of agreement or disagreement: 1 = is very true of me, 2 = is fairly true of me, 3 = is not too true of me, 4 = is not true at all

of me. Reverse scoring is used for statements 1, 3, 4, 5, 6, 7, 8, 9, 11, 12, and 13. The items are summed to yield a possible total score of 14 to 56. Higher scores on the instrument manifest a stronger orientation toward distant rewards and goals in the distant future. The internal reliability of the FTOS has been measured in terms of Cronbach's α coefficient ranging from .57 (Martz & Livneh, 2003) to .67 (Halvari, 1991).

Demographic Questionnaire

A demographic questionnaire has been designed by the investigator to gather the background information about research participants pertinent to the study. Research participants are asked to respond to such questions as age, sex, racial ethnicity, religion, educational attainment, type of disability, current employment status, and age at the onset of disability.

Procedures

The principal investigator (PI) used the Internet search engine to locate web pages of the National Multiple Sclerosis Society (NMSS) and the Muscular Dystrophy Association (MDA). A courtesy letter explicating the purpose of the present study and requesting teleconferences were sent to the program directors at both the national offices and selected local chapters. To expedite the solicitation process, a brief e-mail message containing a flyer document was also forwarded to those program directors whose e-mail addresses are readily available on the Internet. Four or five days after delivering the introductory letter, the PI made formal phone calls to these contact persons inviting them to collaborate in the study. To recruit prospective research participants, the PI submitted to the newsletters and magazines of the NMSS and the MDA a short feature article indicating the importance and benefits of participation in the proposed study. Another

means to increase exposure was to place an advertisement in the aforementioned organizations' printed and electronic media.

Once approval was obtained to contact their members, pre-research invitation cards were mailed to individuals on mailing lists provided by the collaborators. Invitation cards returned by the postal service as undeliverable were eliminated from the mailing list. This step was deemed necessary so that the actual surveys could be launched two weeks afterwards. The contents of the survey packet included an explanatory letter, the measurement instruments (described in the instruments section above), a demographic questionnaire, a consent form, and a prepaid self-addressed envelope for the participants' convenience. Brief instructions were printed on top of the first page of every instrument to guide participants through the surveys. All survey packets were coded so that information generated from the questionnaires could not be traced to individual participants. To ensure participants' anonymity and confidentiality, names and other pieces of identifying information were not collected.

An electronic alternative to the traditional paper format was also available to people with visual impairment and to those who have access to the Internet. SurveyMonkey.com, an external online survey provider was used to collect data. Electronic surveys, built using a web browser interface, were distributed via e-mail and embedded as a part of an existing website. These were a flexible and cost effective means to reach a geographically diverse population. Prospective participants would find the URL link for the surveys in either the advertisement or the introductory letter. A follow-up reminder/thank you card was sent to every participant during eighth week as a final attempt to improve the response rate. Participants were also encouraged to refer the study

to other people with similar disabilities. The amount of time for overall data collection was estimated to be approximately four months. As an added incentive, the first 100 participants received a $5 check.

Statistical Analyses

Heppner and Heppner (2004) recommend using a series of screening and preliminary analyses to detect any irregularities in the normality of distributions, outliers, and multicollinearity in variables before conducting a full scale of statistical analyses. This step is necessary to ensure that demographic variables such as sex, marital status, education, race, age, religion, etc. do not limit scores on the outcome variable of the present study.

A series of independent-samples t-test with Bonferroni procedure was used to compare the mean differences on variables between two types of disability: neuromuscular disease (e.g. muscular dystrophy) and neurological disease (e.g. multiple sclerosis). The t-test was suitable for analysis of one categorical independent variable (type of disability) and one continuous dependent variable (life satisfaction).

Both descriptive and inferential statistical techniques were employed. Initially, descriptive statistics were provided for all study variables. This included means and standard deviations for all continuous variables (i.e. age, duration of knowledge of disability, future time orientation, acceptance of disability, and life satisfaction), and frequencies and percentages for all categorical variables (i.e. gender, marital status, educational attainment, race, type of disability, and employment status). For subsequent analyses, some categories of the categorical variables were collapsed because the observed frequencies were too low.

All inferential analyses were two-tailed using an alpha level of .05. The first research question was: Which demographic and background characteristics (i.e. age, gender, marital status, educational attainment, race, type of disability, employment status, and duration of knowledge of disability) are predictive of future time orientation, acceptance of disability, and life satisfaction? Three multiple regression analyses were conducted to examine this research question, one for each of the three outcome variables. In each case, the eight demographic and background variables were employed as predictor variables. For the nominal variables with more than two categories (i.e. race, marital status, level of education, and employment status), a set of dichotomies was constructed and entered as predictors. The regression analyses were conducted by entering all predictor variables simultaneously.

The second research question was: Are future time orientation, spiritual well-being, hope, importance of religion, and acceptance of disability predictive of life satisfaction? To examine this research question, a multiple regression analysis was conducted with future time orientation and acceptance of disability as predictors of life satisfaction. Bivariate correlations among these three variables were also computed.

The third research question was: Does acceptance of disability or employment status mediate the relationship between future time orientation and life satisfaction? According to Baron and Kenny (1986), and Frazier, Tix, and Baron (2004), there are four steps to performing a test of mediation. First, it must be established that the predictor variable (i.e. future time orientation) is related to the outcome (i.e. life satisfaction). Second, the predictor variable must be related to the mediator (i.e. either acceptance of disability or employment status). Third, the mediator must be related to the outcome

when controlling for the predictor. Fourth, the strength of the relationship between the predictor and the outcome must be reduced when the mediator is added to the model. The mediation can be either complete (if the effect of the predictor is entirely removed when the mediator is added to the model) or partial (if the relationship between the predictor and the outcome is smaller, but not zero, when then the mediator is added to the model). Separate analyses were conducted to test mediation by acceptance of disability and mediation by employment status. For the tests of employment status as a mediator, a set of dichotomous dummy variables were constructed and the mediation test was performed for each.

The fourth research question was: Can acceptance of disability be predicted by hope, spiritual well-being, level of physical functioning, importance of religion, and future time orientation? To examine this research question, a multiple regression analysis was conducted with hope, spiritual well being, level of physical functioning, and future time orientation as predictors of acceptance of disability. Bivariate correlations among these three variables were also computed.

Qualitative Analyses

An adapted phenomenological study was used to help the investigator understand how the uncertainty of progressive disability affects the pursuit of personal goals and influences the life perspectives in the focus group. Two open-ended questions were added to the demographic questionnaire to elicit participants' views on psychological and behavioral manifestations of progressive disability. A three-step strategy guided the interpretations of the qualitative data. The first step was to go through the data to identify metaphors the participants used to describe their lived experiences and views. To extract

meanings, the second step focused on developing a list of tentative codes and matching them with text segments. The last step required the investigator to tally the frequency of codes and categories to note recurrent patterns and themes. The counts determined a chain of logical frameworks in which the meanings were fittingly contextualized.

CHAPTER 4

RESULTS

This study's initial purpose was to test a theoretically based multidimensional model of life satisfaction among people with progressive disabilities. Although the proposed model was influential in helping to conceptualize the myriad relations among the cognitive, physical, spiritual and psychological variables, the investigator was unable to test it due to the sample's small size. Nevertheless, many interesting and useful findings were generated through quantitative and qualitative analyses of the data set.

Quantitative Findings

Of the 228 participants who took part in the present study, 175 (76.8%) chose the online option to submit their responses on line. The remainder used paper-and-pencil packets and 53 of the 64 prospective participants who telephoned to request the packets returned them (a response rate of 82.8%). Calculation of the online participants' response rate was not possible because the website provider did not keep track of the number of hits it received. Moreover, the "consent to participate" page was programmed to deter unsuitable prospective participants. Visitors to the website would exit automatically from the online survey if they did not click the "yes" button on the consent form. Using SPSS 12.0, all data were screened for errors, outliers and skewness. Multicollinearity was checked to detect whether the regression model's independent variables were highly interrelated. Tabachnick and Fidell (2001) suggest that the correlations between the independent variables should not exceed the limit of $r = .70$. None of them appeared to violate the statistical assumptions.

Descriptive Statistics

The present study's internal consistency Cronbach's α coefficients were as follows: Acceptance of Disability Scale-Revised α = .92, Spiritual Well-Being Scale α = .93, Satisfaction With Life Scale α = .93, Hope Scale α = .83, and Future Time Orientation Scale α = .58.

Descriptive statistics for the categorical variables describing the 228 participants are shown in Table 1. Approximately two-thirds of the sample (N = 151, 66.2%) were female, and the vast majority of the respondents were Caucasian (N = 203, 89.0%). The Midwest provided the most respondents (N = 113, 49.6%), followed by the West (N = 45, 19.7%), the South (N = 35, 15.4%), and the Northeast (N = 27, 11.8%). Exactly half of the respondents were Protestant, with an additional 23.2% being Catholic. The respondents tended to report either low (N = 94, 41.2%) or average (N = 66, 28.9%) physical functioning. More than half of the respondents were married (N = 118, 51.8%), but 31.1% (N = 71) had never been married. The most common education levels were bachelor's degrees (N = 78, 34.2%) and high school diplomas (N = 70, 30.7%). The employment status of the respondents varied widely, with 23.2% (N = 53) retired, 21.5% (N = 49) employed full time, and 18.4% (N = 42) unemployed. In addition, 11.4% (N = 26) were students, 10.1% (N = 23) were homemakers, 7.9% (N = 18) were self-employed, and 7.5% (N = 17) were employed part time. Approximately twice as many respondents had neuromuscular diseases (N = 152, 66.7%) as had neurological diseases (N = 73, 32.0%).

Table 2 contains descriptive statistics for the continuous study variables. The average age of the sample was 46.44 years (SD = 13.30 years). The skewness and

kurtosis of age and years since diagnosis of disability were less than 1, indicating the scores from this sample are normally distributed. As a rule of thumb, the closer the values for skewness and kurtosis to 0, the better. Both variables age (skewness = .024, kurtosis = -.469) and years since diagnosis of disability (skewness = .839, kurtosis = -.067) appeared to meet the normality of the distribution assumption. The average rating for the importance of religion was 3.28 (*SD* = 1.48) on a scale from 1 to 5. The respondents had been aware of their disability for an average of 18.08 years (*SD* = 14.10 years). In other words, most of the participants were not new to their disabilities. The mean score for hope was 25.79 (*SD* = 3.65) out of a possible 48. People with progressive disabilities had more hope in general than did women of ages 70 and older (*M* = 22.5, *SD* = 5.4) (Westburg, 2001) and other disability types—diabetes (*M* = 24.66, *SD* = 3.02), spina bifida (*M* = 21.24, *SD* = 4.97) and cerebral palsy (*M* = 22.90, *SD* = 4.50) (Horton & Wallander, 2001). The mean score for spiritual well-being was 79.27 (*SD* = 19.03) out of a possible 120, which is much higher than the mean score of patients (*M* = 55.15, *SD* = 24.33) discharged from a rehabilitation hospital after medical recovery (Kim, Heinemann, et al., 2000). Despite the medium levels of hope and spiritual well-being, people with progressive disabilities seemed to be quite accepting of their disabilities. The average rating for acceptance of disability was 100.93 (*SD* = 16.47) out of a possible 128, which is quite comparable to the sample of women with poliomyelitis sample (*M* = 101.49, *SD* = 12.76) (Barton, 2005). The participants had an average of 30.56 (*SD* = 4.95) for future time orientation. The mean for satisfaction with life was low at 21.73 (*SD* = 7.51), compared to healthy young adults (*M* = 26.18, *SD* = 5.72) (Arrindell, Heesink, & Feij, 1999). The reliabilities of the acceptance of disability (.93), hope (.83), life

satisfaction (.85), and spiritual well being (.93) scales were all high. The reliability of the future time orientation scale was only .58, although this is consistent with existing literature on this scale.

Inferential Statistics

Research Question 1

The first research question of the current study was the following: Which demographic and background characteristics (i.e., age, sex, marital status, educational attainment, race, type of disability, employment status, level of physical functioning, and duration of knowledge of disability) are predictive of future time orientation, acceptance of disability, and life satisfaction? The categories for three of the demographic and background variables, marital status, educational attainment, and race were collapsed based on the observed frequencies. Marital status was collapsed into married, never married, and other. Educational attainment was collapsed into high school or less, associate's degree, bachelor's degree, and graduate degree. Race was collapsed into Caucasian and other. The coding for the categorical variables was as follows: sex was coded as 0 = male, 1 = female; marital status was coded into two dummy variables indicating never married and other individuals (i.e. separated and divorced individuals); education was coded into three dummy variables indicating associate's degree, bachelor's degree, and graduate degree; race was coded as 0 = Caucasian, 1 = other; type of disability was coded as 0 = neuromuscular disease, 1 = neurological; employment status was coded into six dichotomies indicating employed full time, employed part time, self-employed, homemaker, student, and unemployed

Table 3 presents the results of the regression analysis with future time orientation as the outcome variable. Overall, the model was not statistically significant, $F(17, 199) = .90, p = .581, R^2 = .07$. However, two of the predictor variables did have statistically significant individual effects. First, the type of disability was statistically significant ($\beta = .17, p = .035$). Because the coding for this variable was 0 = neuromuscular, 1 = neurological, the positive value for the β coefficient indicates that respondents with neurological disorders had higher scores on future time orientation and were more future oriented. Second, being employed full time was statistically significant ($\beta = -.19, p = .050$). This indicates that respondents who were employed full time tended to have lower scores on future time orientation. In other words, they tended to focus more on the present and less on the future.

Table 4 presents the results of the regression analysis with acceptance of disability as the outcome variable. This model was statistically significant, $F(17, 198) = 2.67, p = .001, R^2 = .19$. The R^2 value was .19, indicating that 19% of the variance in acceptance of disability was explained by the set of predictors. Four of the predictor variables were statistically significant. First, females tended to have higher scores on acceptance of disability than males ($\beta = .16, p = .029$). Second, being employed full time was associated with higher scores on acceptance of disability ($\beta = .18, p = .046$). Third, those with higher levels of physical functioning tended to have higher acceptance of disability scores ($\beta = .15, p = .029$). Fourth, those with more years since diagnosis tended to have higher scores on the acceptance of disability scale ($\beta = .21, p = .005$).

Table 5 presents the results of the regression analysis with life satisfaction as the outcome variable. The model as a whole was statistically significant, $F(17, 199) = 2.80, p$

$< .0005$, $R^2 = .19$. The R^2 value was .19, indicating that 19% of the variance in satisfaction with life was explained by the set of predictors. Five of the predictor variables were statistically significant. First, females tended to have higher life satisfaction scores ($\beta = .24$, $p = .001$). Second, never having been married was associated with lower life satisfaction scores ($\beta = -.21$, $p = .008$). Third, being separated or divorced (i.e. the "other" marital status category) was associated with lower life satisfaction scores ($\beta = -.20$, $p = .005$). Fourth, higher levels of physical functioning were associated with higher life satisfaction scores ($\beta = .14$, $p = .040$). Fifth, a larger number of years since diagnosis was associated with higher life satisfaction scores ($\beta = .15$, $p = .039$).

Research Question 2

The second research question was the following: Are future time orientation, spiritual well-being, hope, importance of religion, and acceptance of disability predictive of life satisfaction? Table 6 presents the bivariate correlations among the six variables. Life satisfaction was positive correlated with spiritual well-being ($r = .39$, $p < .0005$), hope ($r = .55$, $p < .0005$), and acceptance of disability ($r = .58$, $p < .0005$). Future time orientation was negatively correlated with hope ($r = -.18$, $p = .003$) and acceptance of disability ($r = -.15$, $p = .010$). Spiritual well being was positively correlated with hope ($r = .37$, $p < .0005$), importance of religion ($r = .43$, $p < .0005$), and acceptance of disability ($r = .34$, $p < .0005$). Finally, hope and acceptance of disability were positively correlated ($r = .62$, $p < .0005$).

Table 7 contains the results of the corresponding regression analysis. Overall, the model was statistically significant, $F(5, 221) = 32.49$, $p < .0005$, $R^2 = .42$. The R^2 value was .42, indicating that 42% of the variance in life satisfaction was explained by the set

of predictors. Three of the predictors were statistically significant. First, higher spiritual well being scores were associated with higher levels of life satisfaction, $\beta = .17$, $p = .006$. Second, higher hope scores were associated with higher levels of life satisfaction, $\beta = .28$, $p < .0005$. Third, higher acceptance of disability scores were associated with higher levels of life satisfaction, $\beta = .36$, $p < .0005$.

Research Question 3

The third research question was the following: Do acceptance of disability or employment status mediate the relationship between future time orientation and life satisfaction? The first condition of mediation is that future time orientation must be predictive of life satisfaction. This condition must be met before the test for mediation can proceed. As can be seen in Table 6, the correlation between future time orientation and life satisfaction was not statistically significant ($r = -.07$, $p = .132$). Because there is no relationship between future time orientation and life satisfaction, there is no possibility that either acceptance of disability or employment status can be a mediator variable, and therefore no further analyses were performed for the third research question.

Research Question 4

The fourth research question was: Can acceptance of disability be predicted by hope, spiritual well-being, level of physical functioning, importance of religion, and future time orientation? The bivariate correlations among these five variables are shown in Table 8. Eight of the 15 correlations in this table were statistically significant. Acceptance of disability was positively correlated with hope ($r = .62$, $p < .0005$), spiritual well being ($r = .34$, $p < .0005$), and physical functioning ($r = .21$, $p = .001$), and negatively correlated with future time orientation ($r = -.16$, $p = .009$). Hope was

positively correlated with spiritual well being ($r = .38, p < .0005$) and physical functioning ($r = .27, p < .0005$), and negatively correlated with future time orientation ($r = -.19, p = .002$). Importance of religion was positively correlated to spiritual well-being ($r = .43, p < .0005$). No other correlations were statistically significant.

The results of the regression analysis are shown in Table 9. The model was statistically significant, $F(5, 218) = 31.39, p < .0005, R^2 = .42$. The R^2 value was .42, indicating that 42% of the variance in self-acceptance of disability was explained by the set of predictors. Three of the predictors were statistically significant. First, higher scores on the hope scale were associated with higher scores on acceptance of disability, $\beta = .53$, $p < .0005$. Second, higher scores on the spiritual well being scale were associated with higher scores on acceptance of disability, $\beta = .20, p = .001$. Third, higher scores on the importance of religion were associated with lower scores on acceptance of disability, $\beta = -.16, p = .008$.

Table 1

Descriptive Statistics for Categorical Study Variables

	Frequency	Percentage
Gender		
Male	77	33.8
Female	151	66.2
Race		
Caucasian	203	89.0
African American	10	4.4
Hispanic	3	1.3
Asian or Pacific Islander	8	3.5
American Indian or Alaskan Native	2	.9
Multiracial	2	.9
Geographic Location		
Northeast	27	11.8
Midwest	113	49.6
South	35	15.4
West	45	19.7
Other	7	3.1
Missing	1	.4

	Frequency	Percentage
Religion		
Buddhism	2	.9
Catholic	53	23.2
Judaism	10	4.4
Islam	3	1.3
Protestant	114	50.0
Other	45	19.7
Missing	1	.4
Level of Physical Functioning		
Very low	27	11.8
Low	94	41.2
Average	66	28.9
High	27	11.8
Very High	11	4.8
Missing	3	1.3
Marital Status		
Never married	71	31.1
Married	118	51.8
Divorced	34	14.9
Widowed	5	2.2

	Frequency	Percentage
Level of Education		
Less than high school	2	.9
High school	70	30.7
Associate's degree	34	14.9
Bachelor's degree	78	34.2
Graduate degree	43	18.9
Missing	1	.4
Employment Status		
Employed full-time (40 hrs)	49	21.5
Employed part-time (less than 40 hrs)	17	7.5
Self-employed	18	7.9
Retired	53	23.2
Homemaker	23	10.1
Student	26	11.4
Unemployed	42	18.4
Type of Disability		
Neuromuscular disease	152	66.7
Neurological disease	73	32.0
Missing	3	1.3

Table 2

Descriptive Statistics for Continuous Study Variables

	Mean	*SD*	Reliability
Age	46.44	13.30	-
Importance of Religion	3.28	1.48	-
Years Since Diagnosis	18.08	14.10	-
Acceptance of Disability Scale	100.93	16.47	.93
Hope Scale	25.79	3.65	.83
Future Time Orientation Scale	30.56	4.95	.58
Satisfaction with Life Scale	21.73	7.51	.85
Spiritual Well-Being Scale	79.27	19.03	.93

Table 3

Results of Regression Analysis with Demographics and Background Variables Predicting Future Time Orientation

	B	SE_B	β	*t*	*p*
Age	-.02	.03	-.06	-.72	.472
Gender	-.67	.81	-.06	-.83	.409
Never married	1.09	.89	.10	1.23	.219
Other marital status	.63	1.02	.05	.62	.534
Associate's degree	-.92	1.11	-.06	-.82	.412
Bachelor's degree	.02	.86	.00	.03	.978
Graduate degree	-1.24	1.01	-.10	-1.23	.221
Race	.05	1.19	.00	.04	.967
Type of Disability	1.81	.85	.17	2.12	.035
Employed full time	-2.27	1.15	-.19	-1.97	.050
Employed part time	-2.94	1.52	-.16	-1.93	.055
Self employed	-1.36	1.43	-.08	-.95	.342
Homemaker	-1.12	1.43	-.07	-.78	.437
Student	-2.45	1.44	-.16	-1.71	.090
Unemployed	-1.22	1.16	-.09	-1.04	.298
Level of Physical Functioning	.29	.36	.06	.79	.430
Years Since Diagnosis	.01	.03	.02	.31	.753

Note. $F(17, 199) = .90$, $p = .581$, $R^2 = .07$

Table 4

Results of Regression Analysis with Demographics and Background Variables Predicting Acceptance of Disability

	B	SE_B	β	*t*	*p*
Age	.14	.10	.11	1.34	.182
Gender	5.62	2.56	.16	2.20	.029
Never married	-3.12	2.79	-.09	-1.12	.264
Other marital status	-5.33	3.19	-.12	-1.67	.096
Associate's degree	.99	3.50	.02	.28	.777
Bachelor's degree	3.68	2.71	.11	1.36	.176
Graduate degree	4.67	3.18	.11	1.47	.144
Race	-3.10	3.74	-.06	-.83	.408
Type of Disability	.43	2.68	.01	.16	.872
Employed full time	7.26	3.62	.18	2.01	.046
Employed part time	.64	4.78	.01	.13	.893
Self employed	5.90	4.48	.10	1.32	.190
Homemaker	-1.30	4.50	-.02	-.29	.774
Student	6.28	4.52	.12	1.39	.166
Unemployed	-1.69	3.66	-.04	-.46	.644
Level of Physical Functioning	2.52	1.14	.15	2.21	.029
Years Since Diagnosis	.24	.08	.21	2.82	.005

Note. $F(17, 198) = 2.67, p = .001, R^2 = .19$

Table 5

Results of Regression Analysis with Demographics and Background Variables Predicting Life Satisfaction

	B	SE_B	β	*t*	*p*
Age	-.04	.05	-.07	-.87	.387
Gender	3.77	1.16	.24	3.25	.001
Never married	-3.36	1.26	-.21	-2.66	.008
Other marital status	-4.09	1.44	-.20	-2.83	.005
Associate's degree	1.71	1.58	.08	1.08	.281
Bachelor's degree	1.26	1.23	.08	1.03	.306
Graduate degree	.85	1.44	.04	.59	.554
Race	1.36	1.69	.05	.80	.423
Type of Disability	-.73	1.21	-.05	-.61	.546
Employed full time	.67	1.63	.04	.41	.680
Employed part time	-.91	2.16	-.03	-.42	.674
Self employed	1.73	2.03	.06	.85	.396
Homemaker	-1.04	2.04	-.04	-.51	.612
Student	-.41	2.05	-.02	-.20	.843
Unemployed	-3.20	1.66	-.16	-1.93	.055
Level of Physical Functioning	1.07	.52	.14	2.07	.040
Years Since Diagnosis	.08	.04	.15	2.07	.039

Note. $F(17, 199) = 2.80, p < .0005, R^2 = .19$

Table 6

Correlations among Future Time Orientation, Spiritual Well Being, Hope, Importance of Religion, Acceptance of Disability, and Life Satisfaction

	Future Time Orientation	Spiritual Well Being	Hope	Importance of Religion	Acceptance of Disability	Life Satisfaction
Future Time Orientation	1.00					
Spiritual Well Being	-.07	1.00				
Hope	.39*	-.10	1.00			
Importance of Religion	.55*	-.18*	.37*	1.00		
Acceptance of Disability	.06	.03	.43*	.07	1.00	
Life Satisfaction	.58*	-.15*	.34*	.62*	-.02	1.00

*$p < .05$

Table 7

Results of Regression Analysis with Future Time Orientation, Spiritual Well Being, Hope, Importance of Religion, and Acceptance of Disability Predicting Life Satisfaction

	B	SE_B	β	*t*	*p*
Future Time Orientation	.08	.08	.05	.95	.343
Spiritual Well Being	.07	.03	.17	2.76	.006
Hope	.57	.14	.28	4.14	<.0005
Importance of Religion	-.12	.29	-.02	-.39	.696
Acceptance of Disability	.16	.03	.36	5.39	<.0005

Note. $F(5, 221) = 32.49, p < .0005, R^2 = .42$

Table 8

Correlations among Hope, Spiritual Well Being, Physical Functioning, Future Time Orientation, Importance of Religion, and Acceptance of Disability

	Acceptance of Disability	Hope	Spiritual Well-Being	Physical Functioning	Future Time Orientation	Importance of Religion
Acceptance of Disability	1.00					
Hope	.62*	1.00				
Spiritual Well-Being	.34*	.38*	1.00			
Physical Functioning	.21*	.27*	.06	1.00		
Future Time Orientation	-.16*	-.19*	-.10	.05	1.00	
Importance of Religion	-.03*	.07	.43*	.09	.03	1.00

*$p < .05$

Table 9

Results of Regression Analysis with Hope, Spiritual Well Being, Physical Functioning, Importance of Religion, and Future Time Orientation Predicting Acceptance of Disability

	B	SE_B	β	*t*	*p*
Hope	2.37	.27	.53	8.82	.000
Spiritual Well Being	.17	.05	.20	3.22	.001
Physical Functioning	1.18	.89	.07	1.32	.187
Future Time Orientation	-.13	.18	-.04	-.71	.479
Importance of Religion	-1.73	.65	-.16	-2.70	.008

Note. $F(5, 218) = 31.39$, $p < .0005$, $R^2 = .42$

Qualitative Findings

In addition to the instrument, this survey also contained two open-ended questions to allow participants to express their satisfaction with life. The raw data of qualitative inquiry provides the researcher with the opportunity to capture more precisely the inner worlds of survey respondents in a way that might not be quantifiable with standardized questionnaire items on quantitative-based scales.

The investigator used an adapted phenomenological study to explore the central issue of essential influences on life perspective of uncertainty by progressive disabilities. This type of qualitative inquiry aims to extract the meaning of several research participants' individual lived experiences regarding preconceived ideas about the phenomenon (Creswell, 1998). The data were collected from the written answers to the two open-ended questions furnished by the subjects. The research outcome of a sound qualitative study is contingent upon the selection of fitting philosophical and theoretical frameworks. Impartial interpretations of subjective human experiences require the investigator to examine and understand how people with disabilities react to the prospect of uncertainties that are inherent in their future. Purposeful sampling strategies, such as finding prospective participants who have similar disabilities, permit a phenomenological study to establish criteria necessary to generalize patterns of psychological and behavioral manifestations ubiquitous only in the target population.

Social scientists espouse a three-step analytic strategy being considered in the qualitative data dissemination process (Huberman & Miles, 1994; Taylor & Bogdan, 1998; Wolcott, 1994). The initial step of the procedure is to read through all collected information to form a general sense of the data as a whole. Special attention is paid to

identifying the metaphors used by research participants to depict their worldviews and experiences. Further reduction of the text data is made possible by creating a list of tentative codes and categories. In essence, the second step functions as a mechanism to extract meanings systematically by matching a code with a text segment. Lastly, the investigator tallies the frequency of codes and categories to note patterns and themes that seem to appear recurrently. The counts can later be used to determine a chain of logical frameworks in which the meanings are fittingly contextualized.

Participants were asked to answer two open-ended questions to tap into their feelings and beliefs on how disability might have altered the course of their lives. The two questions were the following:

1. In what ways does your disability affect the pursuit of personal goals such as employment and romantic relationships?
2. How does the uncertainty of your disability influence life perspectives?

To extract meaningful themes, a phenomenological existential approach was used to cluster significant statements.

Of the 228 research participants, 107 chose to respond to the qualitative section of the present study, which number consisted of 83 (77.6%) online participants and 24 (22.4%) mail survey participants. Moreover, there were 38 (35.5%) male respondents and 69 (64.5%) female respondents. In term of their disability types, 81 (75.7%) had a neuromuscular disorder and 26 (24.3%) had a neurological disorder. The demographic composition breakdown was 92 (86%) White, 3 (2.8%) Black, 1 (0.9%) Asian, and 11 (10.3%) Other. The descriptive statistics for the categorical variables in the qualitative sample are roughly proportional to the overall sample.

Table 10

Sample Coding for Romantic Relationships, With Quotations From Participants

	Significant Statements: Romantic Relationships
Participant 0016	"Hesitancy in establishing relationships - not everyone is willing to put up with the idiosyncracies of my disease."
Participant 0019	"It's harder to have a relationship with somebody and be in a wheelchair."
Participant 0028	"Romantic relationships are a moot point, as no one really has time or patience for a long term relationship with someone who is not physically able."
Participant 0069	"I felt romance was never to be and I doubted anyone would want to deal with all the assistance I need in order to deal with the day."
Participant 0098	"As far as romantic relationships it made me hesitant as I was unsure how things would or wouldn't work after my first exacerbation. Things worked out fine."
Participant 0126	"Unable to find someone who would want a romantic relationship because of my appearance."
Participant 0136	"Romantic relationships have been frustrating. I still haven't found someone who can handle my disability. The last girl I went out with told me, 'it is too much'."
Participant 0149	"My romantic relationship is hard due to me getting weaker."
Participant 0210	"I am married, but my disability has caused a strain on our relationship as it was built partially on our love of outdoor and forest activities, which I can no longer do."

Table 11

Sample Coding for Becoming a Better/More Accepting Person, With Quotations From Participants

	Significant Statements: Becoming a Better/More Accepting Person
Participant 0020	"I have been treated badly because of my physical disability, and that has showed me how to treat others."
Participant 0039	"Having this disabling disorder has been the best thing that has ever happened to me. I have learned to love each minute knowing it could be my last."
Participant 0045	"...my disability is the reason for my having a great perspective on life."
Participant 0085	"I see many people in the world with pain (physical & emotional), so my Dystonia has opened my eyes even more to helping other people,

	to being more patient with myself and with other people, to not being so hard on myself and on other people, and to living 'in-the-moment'."

Table 12

Sample Coding for Not Wanting Children, With Quotations From Participants

	Significant Statements: Not Wanting Children
Participant 0026	"I do not plan to have children because of the disability."
Participant 0107	"I think about the possibility of one of my children or grandchildren inheriting this disability."
Participant 0113	"My husband and I decided not to have children, in part, because of the uncertainty."
Participant 0155	"We want to be marriend and have a family as well but I feel so scared to pass on my disabil[i]ty to a future child."
Participant 0168	"It has impacted my life...physically...and emotionally because it is genetic and I have two children." "I also have a great deal of grief over the idea that my children have a 50% chance of also having cmt and that their children may have it."
Participant 0196	"I have concerns about how pregnancy would affect my mobility and use of mobility devices."

Table 13

Sample Coding for Burden, With Quotations From Participants

	Significant Statements: Becoming a Burden
Participant 0026	"I resisted romantic relationships because I did not wish to burden another with the disability."
Participant 0047	"i have a terminal illness, and therefore can not seek out a romantic relationship with anyone as it would be a burden on them."
Participant 0066	"You just are sorry that your spouse...is touched with the difficulty of your disease every day."
Participant 0097	"I was (and still am in a way) afraid of becoming dependent upon others, unable to function, unable to support myself financially. I fear losing the quality of my life."

Table 14

Sample Coding for Employment Issues, With Quotations From Participants

Significant Statements: Employment Issues	
Participant 0033	"I BECAME VENT DEPENDAeNT AND HAD TO QUIT A JOB THAT I LOVED."
Participant 0040	"I have to plan for an early exit from the work force..."
Participant 0060	"I have not been sucessful with a part-time job either, due to fatrigue, weakness, stamina, etc associate with CMT."
Participant 0066	"As my disease progressed and I retired."
Participant 0085	"I was forced to resign from a very good job as an editor in educational publishing (and I believe it had a lot to do with my disease)."
Participant 0110	"I stopped working...when I could now longer sit at the computer for more than an hour without symptoms."
Participant 0122	"...employment in the traditional sense(go to an office, work all day) impossible for me."
Participant 0130	"I worked full time until I was 40 yrs. old."
Participant 0144	"I don't think I can be employed due to my fatigue."
Participant 0170	"My progressive disease greatly affected my employment history. The job hunt in itself was a major challenge."
Participant 0205	"...it made choosing a career path very difficult."
Participant 0210	"I am unemployable due to inability to stand and walk for long periods of time and extreme lethargy."

Table 15

Sample Coding for Caregiving, With Quotations From Participants

Significant Statements: Caregivers	
Participant 0027	"...my husband is my sole caregiver..."
Participant 0041	"I ponder my future and worry about what will happen if I don't have family to take care of me."
Participant 0052	"My late husband was always willing to provide assistance."
Participant 0078	"My husband has stood by me through all the trouble...and we still have a loving and committed relationship."
Participant 0081	"I have been blessed with a very wonderful husband."
Participant 0087	"The only thing is I wonder what will happen when I...cannot take care of myself."
Participant 0148	"How will visit them [children and grandchildren] someday if my husband can't take me?"

Table 16

Sample Coding for Transportation Issues, With Quotations From Participants

Significant Statements: Transportation Issues	
Participant 0019	"It's hard to get transportation."
Participant 0027	"...availability of transportation is completely tied to his schedule. Because of this, I spend most days alone at home..."
Participant 0061	"...limited in employment because of transportation."
Participant 0115	"We can't afford a van for social security to adapt for me so I still can't drive places."
Participant 0148	"Transportation seems to be the hardest thing to deal with."

Table 17

Sample Coding for Planning for the Future, With Quotations From Participants

Significant Statements: Planning for the Future	
Participant 0027	"My disability affects all areas of my life...[and] does not allow me to plan too far in the future."
Participant 0036	"I am unable to plan ahead for much of anything, except possibly long-term care and/or my death."
Participant 0038	"Basically...I cannot plan for the future."
Participant 0045	"...the future of my disability is uncertain..."
Participant 0050	"I try not to dwell on what's coming for me..."
Participant 0061	"I'm uncertain about having a family because I don't know how I will handle it."
Participant 0080	"One cannot make long-term future plans because it is impossible to know the status of one's health at any particular time in the future."
Participant 0140	"I don't know what my future holds so I am hesitant to plan ahead."

Table 18

Sample Coding for Diminished Sexual Activities, With Quotations From Participants

Significant Statements: Diminished Sexual Activities	
Participant 0029	"I couldn't care less."
Participant 0058	"...we stopped having much some ten years ago..."
Participant 0073	"Due to medications they have limited my relationship with my wife."
Participant 0112	"...I've lost interest in sex..."
Participant 0130	"...the sex life has slowed somewhat..."

Table 19

Sample Coding for Self-Esteem and Confidence, With Quotation From Participants

	Significant Statements: Self-Esteem and Confidence
Participant 0016	"I think it has had a big influence on my shyness and sense of self."
Participant 0066	"As my disease progressed...my self esteem, confidence and self consciousness are a management issue."
Participant 0115	"I think my disability has given me doubts about myself."
Participant 0126	"Afraid to approach...women because of definite rejection."
Participant 0141	"I sometimes question my self-worth and my self-esteem suffers greatly."

Table 20

Sample Coding for Modified Goals, With Quotations From Participants

	Significant Statements: Modified Goals
Participant 0037	"Over the years I've had to change my personal goals as my disease progressed."
Participant 0045	"...I had to be conscious of the career I pursued because of physical limitations (I use a wheelchair)."
Participant 0046	"Employment options are more limited as I tire easily."
Participant 0050	"It limits the type of work I can do because of weakness...work areas that are not big enough for me to work in them with a wheelchair."
Participant 0065	"It has obliged me to choose a career that does not involve any sort of physical exertion..."
Participant 0069	"I have never gone back to get my Teaching Certificate because of the limitations I face..."
Participant 0092	"I have had to modify various goals in my life. In making career choices, I had to give up ideas about more physically challenging careers."
Participant 0108	"Disability affected my job choices in order to exclude a lot of walking."
Participant 0173	"My biggest regret is my inability to travel via an airplane. Too much medical equipment needed to make trips."
Participant 0195	"Dreams become altered accordingly and activities have been systematically eliminated."

Table 21

Sample Coding for Inability to Sustain Employment, With Quotations From Participants

Significant Statements: Inability to Sustain Employment	
Participant 0074	"I am not employed as I can not get help going to the bathroom at a job. The aides provided by my state are not allowed to help you at a job or at school."
Participant 0099	"I was an RN working in surgery and now I am unemployed due to my disability."
Participant 0112	"MS ruined my career as a statistician... I do not have the energy or clarity of mind for that anymore."
Participant 0141	"I am unable to work due to my MS..."
Participant 0149	"With my disability I am not able to work due to having trouble sitting, standing, lifting, walking-what little I do."

Table 22

Sample Coding for Being an Undesirable Intimate Partner, With Quotations From Participants

Significant Statements: Being an Undesirable Intimate Partner	
Participant 0058	"...now my body is so deformed I can understand that I no longer am a viable partner."
Participant 0067	"...I found that many men shied away from becoming romantically involved with me."
Participant 0125	"it makes me less attractive to women, it has inhibited my seeking romantic relationships.
Participant 0201	"I find myself avoiding romantic relationships because I feel I am missleading the individual."
Participant 0214	"It has also made me more accepting of those who may not find me attractive because of my disability, since I myself still struggle with this."
Participant 0234	"...it does seem like I will never be able to find anyone again that finds me attractive."

Table 23

Sample Coding for Apprehensive of Future, With Quotations From Participants

Significant Statements: Apprehensive of Future	
Participant 0102	"YOU CAN NOT PLAN FROM DAY TO DAY."
Participant 0140	"I don't know what my future holds so I am hesitant to plan ahead."
Participant 0141	"It is very scary. I have no clue what tomorrow will bring, therefore it

	is hard to plan ahead for much."
Participant 0149	"I have found myself to be getting weaker and what the future holds I am not sure of and needless to say I am scared."
Participant 0185	"I wonder how long I'll want to live in a body that is uncreasingly unable to perform basic functions..."
Participant 0211	"...i dont know how long i'll live."

Table 24

Sample Coding for Disability and a Concept of Guiding Deity, With Quotation From Participants

Significant Statements: Disability and a Concept of Guiding Deity	
Participant 0097	"I fear losing the quality of my life. I do, however, have a very strong Christian faith and believe that things happen for a reason."
Participant 0120	"God is with me helping me through this lifetime. "
Participant 0124	"...much of the uncertainty is mitigated by my faith. I cannot emphasize enough the importance of believing in a Savior and a God who is interested in your life and has a plan for your life that is made evident on a consistent basis."
Participant 0148	"I know that God is taking care of me.

Table 25

Sample Coding for Feelings of Loss, Sadness and Turmoil, With Quotation From Participants

Significant Statements: Feelings of Loss, Sadness and Turmoil	
Participant 0168	"I also have a great deal of grief over the idea that my children have a 50% chance of also having cmt and that their children may have it."
Participant 0220	"I am depressed about the furture and unsure what will be next."
Participant 0234	"I try not to think about death and when it will come, but sometimes it is hard not to."

Table 26

Percentage and Frequency of the Sampling Codes

Sampling Codes	Frequency	Percent of Respondents Citing This Concern
Forming/maintaining romantic relationships	26	24.30
Becoming a better person	7	6.54
Concern about sources of caregiving	4	3.73
Passing defective genes to children	9	8.41
Not wanting be a burden	6	5.61
Not wanting to become self-absorbed	1	0.01
Involuntary early retirement	23	21.50
Spouse or partner as a caregiver	7	6.54
Lack of suitable transportation	10	9.35
Not planning too far in the future	10	9.35
Loss of privacy	1	0.01
Loss of hope	3	2.80
Lack of assertiveness; low self-esteem	8	7.48
Changing personal or career goals	18	16.82
Inability to continue working	13	12.15
Feeling less desirable and attractive	11	10.28
Contemplation of suicide	3	2.80
Uncertain about the future	15	14.02

Sampling Codes	Frequency	Percent of Respondents Citing This Concern
Here-and-now mentality; doing things while one still can	7	6.54
Abandonment by spouse/partner	5	4.67
God's plans	8	7.48
Avoidance of human contact	2	1.87
No faith in the Americans with Disabilities Act	3	2.80
Suffering from emotional turmoil & sadness	8	7.48

Emerging Themes

Although there were noteworthy individual divergences in the lived experiences of 107 participants with progressive disabilities, a collective set of experiences characterizing their methods of coping with uncertainties emerged after the investigator had extrapolated inferences from a list of non-repetitive and non-overlapping statements.

Theme 1: Involuntary Early Retirement

Twenty-one point five percent of the study participants (21.5%) stated that they chose to resign from their jobs before the mandatory retirement age for several reasons. An oft-cited reason was that they had little faith in any legal protection of employment rights the Americans with Disabilities Act might offer. Their pessimistic views mirror the trend of unfavorable rulings in recent years by the U.S. Supreme Court, which have favored corporations and business entities. Moreover, the study participants had neither

the knowledge nor financial resources to navigate through the labyrinth of the legal system and challenge their employers. Most of them found it was far easier simply to receive cash benefits from the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) programs than demand that employers agree to the provisions for reasonable accommodations.

Some female respondents with multiple sclerosis felt they were being unfairly accused of malingering because their managers and colleagues did not understand that two individuals with the same disability might not have comparable levels of stamina and strength in performing similar tasks. Because the presence of a personal care attendant at the workplace is not always feasible, people with low levels of physical functioning may not have their basic needs, such as assistance with toileting and feeding, met. Even in cases in which employers were supportive and understanding, some participants with neuromuscular diseases, knowing that they would no longer be able to keep up with their past work productivity, decided to leave their companies on amicable terms before they overstayed their welcomes.

Theme 2: Hindrance to Establishing and Maintaining Romantic and Intimate Relationships

Finding the right person to spend the rest of one's life with is never an easy task. In a pattern consistent with the findings of previous studies (Chen, Brodwin, Cardoso, & Chan, 2002), the occurrence of a progressive disability presented a major roadblock for the participants in the focus group to fulfill goals of relationships and marriage. More than 24% voiced their frustration and despair with forming and maintaining meaningful romantic and intimate relationships with the opposite sex. Fear of rejection probably

explains their hesitancy in becoming romantically involved with other persons. Study participants who were fortunate to be in close relationships felt that equal partnerships were hard to attain because in order to please their partners and keep them in the relationships compromises were made indiscreetly at times.

According to several female respondents, spousal and partner abandonment appeared to coincide with the extent of physical deterioration inflicted by a progressive disability. A marriage or relationship that was built on sheer physical attraction or common interest in, for example, outdoor activities, is especially susceptible to a breakup. Adjustment and adaptation to a new disability involves not only the individual who has a progressive disability but also his or her spouse or partner. The dynamics of a marital or similar relationship shift from egalitarian to subordinate when the role of caregiver is thrust upon the unaffected individual.

Theme 3: Changing Personal and Career Goals

Some of the participants (16.8%) in the study pointed out that the unpredictable course of neuromuscular and neurological disabilities led to leveled expectations and cause them to settle for more attainable personal and career goals. They found themselves compelled to come to terms with their own disabilities and to accept what they could and could not do. For example, flaring up of muscle weakness and loss of motor coordination make jobs that demand high levels of physical exertion, such as those of deliveryman or farmhand, unsuitable choices. Ignorance about rare medical conditions deters prospective employers from hiring job seekers who have progressive disabilities. Some respondents were willing to put up with stressful and unsatisfying jobs because they could not live without the medical insurance coverage provided by their employers. Furthermore, they

considered it too risky to switch jobs given their declining physical conditions and the exodus of many types of jobs overseas.

Theme 4: Fear of Uncertainties

Knowing that one will be taken care of as one ages provides the psychological security to reduce stressors. For many people with progressive disabilities, however, the only known element an uncertain future holds is the inevitable deterioration of physical functioning and degeneration of cognitive modus operandi. Afflicted individuals often wonder where the help will come from when they become incapable of performing the activities of daily life. These legitimate worries have firm grips on the psyches, especially for those who do not have spouses and children on whom to rely. After the initial phase of shock, many newly diagnosed individuals delve into books and web resources to learn more about their disabilities. Fear of uncertainties grows more terrifying when they understand the prognosis for the loss of independence.

Theme 5: Feeling Less Desirable and Attractive

The aesthetic standards for the body projected by the mass media have tremendous impact on personal self-esteem. People with disabilities who do not meet the perceived beauty criteria may encounter rejections in the arena of dating and relationships. Poor body image induces not just a low sense of self-worth but also depression. Many people with disabilities lack the know-how to initiate friendships with other persons within acceptable boundaries, because they never acquired or fully developed appropriate dating etiquettes as youngsters. What is missing in them is the confidence that allows for the dynamics of interaction. The challenges facing people whose onset of disability takes place after they are married or in long-term relationships

include spousal ambivalence toward the new disability identity. Although varied types and degrees of disharmony precede divorce and separation, dissatisfaction with a spouse's altered physical appearance and reduced energy level are often cited as the straw that breaks the camel's back.

Theme 6: Lack of Accessible Transportation

Americans love the freedom and independence of roaming from place to place at their own will. The car culture thrives on the premise that an individual has total control over when and where he or she desires to go. However, this may not always be the case for people with disabilities. The lack of accessible transportation severely limits participants from entering the workforce and from integrating into their communities socially. A handful of the respondents faulted worsening eye-hand coordination, gradual muscle weakness and constant fatigue as the reasons for their eventual relinquishment of driving privileges.

Punctuality is a highly valued work ethic expected of every employee regardless of disability status, which makes keeping a job more difficult if people have to miss work or show up at work late due to transportation problems. This predicament is magnified in rural communities where it is cost prohibitive for local governments to provide door-to-door paratransit services for a small number of riders with disabilities spread out over a vast geographical region. Going out on dates often proves to be an insurmountable obstacle for those respondents who rely on public transportation or rides from family members and friends. Consequently, social lives of people with disabilities are gravely circumvented because reliable, affordable, and accessible transportation is hard to come by.

Theme 7: Here-and-Now Mentality

Short future time orientation is clearly evident among people with neuromuscular and neurological diseases. With no medical breakthrough for their diseases available in the foreseeable future, the study participants' here-and-now mentality seemed to be a frequently adapted coping mechanism that forces them to live an accelerated frame of lifespan. Knowing that time is not on their side, people with progressive disabilities tend to prioritize things they want to accomplish in anticipation of the eventual loss of physical functioning. Many choose to travel the world, to complete college education, to visit family members and friends, to develop new hobbies, etc. The prospect of dying convinces some of them to engage in financially irresponsible lifestyles, as they do not see the need to save money for emergency use or retirement. They would rather spend their money on themselves than leave it to their next-of-kin or the Internal Revenue Service.

Theme 8: Passing on Hereditary Diseases

Children born to parents with neuromuscular and neurological disabilities are at a great risk of developing the same diseases. With rare exceptions, the severity of hereditary disability is more pronounced in successive generations of a lineage. A thorny question often asked of people with these disabilities is whether it is ethically and morally right to bring a child into the world knowing the kind of adversity he or she will endure. Some parents express enormous grief and sorrow that their children will never be able to play sports and to function independently. The bickering between medical ethicists and theologians over who has the right to live once a disability has incapacitated completely seems hollow because the lives of individuals living with progressive disabilities are

changed irrevocably. The quality of life for a child with a disability is bound to be different from that of a child without a disability, no matter how much parents want to believe the children's lives are the same. On the other hand, by allowing eugenics to determine who is fit to live, the world in effect condones a systemic extermination of "undesirable" humans as carried out by the Nazis and the Spartans. Scientists did not discover the gene that is responsible for causing muscle atrophy until recently. This lack of knowledge and information about genetically based diseases strikes at the core of affected parents' hearts as they look at their own offspring and wonder if they would have made the same decision to conceive children if they had known that they were to be extremely susceptible to devastating medical conditions.

CHAPTER FIVE

DISCUSSION

The current study was an attempt to deduce empirical evidence on life satisfaction in people with neuromuscular and neurological diseases by investigating the relationships among self-acceptance of disability, spiritual well-being, future time orientation, and hope using multiple regression methods and qualitative procedures.

Self-Acceptance of Disability

Employment status, sex, level of physical functioning, and years since diagnosis were found to be significant predictors of self-acceptance of disability. The mean scores were higher for those participants who held full-time employment. The vanishing of a highly stratified caste system of the medieval era has led to redefinition of social status by occupation of choice and its potential earning in the contemporary time. Employment provides not only a financial security net; it also allows persons with disabilities to make inroads into mainstream society. Evidence has revealed a strong correlation between self-acceptance of disability and community integration (Snead & Davis, 2002). The identity of a person, with or without a disability, is chiefly superimposed and defined by the type of work he or she performs.

This study's data support a relationship between sex and self-acceptance of disability. Rigid societal expectations of gender roles that confirm men are less accepting of their own disabilities than women. Disability connotes imperfection and incompleteness, which evokes the image of emasculated manhood and feeble masculinity. Once men with visible and significant disabilities realize they fall short of

the expected norms, feelings of inadequacy, unattractiveness and shame are internalized into an inferiority complex. Moreover, the female fertility instinct further precludes men with disabilities from the mate selection process. On the contrary, women in most cultures are not subjected to the same high expectations. Because women tend to be more religious (Dickie, Ajega, Kobylak, & Nixon, 2006), they can come to terms with their disabilities knowing adversity and hardship are parts of God's grand plans.

Contradictory to the conclusion of Attawong and Kovindha (2005), time since onset of disability and levels of physical functioning have considerable effects on self-acceptance of disability. Outright rejection of a disability by people with progressive disabilities seems to wane noticeably, coinciding with the number of years since diagnosis. Harrison and her colleagues (2004) speculate that the social and cultural implications of aging mitigate the demand for being a strong and independent individual. In other words, as able-bodied persons enter their golden years, they are no longer asked or expected to play the roles of provider, protector, and dominator. Subsequently, the confluences of lifestyles between the disabled and the elderly populations help lighten the stigma and make acceptance of disability easier. Another possible explanation for the divergence in opinion on acceptance of disability is that people with progressive disabilities have a better understanding of how their bodies work. They learn new ways to compensate and adapt to the physiological dysfunctions that may otherwise aggravate fatigue and injuries. The perceived rising levels of physical functioning might be in fact resultant of more efficient use of existing abilities and better conservation of energies.

The current investigation indicates that high hope correlates with high acceptance of disability. Acceptance of disability does not mean one has given up hope on being

restored to his or her premorbid health status. On the contrary, high hope works as a coping mechanism to fend off psychological distress and anguish. Recognizing the futility of attempting to undo a disability, however agonizing, is the beginning of a long sequence of detaching the old identity and creating a new self-image that resonates with the post-disability psyche. It comes as no surprise that in this study people who are more accepting of their own disabilities also have better life satisfaction. Increased self-esteem is instrumental in helping how a person lives with his or her disability. Rejection of a disabled body is responsible for the high levels of depression experienced among people who have low body esteem (Taleporos & McCabe, 2002).

It is worthwhile to note the inverse relationship between acceptance of disability and the importance of religion to self. The puzzling finding that people with strong religious convictions are less accepting of their own disabilities is difficult to explain. The hypothesis that people who have strong faith in God, in spite of the presence of a disability, would have an easier time accepting a life-altering happenstance as they look forward to living a suffering-free eternal life was not validated. To ask why God allows tragedy to befall innocent people is a blasphemy, offending firmly held religious beliefs. Humankind sees judging God's action as a direct challenge to the biblical teaching of complete obedience and submission. Therefore, a pious person should reject the disability and not question God's motive. Gourgey (1994) states that faith, not healing and miracles, is the true content of Jesus' teaching. Divine use of the trials of life forces the afflicted individuals to reinterpret the meanings of suffering. Cognitive dissonance is hence created when the perception of incompatibility between the actual disability and the rhetorical ordeal becomes too stunning. The fact that the current study shows that

people with high spiritual well-being are more accepting of disability refutes the belief that spiritual well-being and importance of religion mean the same thing to people with progressive disabilities. As the levels of spiritual well-being increased, problems pertinent to living with a chronic illness appeared to decrease significantly (Landis, 1996).

Satisfaction with Life

Results of the current study fail to support employment status as a significant contributor to satisfaction with life among people with progressive disabilities. Contrary to an Australian study of people with intellectual disability who were placed on the open competitive market (Eggleton, Robertson, Ryan, & Kober, 1999), being able to hold down a job does not necessarily translate into personal fulfillment and contentment for people with progressive disabilities. Although more than half of the research participants have earned at least a bachelor's or advanced degree, the startling high unemployment rates among them reflect a rather bleak yet accurate employment outlook. Moreover, the issues of being passed over for promotion and continuous underemployment can adversely afflict their mental health. What frustrates employees with chronic illnesses and disabilities even more is their inability to quit an unsatisfying job that offers health insurance coverage.

Life satisfaction is also influenced by martial status according to the present study. Compared with the married, never having been married and divorced people indicated lower satisfaction with life. For many people with disabilities, singlehood is not always a consciously chosen status. Desolation, isolation and a general lack of social support engender feelings of loneliness. One of the benefits that marriage brings is

emotional support. The never married are less likely than the married or divorced to have a confidant as the frequency of interpersonal interaction outside of the social realm decreases substantially in later adulthood (Barrett, 1999).

Contrary to expectations that men with disabilities have a better quality of life (Riedinger, Dracsup, Brecht, et al. 2001), this study implies that women with disabilities seem to be happier. The rise of the human rights movement in recent decades, particularly for women, the minority and the disabled, has changed the landscape of the power structure in American society. Perhaps women are more satisfied than men with the progresses made in education, careers, intimate relationships and social status. By nature women are also more cooperative, collaborative and gregarious (Catipovic-Veselica, Ilakovac, Durjancek, Amidzc, et al., 1995). On the other hand, the pressure to stay on top of the game, driven by unhealthy competitiveness and territorial mentality, might cause men with or without disabilities alike to feel less satisfied with their lives.

Duration after disability correlating positively with life satisfaction is somewhat perplexing to explicate. Life satisfaction is subjective and may change in different contexts and times. No one is more aware of any functional changes in his or her body than persons with disabilities themselves. They are adroit in adapting to and utilizing their remaining physical capabilities to the fullest extent. Rehabilitation theories posit that adaptation to a disability is an ongoing instead of a static learning process. As the intensity of initial feelings of anger, confusion, and embarrassment subsides over the years, disability is then infused into the overall self-identity. Disability becomes part of but not the only defining trait of that individual. Life satisfaction in people with disabilities will remain low if they fail to move forward with their lives. To pursue more

achievable goals they may alter their original ones. This sense of accomplishment feeds off self-worthiness, which in turn greatly enhances the perceived quality of life.

The finding of this study indicates that participants with high hope reported enjoying high life satisfaction. Earlier research has documented similar results among people with spinal cord injuries (Elliott, Witty, Herrick, & Hoffman, 1991). It is a cliché to say that life without hope is meaningless. Hope symbolizes the light at the end of the tunnel to many individuals who have been scarred physically and emotionally following the occurrence of a disability. Realizing that hope offers a vision of how one could transform a grim situation to a better tomorrow is critical to heightening satisfaction with life. The positive effects of spiritual well-being on the level of life satisfaction exemplified by research participants in the current study further reinforces that the contemplation of priorities in life is indeed a cognitively learned process.

The present investigation finds a significant relationship between high levels of physical functioning and satisfaction with life. Hope mediates the relationship between perceived functional ability and coping (Jackson, Taylor, Palmatier, Elliott, & Elliott, 1998). Underlying the interrelatedness of hope, functional ability and life satisfaction is society's premium value on independence and self-reliance. Dutch researchers (Post, de Witte, van Asbeck, et al., 1998) have found that perceived self-care abilities in people with spinal cord injuries are an accurate predictor of life satisfaction. Life satisfaction is influenced by an individual's functional ability to perform basic hygiene-related activities such as bathing, feeding, dressing, and toileting (Hicken, Putzke, Novack, et al., 2002). Autonomy, self-control, and self-determination are integral to the psychological empowerment of people with disabilities.

Future Time Orientation

An unexpected result of the current study is the contrasting view toward future time orientation between individuals with neuromuscular diseases and those with neurological diseases. The latter group appears to gravitate more toward the distant future. While both types of disabilities are characterized by ineluctable physical deterioration and in some cases cognitive decline as well, the rapidness and course of degeneration may set them apart. The life expectancy of people with multiple sclerosis is normally longer than for those with muscular dystrophy. Someone with Duchenne muscular dystrophy, who normally does not live beyond the second decade, is likely to envision the clock ticking down faster than usual.

Given the unpredictable nature of progressive disabilities, it is not astounding to find people with full-time employment are low on future time orientation. The unusually high prevalence of involuntary retirement in this population demonstrates the worries and fears they have when planning long-term professional goals. The devastating effects of uncontrollable rapid spurts of muscle atrophy and diminished cognitive function can have a disastrous impact on the ability to conduct simple activities of daily living. The one-day-at-a-time approach to overcome uncertainties must not be mistaken as mere maladjusted pathological responses to highly stressful demands of life.

The present study was unable to establish mediating effects of acceptance of disability and employment status on the relationship between future time orientation and life satisfaction. The absence of a relationship between future time orientation and life satisfaction has already been speculated about in the preceding paragraphs. People with progressive disabilities are so engrossed in maintaining the present levels of physical

functioning that they either will not or do not want to think too far ahead about what might happen in the future.

Other Emerging Themes

Availability of accessible transportation emerges from the analysis of qualitative data as an urgent issue. This finding echoes the same concern of Swedish people with muscular dystrophy (Bostrom & Ahlstrom, 2004). Low-income status means that private vehicles that require expensive adaptations are beyond the means of people with disabilities. Likewise, the provision of public transport subsidies tends to fluctuate with the existing political climate and economic trends. With no reliable accessible buses and vans available to people with mobility and sensory impairments, their freedom of movement, which leads to independence, recreation, and employment, is severely compromised.

Consistent with previous research on dating and marital issues in other disability groups, the present qualitative data show that people who have been diagnosed with neuromuscular and neurological diseases experience dissatisfaction with forming and maintaining intimate relationships with the opposite sex. This frustration comes from poor perception of self-image and disinterest in people without disabilities. Deprived of the courtship skills normally developed during the teenage period, many people diagnosed with neuromuscular and neurological diseases do not know how to initiate friendships in an appropriate manner. Fear of rejection paralyzes people with progressive disabilities from approaching persons in whom they are interested. For those whose onset of disability occurs after they enter a marriage or relationship, the spouse or partner tends to assume the role of caregiver. Many marriages and relationships fall apart eventually

because the caregivers never quite anticipate the physical and psychological demands of tending partners with disabilities. The restriction on personal time for recreational activities and work grows to be a huge stressor.

The high probability of passing on hereditary diseases to the next generation worries many married couples and those who plan to enter long-term, committed, monogamous relationships. They are absolutely torn at the gloomy prospect of seeing their children endure the exact struggles and discrimination they have dreaded so much as persons with progressive disabilities. Moreover, a sound decision to determine whether the joy of parenthood would outweigh the astronomical costs of lifetime health care for that child is next to impossible to arrive at when being pressured from both sides by eugenics and pro-life proponents. Most importantly, no informed parents in the whole world would want to live with regrets about a difficult decision they made years ago.

Although the scores on the revised AD scale seem to be relatively high, findings from the qualitative data suggested otherwise. One plausible explanation is that the instrument may not accurately measure acceptance of disability and life satisfaction from a multidimensional perspective. Another possibility is that it is human nature to fear uncertainty. Self-acceptance of disability may help people with progressive disabilities to recognize and redefine their disability identity; however, worries about the future persist. A third possibility is that the negative wording used in the qualitative research questions may have contributed to the observation of the participants' pessimistic outlook on life satisfaction.

Some other surprising findings emerged, including the lack of association between employment status and life satisfaction. People with severe disabilities who have

never worked in their whole life can still be content because nobody expects them to make a living for themselves. Their urgency to enter the job market may be weak because of society's lowered expectations for them and because monetary support from social welfare programs removes pressure from people with progressive disabilities to aggressively search for gainful employment and to construct a career path. The absence of a correlation between employment status and life satisfaction for those who currently work or who had worked in the past is intriguing. It could be that people with progressive disabilities were resigned to the necessity of early retirement because of their declining physical condition. In addition, early retirement in their 50s and 60s may seem an acceptable deal when they are eligible to receive benefits from Social Security Disability Insurance or Supplementary Security Income.

Limitations of the Study

Several caveats must be considered when interpreting the present study's findings. The sample's small size is problematic. The prevalence numbers for muscular dystrophy and multiple sclerosis in the U.S. are estimated at about 200,000 (Siegel, 1999) and 350,000 (Brandes & Willmott, 2002), respectively. Admittedly, it would be imprudent to conclude that the responses of the 228 participants, a tiny fraction of this population, reflect those of the majority who were not polled in the current study. MD consists of some 40 different types of muscle diseases including amyotrophic lateral sclerosis (ALS). Duchenne the most common affects males, although other types affect females. MS also affects both sexes but it seems to disproportionately occur in Caucasian women living in regions away from the equator. Within the present sample, almost 90% of the respondents claimed to be of European American descent. Therefore, the sample

population's homogeneity may limit the ability to generalize the results of ethnic minority members with progressive disabilities.

To avoid inundating prospective study participants with too many survey items, proven standardized instruments were not used to measure either the constructs of the levels of physical functioning or the importance of religion. Rather, estimation was derived from the self-report of the participants' subjective perception of their own physical well-being and religiousness. Another possible shortcoming that might invalidate the results' generalization is the under-representation of Buddhists and Muslims in the datasets. Christian values and beliefs perhaps influence the nature of the results collected.

It is not feasible to extrapolate the personality and attitudinal differences between people with progressive disabilities who chose to take part in the study and those who did not. Only about half of the participants answered the two open-ended qualitative research questions. This lack of the overall sample's full participation somewhat curtails the valid representation of participants' views toward certain themes and issues, as evidenced in the apparent contradiction between quantitative and qualitative data. Finally, the two open-ended questions might have unintentionally been stated in a way that skewed to less positive comments and a more downbeat perception of the disability and its adverse effects on life perspectives.

Implications

Implications for Rehabilitation Practice

The benefits of having a strong support system for a person with a disability are indisputable and well documented in psychological and social research. However,

permanent disability alters not only the lives of the care recipients but also the lives of the care providers. The need for around-the-clock continuous physical tending can take a toll on the most patient and caring person. Declines in spousal impairment and caregiver strain have been found to correlate to increased anxiety and depression (Beach, Schultz, Yee, & Jackson, 2000). Cannuscio, Jones, Kawachi, Colditz, et al. (2002) concurred with similar conclusions in a four-year longitudinal study of spousal caregiving responsibilities and mental health. Women who provided care to a disabled or chronically ill spouse were almost six times more likely to exhibit depressive and anxious symptoms than noncaregivers. Indeed, prevention of caregiver burnout is an issue that has not been talked about much in part due to the reluctance on the part of family members and spouses to admit their own emotional and physical drains. The pressure is particularly acute in the Asian American and Hispanic communities where societal expectations about caring for disabled and chronically ill parents and spouses are high and deeply engrained. Rehabilitation counselors, when appropriate, need to explicate to their clients and family members that placement in a community-based, long-term care facility is not equivalent to abandonment of loved ones. Vulnerability also makes people with progressive disabilities easy targets for mistreatment. To protect the clients, rehabilitation counselors must detect any signs of spousal and familial neglect and abuse. Conversely, support group meetings for caregivers and identification of resources within the community will no doubt help caregivers alleviate their pent-up negative energies, such as tension and stress.

Improving rehabilitation counselors' understanding of the progressive nature of neuromuscular and neurological diseases has important implications for writing short-

term and long-term vocational rehabilitation plans. In circumstances in which uncertainty is likely to impede fruition of positive vocational outcomes, rehabilitation counselors need to be able to foresee possible challenges their clients might face in 3, 5 and 10 years down the road. Advocating employment rights for people with disabilities and educating prospective and current employers on compliance with the ADA and provision for job accommodations will be key to keeping people with progressive disabilities in the workforce.

Social and cultural forces have immense influences in shaping the collective attitudes toward disability. Humankind has been using religion and pseudoreligion to explain the occurrence of tragic, catastrophic and joyful events since the beginning of recorded civilization. Organized religion provides psychological relief to the masses who are experiencing internal mental anguish. Therefore, rehabilitation counselors should consider incorporating different counseling modalities to dispel myths about disability as God's punishment. A prime example is cognitive behavioral therapy, which aims at helping a client to disconnect a distorted picture of bothersome situations from unhealthy and improper reactions. Rehabilitation counselors attempt to convince their clients that disabilities are not divine retributions for indiscretion and transgressions. Nothing productive will come for the clients if they are fixated on finding a seemingly nonexistent answer. On the other hand, referral to church clergies for counseling is most effective when working with clients who are deeply religious and pious.

Learned helplessness attributes to low self-esteem and lack of assertiveness prevalent in such oppressed groups of people as domestic violence victims and persons with disabilities, who tend to perceive themselves as powerless. Such a psychological

impasse usually stems from the faulty thought that their efforts in command of life events will be ineffective. Successful job placement and rehabilitation service outcomes lie largely in rehabilitation clients' preparedness of vocational skills, as well as their mental readiness to work. Rehabilitation counselors can play a vital role in helping persons with disabilities transcend feelings of hopelessness and uncertainty in the face of adversity.

Directions for Future Research

Psychology theorists and social scientists have presented an array of suppositions in an attempt to unlock the myths of human cognitive adaptation and psychological defense mechanisms in unfamiliar intimidating situations. Although the call for secularism in governmental and judicial affairs has gained steadfast support in the increasingly diverse American society, it would be nonetheless of great benefit for rehabilitation researchers to identify and differentiate the coping strategies utilized by religious and nonreligious people with disabilities alike. With 49 participants in the present study atheists and agnostics, the numbers are too large not to be reckoned with by service providers as a unique subgroup of the rehabilitation population.

To enhance the generalizability of the findings, this study could be replicated in other types of disability groups to corroborate how disposition to future time orientation might exert influence on the rehabilitation client's preference in choosing short-term over long-term vocational plans or vice versa. People with disabilities' perceived uncertainty about the unpredictable progression of disability may instill in them a strong urgency to accomplish personal and vocational goals on a pace that is fast relative to people without progressive disabilities. It is therefore highly recommended that a future direction for research concentrates on seeking additional factors that contribute to the lessening of

death anxiety and better mental preparation for the ever-deteriorating physical functioning.

One crucial topic for future empirical studies on life satisfaction will be the development of a structural model to evaluate the theoretical assumptions of self-acceptance of disability and spiritual well-being. Due to the present study's small sample size, statistical analyses of the present study were limited to the use of a series of multiple regressions. In general, an effective structural equation modeling (SEM) requires a sample size of not less than 300. Klein (1998) states that SEM provides a far more rigorous alternative to multiple regressions to testing an overall fit of a proposed model to the data by inspecting many relationships among interdependent variables simultaneously.

Buddhism, Islam, Hinduism, and Eastern Orthodox Christianity have flourished in recent years as more non-European immigrants settle in the U.S. Because European-American Christians comprise the majority of rehabilitation practitioners, there is an urgent need for them to grasp different religions' dogmatical interpretations of the meanings of disability, of suffering, and of eternal life. This could be done by conducting surveys in the communities that subscribe to non-Judaeo-Christian beliefs or by interviewing their religious and spiritual leaders at places of worship.

Health, in physical and mental forms, affects the quality of life in persons with disabilities and their ability to search and maintain gainful employment. The emergence of positive psychology offers rehabilitation researchers an exciting new arena to examine health outcomes and human strength and virtue. Further understanding is needed of this body of knowledge, particularly how living with uncertainty and unpredictability can

moderate adjustment to disability. More importantly, future studies must emphasize the importance of promoting personal well-being by highlighting the gradual shift in focus from a decrease in pathology to an increase in untapped potential and potency.

Conclusion

The objective of this investigation was to better understand the unpredictable nature of progressive disability in relation to satisfaction with life. Specifically, the study attempted to examine the issues and effects of self-acceptance of disability, spiritual well-being, future time orientation, and hope in people with incurable neuromuscular and neurological diseases. The results suggested that life satisfaction was positively correlated with spiritual well-being, hope, and acceptance of disability. In the analysis of future time orientation, respondents with neurological disorders had higher scores, and full-time employment was associated with lower scores. Self-acceptance of disability was positively correlated with hope, spiritual well-being, and physical functioning, and negatively correlated with future time orientation. However, the results failed to establish the mediating effects of acceptance of disability and employment status on the relationship between future time orientation and life satisfaction. Finding means of accessible transportation remains a daunting barrier to the seeking of independence and employment for people with mobility and sensory disabilities. Another controversial theme is the benefits and costs of bringing babies replete with cureless hereditary diseases to the world. Despite the present study's limitations, it has added new understanding of life satisfaction and acceptance of disability in relation to people with progressive disabilities.

APPENDICES

Appendix A

Self-Introductory Letter

Dear Program Director,

My name is Roy Chen and I'm a Ph.D. Candidate in the Rehabilitation Counseling Program in the Department of Counseling, Educational Psychology, and Special Education in the College of Education at Michigan State University. I'm writing to request your kind assistance to help me recruit participants for my dissertation research.

The purpose of my study is to explore the joint contribution of demographic variables, hope, religiosity, future time orientation, disability acceptance, and physical function to life satisfaction and employment status in people with multiple sclerosis. The short time your clients spend filling out this survey will generate useful information for rehabilitation professionals to deliver better rehabilitation services.

Also attached is an abbreviated curriculum vitae for your reference. It contains my academic training, professional experience, and selected publications. I will conduct this study independently under the supervision of my major professor, Dr. Nancy Crewe. I will be contacting you by phone in a few days. I hope you will give me an opportunity to discuss my study with you in length. Thank you very much.

Sincerely,

Roy Chen, Ph.D. Candidate, CRC
Michigan State University
College of Education
Rehabilitation Counseling Program
935 Cherry Lane # D
East Lansing, MI 48823
(517) 355 –8091
chenroy@msu.edu

CC:
Nancy Crewe, Ph.D., CRC, LP, ABPP
Professor
Michigan State University
College of Education
Rehabilitation Counseling Program
459 Erickson Hall
East Lansing, MI 48824-1034
(517) 432-0606
ncrewe@msu.edu

Appendix B

Life Satisfaction Among People With Progressive Disabilities

Consent Form

In this study you will be asked to fill out a questionnaire regarding your attitudes and feelings about self-acceptance of disability and life satisfaction. It will take 15 to 20 minutes to complete the survey.

Your participation in this study is voluntary and will be used for research purposes only. You may discontinue participation at any time. Results of the study will report only aggregate findings from the group, and no individuals will be identified.

The first 100 participants who complete all parts of the survey will each receive a $5 check in appreciation for their time. If you would like to be eligible to receive the $5 check, please provide your name and mailing address in the space below.

YOU INDICATE YOUR VOLUNTARY AGREEMENT TO PARTICIPATE BY COMPLETING AND RETURNING THE QUESTIONNARE.

If you have any questions regarding this research study, please contact:

Roy Chen, Ph.D. Candidate
Michigan State University
935 Cherry Lane # D
East Lansing, MI 48823
(517) 355-8091
chenroy@msu.edu

Peter Vasilenko, Ph.D., Chair
The University Committee On Research Involving Human Subjects
Michigan State University
202 Olds Hall
East Lansing, MI 48824
(517) 355-2180
vasilenk@msu.edu

---------- Cut and mail with the questionnaire ----------

Name:

Address:

Debriefing

Thank you very much for participating in this research study. The purpose of this project is to understand the relationship between life satisfaction and self-acceptance of disability in people with progressive disabilities. Your participation will contribute to this important knowledge base.

I expect to have the results analyzed by May 2006 and if you are curious about the findings, please contact me at chenroy@msu.edu or (517) 355-8091. Questions asked in the survey may evoke your thoughts and feelings about your own disability. Although there are no foreseeable risks, please read the suggested book or use the online counseling and support groups provided by the National Multiple Sclerosis Society or the Muscular Dystrophy Association should you experience emotional issues.

Smart, J. (2001). *Disability, society, and the individual.* Gaithersburg, MD: Aspen Publishers, Inc.

Appendix C

Recruitment Flyer

Research Participants Wanted

Study On Life Satisfaction People With Disabilities

Researchers at Michigan State University are interested in studying the relationship between acceptance of disability and life satisfaction in people with progressive disabilities.

IF YOU

- Are 18 years of age or older
- Have been diagnosed with neuromuscular diseases (e.g. muscular dystrophies, motor neuron diseases) or neurological disorders (e.g. multiple sclerosis)

First 100 participants who complete all parts of the survey will each receive $5 in appreciation for their time. Please respond by March 31, 2006.

This survey contains 83 questions, which will require about 15 to 20 minutes to complete.

You are cordially invited to take part in this research study. To obtain a copy of the questionnaire or instructions for completing the survey online, please contact Roy Chen at (517) 355-8091; **chenroy@msu.edu**

If you have questions or concerns about this study, please contact Dr. Nancy Crewe, (517) 432-0606, e-mail: **ncrewe@msu.edu**, or regular mail: 459 Erickson Hall, East Lansing, MI 48824.

MICHIGAN STATE UNIVERSITY

Appendix D

Demographic Questionnaire

Please circle the answer that best describes you. It is extremely important that you answer every question. Thank you for your cooperation.

Sex:

1. Male
2. Female

Age: _____

Race/Ethnicity:

1. Caucasian
2. African American
3. Hispanic
4. Asian or Pacific Islander
5. American Indian or Alaskan Native
6. Multiracial
7. Other, please specify _____

Where are you located? _____

Religion:

1. Buddhism
2. Catholic
3. Judaism
4. Muslim
5. Protestant
6. Other, please specify _____

How important is religion to you? (1 = very unimportant, 5 = very important)

1	2	3	4	5

Marital Status:

1. Never married
2. Married
3. Divorced
4. Widowed

Level of Education:

1. Less than high school
2. High school

3. Associate degree (e.g. AA)
4. Bachelor's degree (e.g. BA)
5. Graduate degree (e.g. MA, PhD)

Current Employment Status:

1. Employed full-time (40 hours/week or more)
2. Employed part-time (less than 40 hours/week)
3. Self-employed
4. Retired
5. Homemaker
6. Student
7. Unemployed

Type of Disability:

1. Neuromuscular diseases (e.g. Duchenne, Becker, ALS, Myasthenia Gravis)
   Please specify _____

2. Neurological disease (e.g. Multiple Sclerosis, Parkinson's Disease)
   Please specify _____

How long have you been diagnosed with this disability? _____ years

In what ways does progressive disability affect the pursuit of personal goals such as employment and romantic relationships?

How does the uncertainty of progressive disability influence life perspectives?

Appendix E

The Satisfaction With Life Scale

Instructions: Please use one of the following numbers from 1 to 7 to indicate how much you agree with or disagree with the following statements.

7 = Strongly agree
6 = Agree
5 = Slightly agree
4 = Neither agree nor disagree
3 = Slightly disagree
2 = Disagree
1 = Strongly disagree

1. _____ In most way my life is close to my ideal.
2. _____ The conditions of my life are excellent.
3. _____ I am satisfied with my life.
4. _____ So far I have gotten the important things I want in my life.
5. _____ If I could live my life over, I would change almost nothing.

Appendix F

The Hope Scale (The Goals Scale)

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

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

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

Appendix G

The Spiritual Well-Being Scale

For each of the following statements, circle the choice that indicates the extent of your agreement or disagreement as it describes your personal experience:

SA = Strongly Agree	D = Disagree
MA = Moderately Agree	MD = Moderately Disagree
A = Agree	SD = Strongly Disagree

1.	I don't find much satisfaction in private prayer with God.	SA	MA	A	D	MD	SD
2.	I don't know who I am, where I came from, or where I am going.	SA	MA	A	D	MD	SD
3.	I believe that God loves me and cares about me.	SA	MA	A	D	MD	SD
4.	I feel that life is a positive experience.	SA	MA	A	D	MD	SD
5.	I believe that God is impersonal and not interested in my daily situations	SA	MA	A	D	MD	SD
6.	I feel unsettled about my future.	SA	MA	A	D	MD	SD
7.	I have a personally meaningful relationship with God.	SA	MA	A	D	MD	SD
8.	I feel very fulfilled and satisfied with life.	SA	MA	A	D	MD	SD
9.	I don't get much personal strength and support from my God.	SA	MA	A	D	MD	SD
10.	I feel a sense of well-being about the direction my life is headed in.	SA	MA	A	D	MD	SD
11.	I believe that God is concerned about my problems.	SA	MA	A	D	MD	SD
12.	I don't enjoy much about life.	SA	MA	A	D	MD	SD
13.	I don't have a personally satisfying relationship with God.	SA	MA	A	D	MD	SD
14.	I feel good about my future.	SA	MA	A	D	MD	SD
15.	My relationship with God helps me not to feel lonely.	SA	MA	A	D	MD	SD
16.	I feel that life is full of conflict and unhappiness.	SA	MA	A	D	MD	SD
17.	I feel most fulfilled when I'm in close communion with God.	SA	MA	A	D	MD	SD
18.	Life doesn't have much meaning.	SA	MA	A	D	MD	SD
19.	My relationship with God contributes to my sense of well-being.	SA	MA	A	D	MD	SD
20.	I believe there is some real purpose for my life.	SA	MA	A	D	MD	SD

Note: Items are scored from 1 to 6, with the higher number representing more well-being. Negatively worded items (#1, 2, 5, 6, 9, 12, 13, 16, 18) are reversed scored. Odd number items assess religious well-being; even numbered items assess existential well-being.

Appendix H

The Future Time Orientation Scale

Instructions: Please answer all of the following questions concerning your view of time:

4 = Is not at all true of me
3 = Is not too true of me
2 = Is fairly true of me
1 = Is very true of me

1.	I always seem to be doing things at the last moment.	1	2	3	4
2.	I have been thinking a lot about what I am going to do in the future.	1	2	3	4
3.	I find it hard to get things done without a deadline.	1	2	3	4
4.	I need to feel rushed before I can really get going.	1	2	3	4
5.	Half a year seems to me a long time.	1	2	3	4
6.	I think about the future only to a very small extent.	1	2	3	4
7.	I am most concerned about how I feel now in the present.	1	2	3	4
8.	I am not so very much concerned about things a little ahead in time.	1	2	3	4
9.	It's really no use worrying about the future, because what will be, will be.	1	2	3	4
10.	I reflect a great deal about the future, and I feel it is rapidly approaching.	1	2	3	4
11.	It often seems like the day will never end.	1	2	3	4
12.	I often find myself looking for ways to kill time.	1	2	3	4
13.	The future seems very vague and uncertain to me.	1	2	3	4
14.	Usually I feel time is going too fast.	1	2	3	4

Appendix I

The Acceptance of Disability Scale-Revised

Instructions: Please read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.

1 = Strongly disagree
2 = Disagree
3 = Agree
4 = Strongly agree

1.	With my disability, all areas of my life are affected in some major way.	1 2 3 4
2.	Having my disability, I am unable to do things like people without disabilities do.	1 2 3 4
3.	Disability or not, I am going to make good in life.	1 2 3 4
4.	Because of disability, I have little to offer other people.	1 2 3 4
5.	Good physical appearance and physical ability are the most important things in life.	1 2 3 4
6.	A person with a disability is restricted in certain ways, but there is still much s/he is able to do.	1 2 3 4
7.	No matter how hard I try or what I accomplish, I could never be as good as the person who does not have my disability.	1 2 3 4
8.	It makes me feel very bad to see all the things that people without disabilities can do that I cannot.	1 2 3 4
9.	The most important thing in this world is to be physically capable.	1 2 3 4
10.	Because of my disability, other people's lives have more meaning than my own.	1 2 3 4
11.	Because of my disability, I feel miserable much of the time.	1 2 3 4
12.	Though I have a disability, my life is full.	1 2 3 4
13.	The kind of person I am and my accomplishments in life are less important than those of persons without disabilities.	1 2 3 4
14.	A physical disability affects a person's mental ability.	1 2 3 4
15.	Since my disability interferes with just about everything I try to do, it is foremost in my mind practically all of the time.	1 2 3 4
16.	There are many things a person with my disability is able to do.	1 2 3 4
17.	My disability in itself affects me more than any other characteristics about me	1 2 3 4
18.	There are many more important things in life than physical	1 2 3 4

ability and appearance.

19.	Almost every area of life is closed to me.	1 2 3 4
20.	My disability prevents me from doing just about everything I really want to do and from becoming the kind of person I want to be.	1 2 3 4
21.	I feel like an adequate person regardless of the limitation of my disability.	1 2 3 4
22.	My disability affects those aspects of life that I care most about.	1 2 3 4
23.	A disability such as mine is the worst possible thing that can happen to a person.	1 2 3 4
24.	You need a good and whole body to have a good mind.	1 2 3 4
25.	There are times that I completely forget that I have a disability.	1 2 3 4
26.	If I didn't have my disability, I think I would be a much better person.	1 2 3 4
27.	When I think of my disability, it makes me so sad and upset that I am unable to do anything else.	1 2 3 4
28.	People with disabilities are able to do well in many ways.	1 2 3 4
29.	I feel satisfied with my abilities and my disability does not bother me too much.	1 2 3 4
30.	In just about everything, my disability is annoying to me so that I can't enjoy anything.	1 2 3 4
31.	Physical wholeness and appearance make a person who s/he is.	1 2 3 4
32.	I know what I can't do because of my disability, and I feel that I can live a full life.	1 2 3 4

REFERENCES

Alston, R. J., McCowan, C. J., & Turner, W. L. (1994). Family functioning as a correlate of disability adjustment for African Americans. *Rehabilitation Counseling Bulletin, 37*, 277-289.

Arrindell, Heesink, & Feij, (1999). The satisfaction with life scale (SWLS): Appraisal from 1700 healthy young adults in The Netherlands. *Individual and Personality Differences, 26*, 815-826.

Attawong, T., & Kovindha, A. (2005). The influencing factors in acceptance of disability in spinal cord injured patients. *Nepal Journal of Neuroscience, 2*, 67-70.

Ayrault, E. W. (1997). Adjusting to a disability. *Accent on Living, 42*, 84-85.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173–1182.

Barrett, A. (1999). Social support and life satisfaction among the never married: Examining the effects of age. *Research on Aging, 21*, 46-72.

Barton, B. A. (2005). *The relationship between adaptation to disability, and sexual and body esteem in women with polio*. Unpublished doctoral dissertation. Michigan State University.

Bausell, R. B., & Li, Y-F. (2002). *Power Analysis for experimental research: A practical guide for biological, medical and social sciences*. Cambridge, UK: Cambridge University Press.

Beach, S. R., Schultz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*, 259-271.

Bellini, J. L., & Rumrill, P. D. (1999). *Research in rehabilitation counseling: A guide to design, methodology, and utilization*. Springfield, IL: Charles C Thomas Publisher, Ltd.

Boris, H. N. (1994). About time. *Contemporary Psychoanalysis, 30*, 301-322.

Boschen, K. A. (1996). Correlates of life satisfaction, residential satisfaction, and locus of control among adults with spinal cord injuries. *Rehabilitation Counseling Bulletin, 39*, 230-243.

Bostrom, K., & Ahlstrom, G. (2004). Living with a chronic deteriorating disease: The trajectory with muscular dystrophy over ten years. *Disability & Rehabilitation, 26*, 1388-1398.

Boswell, B., Dawson, M., & Heininger, E. (1998). Quality of life as defined by adults with spinal cord injury. *Journal of Rehabilitation, 64*, 27-32.

Brandenburg, J. B. (1971). *The relationship between future time perspective and academic achievement: The relationship of three dimensions of future time perspective to academic achievement with respect to scholastic aptitude, sex and socioeconomic status among college freshmen.* Unpublished doctoral dissertation, New York University, New York.

Brandes, D. W., & Willmott, L. J. (2002). Multiple Sclerosis. In M. G. Brodwin, F. A. Tellez, & S. K. Brodwin (Eds.), *Medical, Psychosocial and Vocational Aspects of Disability* (pp. 351-362). Athens, GA: Elliott & Fitzpatrick, Inc.

Caine, E. D., & Schwid, S. R. (2002). Multiple sclerosis, depression, and the risk of suicide. *Neurology, 59*, 662-663.

Cannuscio, C. C., Jones, C., Kawachi, I., Colditz, G. A., Berkman, L., & Rimm, E. (2002). Reverberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health, 92*, 1305-1311.

Catipovic-Veselica, K., Ilakovac, V., Durjancek, J., Amidzc, V., Buric, D., & Kozmar, D. (1995). Relationship of eight basic emotions with age, sex, education, satisfaction of life needs, and religion. *Psychological Reports, 77*, 115-121.

Carr, A. J., Gibson, B., Robinson, P. G. (2003). Is quality of life determined by expectations or experience? In A. J. Carr, I. J. Higginson, & P. G. Robinson (Eds.), *Quality of life* (pp. 9-18). London, UK: BMJ Books.

Carstensen, L. L., Issacowitz, D. M., & Charles, S. T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist*, 54, 165-181.

Chang, E. C. (2003). A critical appraisal and extension of hope theory in middle-aged men and women: Is it important to distinguish agency and pathways components? *Journal of Social and Clinical Psychology, 22*, 121-143.

Chang, E. C., & DeSimone, S. L. (2001). The influence of hope on appraisals, coping, and dysphoria: A test of hope theory. *Journal of Social and Clinical Psychology, 20*, 117-129.

Chen, R. K. (2002). Muscular dystrophy. In M. G. Brodwin, F. A. Tellez, & S. K. Brodwin (Eds.), *Medical, Psychosocial and Vocational Aspects of Disability* (2nd ed., pp. 419-427). Athens, GA: Elliott & Fitzpatrick, Inc.

Chen, R. K. (2001). Helping adults with muscular dystrophy: Rehabilitation counseling implications. *The Australian Journal of Rehabilitation Counseling, 7*, 51-63.

Chen, R. K., Jo, S., & Donnell, C. (2004). Enhancing the rehabilitation counseling process: Understanding the obstacles to Asian Americans' utilization of services. *Journal of Applied Rehabilitation Counseling, 35*, 29-35.

Cleary, P. D., & Jette, A. M. (2000). Reliability and validity of the Functional Status Questionnaire. *Quality of Life Research, 9*, 747-753.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.

Collins, A. B., & Kuehn, M. D. (2004). The construct of hope in the rehabilitation process. *Rehabilitation Education, 18*, 175-183.

Corey, G. (1996). *Theory and practice of counseling and psychotherapy* (5th ed.). Pacific Grove, CA: Brooks/Cole Publishing Company.

Cottle, T. J., & Klineberg, S. L. (1974). *The present of things future: Explorations of time in human experience*. New York: The Free Press.

Cotton, S. P., Levine, E. G., Fitzpatrick, C. M., Dold, K. H., & Targ, E. (1999). Exploring the relationships among spiritual well-being, quality of life, and psychological adjustment in women with breast cancer. *Psycho-Oncology, 8*, 429-438.

Coyle, C., Lesnik-Emas, S., & Kinney, W. (1994). Predicting life satisfaction among adults with spinal cord injuries. *Rehabilitation Psychology, 39*, 95-112.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: SAGE Publications.

Danoff-Burg, S., Prelow, H. M., & Swenson, R. R. (2004). Hope and life satisfaction in black college students coping with race-related stress. *Journal of Black Psychology, 30*, 208-228.

Davis, L. J. (1997). Constructing normalcy. In L. J. Davis (Ed.), *The disability studies reader* (pp. 9-28). New York: Routledge.

DeLoach, C., & Greer, B. G. (1981). *Adjustment to severe physical disability: A metamorphosis*. New York: McGraw-Hill Book Company.

Dembo, T., Leviton, G. L., & Wright, B. A. (1956). Adjustment to misfortune: A problem of social-psychological rehabilitation. *Artificial Limbs, 3*, 4-62.

Dickie, J. R., Ajega, L. V., Kobylak, J. R., & Nixon, K. M. (2006). Mother, father, and self: Sources of young adults' God concepts. *Journal for the Scientific Study of Religion, 45*, 57-71.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment, 49*, 71-75.

Eggleton, I., Robertson, S., Ryan, J., & Kober, R. (1999). The impact of employment on the quality of life of people with an intellectual disability. *Journal of Vocational Rehabilitation, 13*, 95-107.

Ellison, C. W. (1983). Spiritual well-being: Conceptualization and measurement. *Journal of Psychology and Theology, 11*, 330-340.

Elliot, T. R., Shewchuk, R. M., & Richards, J. S. (1999). Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. *Rehabilitation Psychology, 44*, 104-123.

Elliott, T. R., Witty, T. E., Herrick, S., & Hoffman, J. T. (1991). Negotiating reality after physical loss: Hope, depression, and disability. *Journal of Personality and Social Psychology, 61*, 608-613.

Fabricatore, A. N., Handal, P. J., & Fenzel, L. M. (2000). Personal spirituality as a moderator of the relationship between stressors and subjective well-being. *Journal of Psychology and Theology, 28*, 221-228.

Faull, K., Hill, M. D., Cochrane, G., Gray, J., Hunt, M., McKenzie, C., & Winter, L. (2004). Investigation of health perspectives of those with physical disabilities: the role of spirituality as a determinant of health. *Disability and Rehabilitation, 26*, 129-144.

Feather, N. T., & Bond, M. J. (1994). Structure and purpose in the use of time. In Z. Zaleski (Ed.), *Psychology of future orientation* (pp. 121-140). Lublin, Poland: Towarzystwo Naukowe KUL.

Feather, N. T. & Bond, M. J. (1983). Time structure and purposeful activity among employed and unemployed university graduates. *Journal of Occupational Psychology, 56*, 241-254.

Fowler, W. M., Abresch, R. T., Koch, T. R., Brewer, M. L., Bowden, R. K., & Wanlass, R. L. (1997). Employment profiles in neuromuscular diseases. *American Journal of Physical Medicine & Rehabilitation, 76*, 26-37.

Frankl, V. E. (1984). *Man's search for meaning*. New York: Simon & Schuster, Inc.

Frazier, P. A., Tix, A. P., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology. *Journal of Counseling Psychology, 51*, 115-134.

Fung, H. H., & Carstensen, L. L. (2004). Motivational changes in response to blocked goals and foreshortened time: Testing alternatives to socioemotional selectivity theory. *Psychology and Aging, 19*, 68-78.

Fung, H. H., Carstensen, L. L., & Lutz, A. M. (1999). The influence of time on social preferences: Implications for life-span development. *Psychology and Aging, 14*, 595-604.

Gjesme, T. (1983a). Introduction: An inquiry into the concept of future orientation. *International Journal of Psychology, 18*, 347-350.

Gjesme, T. (1983b). On the concept of future time orientation: considerations of some functions' and measurements' implications. *International Journal of Psychology, 18*, 443-461.

Gjesme, T. (1979). Future time orientation as a function of achievement motives, ability, delay of gratification, and sex. *The Journal of Psychology, 101*, 173-188.

Goggin, G., & Newell, C. (2004). Uniting the nation? Disability, stem cells, and the Australian media. *Disability & Society, 19*, 47-60.

Gourgey, C. (1994). Faith, Despair, and Disability. *Journal of Religion in Disability and Rehabilitation,* 1, 51-63.

Hahn, H. (1988). The politics of physical difference: Disability and discrimination. *Journal of Social Issues, 44,* 39-47.

Halvari, H. (1991). Maximal aerobic power as a function of achievement motives, future time orientation, and perceived intrinsic instrumentality of physical tasks for future goals among males. *Perceptual and Motor Skills, 72*, 367-381.

Hampton, N. Z., & Crystal, R. (1999). Gender differences in acceptance of disabilities among vocational rehabilitation consumers. *Journal of Applied Rehabilitation Counseling, 30*, 16-21.

Harrison, T., Stuifbergen, A., Adachi, E., & Becker, H. (2004). Marriage, impairment, and acceptance in person with multiple sclerosis. *Western Journal of Nursing Research, 26*, 266-285.

Heckman, T. G. (2003). The chronic illness quality of life (CIQOL) model: Explaining life satisfaction in people living with HIV disease. *Health Psychology, 22*, 140-147.

Heimberg, L. K. (1963). *The measurement of future time perspective.* Unpublished doctoral dissertation, Vanderbilt University.

Heppner, P. P., & Heppner, M. J. (2004). *Writing and publishing your thesis, dissertation, and research: A guide for students in the helping professions.* Belmont, CA: Brooks/Cole.

Hicken, B. L., Putzke, J. D., Novack, T., Sherer, M., & Richards, J. S. (2002). Life satisfaction following spinal cord and traumatic brain injury: A comparative study. *Journal of Rehabilitation Research & Development, 39*, 359-65.

Hill, P. C., & Pargament, K. I. (2003). Advances in the conceptualization and measurement of religion and spirituality: Implications for physical and mental health research. *American Psychologist, 58*, 64-74.

Hinckley, J. J. (2002). Vocational and social outcomes of adults with chronic aphasia. *Journal of Communication Disorders, 35*, 543-560.

Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*, 382-399.

Huberman, A. M., & Miles, M. B. (1994). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-444). Thousand Oaks, CA: SAGE Publications.

Jackson, W. T., Taylor, R. E., Palmatier, A. D., Elliott, T. R., & Elliott, J. L. (1998). Negotiating the reality of visual impairment: Hope, coping, and functional ability. *Journal of Clinical Psychology in Medical Settings, 5*, 173-185.

Jette, A. M., & Cleary, P. D. (1987). Functional disability assessment. *Physical Therapy, 67*, 1854-1859.

Jette, A. M., Davies, A. R., Cleary, P. D., Calkins, D. R., et al. (1986). The Functional Status Questionnaire: Reliability and validity when used in primary care. [published erratum appears in *Journal of General Internal Medicine, 1*, 427]. *Journal of General Internal Medicine, 1*, 143-149.

Karniol, R., & Ross, M. (1996). The motivational impact of temporal focus: Thinking about the future and the past. *Annual Review of Psychology, 47*, 593-620.

Kemp, B. J., & Krause, J. S. (1999). Depression and life satisfaction among people ageing with post-polio and spinal cord injury. *Disability & Rehabilitation, 21*, 241-249.

Kim, J., Heinemann, A. W., Bode, R. K., Sliwa, J., & King, R. B. (2000). Spirituality, quality of life, and functional recovery after medical rehabilitation. *Rehabilitation Psychology, 45*, 365-385.

Klein, R. B. (1998). *Principles and practices of structural equation modeling*. New York: Guilford Press.

Klineberg, S. L. (1968). Future time perspective and the preference for delayed reward. *Journal of Personality & Social Psychology, 8*, 253-257.

Klineberg, S. L. (1967). Changes in outlook on the future between childhood and adolescence. *Journal of Personality and Social Psychology, 7*, 185-193.

Koenig, H. G., McCullough, M. E., & Larson, D. B. (2001). *Handbook of religion and health*. New York: Oxford University Press.

Kwon, P. (2000). Hope and dysphoria: The moderating role of defense mechanism. *Journal of Personality, 68*, 199-223.

Landis, B. J. (1996). Uncertainty, spiritual well-being, and psychosocial adjustment to chronic illness. *Issues in Mental Health Nursing, 17*, 217-231.

Lessing, E. E. (1972). Extension of personal future time perspective, age, and life satisfaction of children and adolescents. *Developmental Psychology, 6*, 457-468.

Lessing, E. E. (1968). Demographic, developmental, and personality correlates of length of future time perspective (FTP). *Journal of Personality, 36*, 183-201.

Li, L., & Moore, D. (2001). Disability and illicit drug use: An application of labeling theory. *Deviant Behavior, 22*, 1-21.

Li, L., & Moore, D. (1998). Acceptance of disability and its correlates. *Journal of Social Psychology, 138*, 13-25.

Livneh, H. (1991). A unified approach to existing models of adaptation to disability: A model of adaptation. In R. P. Marinelli & A. E. Dell Orto (Eds.), *The psychological and social impact of disability* (3rd ed., pp. 111-138). New York: Springer Publishing Company.

Livneh, H., & Antonak, R. F. (1997). *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen Publishers, Inc.

Livneh, H., & Parker, R. M. (2005). Psychological adaptation to disability: Perspectives from chaos and complexity theory. *Rehabilitation Psychology, 49*, 17-28.

Lucas, R. E., Diener, E., & Larsen, R. J. (2003). Measuring positive emotions. In S. J. Lopez & C. R. Snyder (Eds.), *Positive psychological assessment: A handbook of models and measures* (pp. 201-218). Washington, DC: American Psychological Association.

Makros, J., & McCabe, M. (2003). The relationship between religion, spirituality, psychological adjustment, and quality of life among people with multiple sclerosis. *Journal of Religion and Health, 42*, 143-159.

Marler, P. L., & Hadaway, C. K. (2002). "Being religious" or "being spiritual" in America: A zero-sum proposition? *Journal for the Scientific Study of Religion, 41*, 289-300.

Martz, E. (2003). Future time orientation and employment of individuals with a spinal cord injury: Does current work status reflect a greater orientation toward the future? *Work, 21*, 257-263.

Martz, E., & Livneh, H. (2003). Death anxiety as a predictor of future time orientation among individuals with spinal cord injuries. *Disability & Rehabilitation, 25*, 1024-1032.

Martz, E., Livneh, H., & Turpin, J. (2000). Locus of control orientation and acceptance of disability. *Journal of Applied Rehabilitation Counseling, 31*, 14-21.

Maxwell, R. J. (1972). Anthropological perspective. In H. Yaker, H. Osmond, & F. Cheek (Eds.), *The future of time: Man's temporal environment* (pp. 36-72). Garden City, NY: Doubleday & Company, Inc.

Mehnert, T., Krauss, H. H., Nadler, R., & Boyd, M. (1990). Correlates of life satisfaction in those with disabling conditions. *Rehabilitation Psychology, 35*, 3-17.

Moore, D., & Li, L. (1998). Prevalence and risk factors of illicit drug use by people with disabilities. *American Journal on Addictions, 7*, 93-102.

Nosek, M. A., Fuhrer, M. J., & Potter, C. (1995). Life satisfaction of people with physical disabilities: Relationship to personal assistance, disability status, and handicap. *Rehabilitation Psychology, 40*, 191-202.

Nuttin, J. (1985). *Future time perspective and motivation: Theory and research method.* Leuven, Belgium: Leuven University Press; Hillsdale, NJ: Erlbaum Associates.

Oaksford, K., Frude, N., & Cuddihy, R. (2005). Positive coping and stress-related psychological growth following lower limb amputation. *Rehabilitation Psychology, 50*, 266-277.

Olkin, R. (1999). *What psychotherapists should know about disability*. New York: The Guilford Press.

Olney, M. F., Brockelman, K. F., Kennedy, J., & Newsom, M. A. (2004). Do you have a disability? A population-based test of acceptance, denial, and adjustment among adults with disabilities in the U.S. *Journal of Rehabilitation, 70*, 4-9.

Ososkie, J. N. (1998). Existential perspectives in rehabilitation counseling. *Rehabilitation Education, 12*, 217-222.

Ososkie, J. N., & Schultz, J. C. (2003). Disability acceptance theories and logotherapy. *International Forum for Logotherapy, 26*, 21-26.

Paloutzian, R. F., & Ellison, C. W. (1982). Loneliness, spiritual well-being and quality of life. In L. A. Peplau & D. Perlman (Eds.), *Loneliness: A sourcebook of current theory, research and therapy* (pp. 224-237). NY: Wiley.

Paloutzian, R. F., & Ellison, C. W. (1991). *Manual for the Spiritual Well-Being Scale*. Nyack, NY: Life Advance, Inc.

Pargament, K. I. (2002). The bitter and the sweet: An evaluation of the costs and benefits of religiousness. *Psychology Inquiry, 13*, 168-181.

Pargament, K. I. (1997). *The psychology of religion and coping*. New York: The Guilford Press.

Pavot, W., & Diener, E. (1993). Review of the satisfaction with life scale. *Psychological Assessment*, 5, 164-172.

Popovich, P. M., Scherbaum, C. A., Scherbaum, K. L., & Polinko, N. (2003). The assessment of attitudes toward individuals with disabilities in the workplace. *Journal of Psychology, 137*, 163-177.

Post, W. M., de Witte, L. P., van Asbeck, F. W., van Dijik, A. J., & Schrijvers, A. J. (1998). Predictors of health status and life satisfaction in spinal cord injury. *Archives of Physical Medicine & Rehabilitation, 79*, 395-401.

Powell, L. H., Shahabi, L., & Thoresen, C. E. (2003). Religion and spirituality: Linkages to physical health. *American Psychologist, 58*, 36-52.

Prenda, K. M., & Lachman, M., E. (2001). Planning for the future: A life management strategy for increasing control and life satisfaction in adulthood. *Psychology and Aging, 16*, 206-216.

Prince, P. N., & Prince, C. R. (2002). Perceived stigma and community integration among clients of assertive treatment. *Psychiatric Rehabilitation Journal, 25*, 323-331.

Randolph, D. S. (2004). Predicting the effect of disability on employment status and income. *Work, 23*, 257-266.

Reinders, H. S. (2000). The future of the disabled in liberal society. Notre Dame, IN: University of Notre Dame Press.

Riedinger, M. S., Dracsup, K. A., Brecht, M-L., Padilla, G., Sarna, L., & Ganz, P. (2001). Quality of life in patients with heart failure: Do gender differences exist? *Heart & Lung, 30*, 105-116.

Rippentrop, A. E. (2005). A review of the role of religion and spirituality in chronic pain population. *Rehabilitation Psychology, 50*, 278-284.

Rothspan, S., & Read, S. J. (1996). Present versus future time perspective and HIV risk among heterosexual college students. *Health Psychology, 15*, 131-134.

Schou, K. C., & Hewison, J. (1999). *Experiencing cancer: Quality of life in treatment.* Buckingham, UK: Open University Press.

Scott, R. O. (2001, Spring). Are you religious or are you spiritual: A look in the mirror. *Spirituality and Health*, 26-28.

Siegel, I.M. (1999). *Muscular dystrophy in children: A guide for families*. NY: Demos Medical Publishing, Inc.

Smart, J. (2004). Models of disability: The juxtaposition of biology and social construction. In T. F. Riggar & D. R. Maki (Eds.), *Handbook of rehabilitation counseling* (pp. 25-49). New York: Springer Publishing Company.

Smart, J. (2001). *Disability, society, and the individual.* Gaithersburg, MD: Aspen Publishers, Inc.

Snead, S. L., & Davis, J. R. (2002). Attitudes of individuals with acquired brain injury towards disability. *Brain Injury, 16*, 947-953.

Snowdon, J., & Baume, P. (2002). A study of suicide of older people in Sydney. *International Journal of Geriatric Psychiatry, 17*, 261-269.

Snyder, C. R. (1995). Conceptualizing, measuring, and nurturing hope. *Journal of Counseling & Development, 73*, 355-360.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., et al. (1991). The will and the ways: Development and validation of an individual differences measure of hope. *Journal of Personality and Social Psychology, 60*, 670-585.

Snyder, C. R., Lopez, S. J., Shorey, H. S., Rand, K. L., & Feldman, D. B. (2003). Hope theory, measurements, and applications to school psychology. *School Psychology Quarterly, 18*, 122-139.

Snyder, C. R., Shorey, H. S., Cheavens, J., Pulvers, K. M., Adams III, V. H., & Wiklund, C. (2002). Hope and academic success in college. *Journal of Educational Psychology, 94*, 820-826.

Soderback, I., Schult, M. L., & Nordemar, R. (1993). Assessment of patients with chronic back pain using the "Functional Status Questionnaire". *Scandinavian Journal of Rehabilitation Medicine, 25*, 139-143.

Spilka, B., Hood, R. W., Hunsberger, B., & Gorsuch, R. (2003). *The psychology of religion: An empirical approach* (3rd ed.). New York: The Guilford Press.

Tabachnick, B. G., & Fidell, L. S. (2001). *Using multivariate statistics (4th edition).* Needham Heights, MA: Allyn & Bacon.

Taleporos, G., & McCabe, M. P. (2002). The impact of sexual esteem, body esteem, and sexual function on psychological well-being in people with disabilities. *Sexuality & Disability, 20*, 177-183.

Taylor, S. T., & Bogdan, R. (1998). *Introduction to qualitative research methods: A guidebook and resource (3rd ed.).* New York: Wiley.

Teahan, J., & Kastenbaum, R. (1970). Subjective life expectancy and future time perspective as predictors of job success in the "hard-core unemployed." *Omega, 1*, 189-200.

Thoresen, C. E., & Harris, A. H. (2002). Spirituality and health: What's the evidence and what's needed? *Annals of Behavioral Medicine, 24*, 3-13.

Tsang, H., Cheung, L., & Lak, D. (2002). Qigong as a psychosocial intervention for depressed elderly with chronic physical illness. *International Journal of Geriatric Psychiatry, 17*, 1146-1154.

Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability.* New York: Routledge.

Westburg, N. (2001). Hope in older women: The importance of past and current relationships. *Journal of Social and Clinical Psychology, 20*, 354-365.

Wolbring, G. (2003). Disability rights approach toward bioethics? *Journal of Disability Policy Studies, 14*, 174-180.

Wolcott, H. F. (1994). *Transforming qualitative data: Description, analysis, and interpretation.* Thousand Oaks, CA: SAGE Publications.

Wright, B. A. (1983). *Physical disability: A psychosocial approach* (2nd ed.). New York: Harper & Row.

Wulff, D. M. (1996). The psychology of religion: An overview. In E. P. Shafranske (Ed.), *Religion and the clinical practice of psychology* (pp. 43-70). Washington, DC: American Psychological Association.

Vash, C. L. (1994). *Personality and adversity: Psychospiritual aspects of rehabilitation.* New York: Springer Publishing Company.

Vash, C. L. (1981). *The psychology of disability.* New York: Springer Publishing Company.

Viemero, V., & Krause, C. (1998). Quality of life in individuals with physical disabilities. *Psychotherapy and Psychosomatics, 67*, 317-322.

Zimbardo, P. G., & Boyd, J. N. (1996). Putting time in perspective: A valid, reliable individual-differences metric. *Journal of Personality and Social Psychology, 77*, 1271-1288.

Zimbardo, P. G., Keough, K. A., & Boyd, J. N. (1997). Present time perspective as a predictor of risky driving. *Personality and Individual Differences, 23*, 1007-1023.

Zinnbauer, B. J., Pargament, K. I., Cole, B. C., Rye, M. S., Butter, E. M., Belavich, T., Hipp, K., Scott, A., & Kadar, J. (1997). Religion and spirituality: Unfuzzying the fuzzy. *Journal for the Scientific Study of Religion, 36*, 549-564.