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The Relationships Between Age of Disability Onset, Adaptation to Disability, and Quality of Life Among Older Adults with Physical Disabilities

Virginia L. Grist



THE FLORIDA STATE UNIVERSITY
COLLEGE OF EDUCATION

THE RELATIONSHIPS BETWEEN AGE OF DISABILITY ONSET,
ADAPTATION TO DISABILITY, AND QUALITY OF LIFE AMONG OLDER
ADULTS WITH PHYSICAL DISABILITIES

By

VIRGINIA L. GRIST

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The members of the committee approve the dissertation of Virginia L. Grist defended on March 2, 2010.

Deborah J. Ebener
Professor Directing Dissertation

Linda Vinton
University Representative

Susan M. Smedema
Committee Member

Barbara J. Edwards
Committee Member

Approved:

Betsy Becker, Chair, Educational Psychology and Learning Systems

Marcy P. Driscoll, Dean, College of Education

The Graduate School has verified and approved the above-named committee members.

I dedicate this dissertation to my parents, Buck and Pam Grist, for their unfailing support and encouragement throughout the course of my graduate studies.

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TABLE OF CONTENTS

List of Tables	vii
Abstract	viii
1. INTRODUCTION.....	1
Statement of the Problem	2
Theoretical Perspectives.....	7
Significance of Study	9
Purpose of Study	10
Summary	12
2. REVIEW OF THE LITERATURE.....	14
Quality of Life	15
Models of Quality of Life	20
Measurement of Quality of Life	21
Adaptation to Disability	25
Theories of Adaptation to Disability.....	26
Disability Centrality Model.....	29
Age of Disability Onset.....	32
Summary	36
3. METHOD.....	38
Participants	38
Instruments	40
Procedures	49
Research Design	51
Data Analyses.....	52
Limitations.....	55
4. RESULTS.....	57
Sample Description.....	57
Preliminary Analysis of Composite Scores	58
Research Question 1	66
Research Question 2	70
Summary of Findings	70

5. DISCUSSION.....	72
Age of Disability Onset, Adaptation to Disability & Quality of Life	73
Demographic Variables.....	75
Differences between Early-Onset & Late-Onset Disabilities	76
Limitations of the Study.....	78
Future Research Recommendations	80
Implications for Practice.....	80
 APPENDICES	 83
A SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE	83
B HEALTH ASSESSMENT QUESTIONNAIRE.....	84
C ADAPTATION TO DISABILITY SCALE - REVISED	85
D SENSE OF WELL-BEING INVENTORY	90
E DEMOGRAPHIC QUESTIONNAIRE	93
F PARTICIPANT CONSENT FORM	94
G HISTOGRAMS FOR ADAPTATION TO DISABILITY AND QUALITY OF LIFE MEASURES.....	95
 REFERENCES	 105
 BIOGRAPHICAL SKETCH.....	 124

LIST OF TABLES

Table 1: Descriptive Statistics for Categorical Demographical and Background Variables.....	59
Table 2: Descriptive Statistics for Continuous Demographical and Background Variables.....	61
Table 3: Descriptive Statistics for Adaptation to Disability and Quality Of Life	62
Table 4: Skewness and Kurtosis for Adaptation to Disability and Quality Of Life Measures.....	63
Table 5: Pearson Correlations among Adaptation to Disability and Quality of Life Measures	64
Table 6: Descriptive Statistics for Adaptation to Disability and Quality of Life as a Function of Timing of Disability Onset	65
Table 7: Results of Multiple Regression Analysis Testing the Relationship between Adaptation to Disability and Quality Of Life	67
Table 8: Results of Multiple Regression Analysis Testing the Moderating Effect of Age of Disability Onset.....	69

ABSTRACT

Due to a number of scientific and socioeconomic advances made during the 20th century, older adults with physical disabilities of both early- and late-onset now have the potential to reach average life expectancy. With a considerable body of empirical evidence supporting an inverse relationship between disability and quality of life in older adult populations, research is needed to determine factors that influence the quality of life of older adults with physical disabilities. There are indications in the literature related to quality of life, adaptation to disability, and the sociological approach known as the life course perspective that suggests that quality of life in older adult populations may be different for individuals with disabilities based on: (a) age of disability onset and (b) adaptation to disability. This study utilized a convenience sample of 160 older adult subjects with physical disabilities to answer two research questions: (1) What are the relationships between age of disability onset, adaptation to disability, and quality of life, and (2) Are there differences in quality of life and adaptation to disability between older adults with early-onset and late-onset physical disabilities? Two separate hierarchical regression analyses were conducted to test two specific null hypotheses associated with the first research question: (a) there is no significant association between adaptation to disability and quality of life, and (b) there is no significant moderating effect of age of disability onset on the relationship between adaptation to disability and perceived quality of life. The first null hypothesis was rejected, and it was concluded that a significant positive relationship does exist between adaptation to disability and quality of life. The second null hypothesis was not rejected: Age of disability onset did not moderate the relationship between adaptation to disability and quality of life. A multivariate analysis of variance (MANOVA) was conducted to test the corresponding null hypothesis for the second research question: There are no significant differences in quality of life or adaptation disability between older adults with early-onset physical disabilities and late-onset physical disabilities. Results showed that participants in the early-onset group had significantly higher adaptation to disability scores than individuals in the late-onset group, but that there were no differences between the groups in terms

of quality of life scores. Therefore, this null hypothesis was rejected for adaptation to disability scores but not rejected for quality of life scores. Additional analyses performed for the second research question reveal supported that age of disability onset did not affect the relationship between the adaptation to disability and quality of life scores, a finding from the analyses for the first research question. The results of this research study add further evidence for Bishop's disability centrality model, a quality of life-based model of adaptation to disability that is based on the premise that adaptation to disability and quality of life are similar yet unique constructs. This model appears to offer rehabilitation counselors a means of understanding, measuring, and exploring adaptation to disability with their clients that has significant potential for furthering the understanding of individual differences in the response to disability.

CHAPTER 1

INTRODUCTION

The medical, technological, and socioeconomic progress of the 20th century has resulted in a dramatic increase in life expectancy in the United States (Partnership for Solutions, 2004). Today in the 21st century, Americans can expect to live longer than any previous generation. A child born in 2006 can expect to live 78.1 years, about 30 years longer than a child born in 1900 (Administration on Aging, 2008). The same year, persons reaching the age of 65 had an average life expectancy of an additional 19.0 years (20.3 years for females and 17.4 years for males (U.S. Bureau of the Census, 2006). These increases in longevity in confluence with other demographic trends, including declines in mortality and birth rates, have resulted in a population of older adults that comprised a record 12.6% of the nation's total population in 2007 (Administration on Aging, 2008). As the "Baby Boom" generation (e.g., those persons born in the United States between 1946 and 1964) reaches and exceeds the threshold of older adulthood, this already substantial segment of the population is expected to grow from 12.6% to 26.2% by the year 2050, making older adults one of the most rapidly growing subpopulations in American society (U.S. Bureau of the Census, 2008).

As disability increases in both frequency and severity as age increases, (National Health Interview Survey, 2006), this demographic shift known as "population aging" will substantially increase the numbers of people and the proportion of the population most at risk for disability. For community-dwelling older adults in the United States, the percentage of individuals with disabilities is now approximately 40 percent, a figure that is three times that for younger people (National Health Interview Survey, 2006). In most discussions about aging and disability, as well as most disability-related research involving older adults, a focus on aging typically refers to the increasing level of chronic illness and disability in later life. That is, the emphasis is on persons with late-onset disability. However, for the first time in this nation's history, there are growing numbers of individuals who were born with or acquired disability early in the life span that are reaching older ages and experiencing premature or atypical aging related to their condition, its management, or other environmental factors.

Ironically, the same 20th century advances that have allowed most Americans to live longer and healthier lives have also made it possible for many individuals to live an extended number of years with one or more disabilities. As people with many kinds of chronic conditions acquired in early, middle, or late life live longer, both people with disabilities and service providers are recognizing the importance of considering and planning for a long-term future. Whether an older adult is experiencing late-onset disability for the first time in later life or confronting the onset of secondary disabilities and increasing functional limitations associated with aging with early-onset disability, more older adults than ever before are faced with the challenge of preserving their quality of life by successfully adapting to the physical, mental, social, and environmental limitations imposed by chronic illness and disability.

Statement of the Problem

Although the disablement process can occur at any age, more Americans will experience disability during older adulthood than any other stage of the life cycle (National Health Interview Survey, 2006). Most of these individuals will acquire disability for the first time later in the life cycle (Verbrugge & Yang, 2002). However, a growing number of Americans who were born with or acquired disability early in the life span are now reaching older adulthood for the first time in this nation's history (Campbell, 1996). This unique segment of the population is comprised of persons with a variety of conditions that were present before middle-age and have persisted throughout the life span, such as polio, spinal cord injury, traumatic brain injury, cerebral palsy, and rheumatoid arthritis (Triesmann, 1987). These individuals have spent most of their lives adjusting to an altered lifestyle in order to reduce the impact of disability on the quality of their lives. Now after living twenty or more years with physical disability, they are experiencing the onset of new symptoms and functional limitations which threaten to further erode their health and independence.

Before World War II, secondary medical conditions such as respiratory illness, renal failure, accidents, infections and depression coupled with a general lack of adequate primary medical care, prevented most persons with early-onset disabilities from experiencing their true life expectancy. Today, advances in medicine and rehabilitation have made the expectation of living to late life fairly reasonable for most persons with early-onset disabilities. The average age of persons living with spinal cord injury in the United States is now approximately 43 years, and over 40 percent are over the age of 45 (Jackson, Djikers, DeVivo, & Poczatek,

2004). These statistics are not surprising considering the cumulative 20-year survival rate for persons with spinal cord injury has reached a record 69.89 percent, with average life expectancies ranging from 84 years of age for persons remaining motor functional post-injury to 68 years of age for those with C1-C4 injuries (National Spinal Cord Injury Statistical Center, 2006). Likewise, the average age of people who acquired the polio virus in the United States is now over 50 years of age and more than 20% are now in their 60's and 70's (Kemp, Adams, & Campbell, 1997; Kemp & Krause, 1999).

Research on aging with early-onset disability began in the early 1980's. Since then, a great deal has been learned about the physiological process of aging in this population through comparison studies using age-matched, nondisabled normative results from previously conducted longitudinal research on "normal" aging. Perhaps the most significant finding from this body of research is that disability does not remain stable across the life span (Bauman & Spungen, 1996; Halstead, 1991; Murphy, Molnar, & Kankasky, 1995; Sie, Waters, Adkins, & Gellman, 1992). Many, if not most, persons who have lived 20 years or more with a physical disability encounter significant new medical, functional, and psychosocial problems that were neither expected nor planned for at an earlier age. While the exact causes of this "premature aging" are unknown, persons with early-onset disabilities typically experience high rates of medical and functional problems 20 to 25 years sooner than their age-matched peers without disabilities (Kailes, 2001; Trieschmann, 1987). This population also has three to four times the number of secondary health problems, such as respiratory and cardiovascular disease, diabetes and osteoporosis, as their age-matched peers without disability (Kemp, 1993).

Psychosocial research concerning aging with early-onset disability has necessarily lagged behind that of its physiological investigation. Of the few studies that have been conducted, the onset of age-related health and functional decline in this population appears to be a precursor of a variety of negative psychosocial outcomes, including an increased incidence of psychological disturbances. Incidence rates of depressive disorder are generally two to three times higher among persons aging with early-onset disability compared to their age-matched peers without disability (Fuhrer et al., 1993; Kemp, Adams, et al., 1997; McColl & Rosenthal, 1994). Contrary to popular belief, depression is not a natural consequence of disability or advancing age. Studies have shown that depression does not correlate with the age, the severity of physical impairment, or the level of disability in persons aging with early-

onset physical disabilities (Fuhrer et al., 1993; McColl & Rosenthal, 1994; Reinhardt, 1996; Tate et al., 1994). However, depression has been shown to correlate with difficulties in coping with changes in health, functioning and social roles that accompany aging. For instance, Kemp and colleagues (1997) found that depression scores among older adults with post-polio were only higher than their age-matched peers without disabilities if the individuals experienced more age-related changes in functioning and/or poor family cohesion.

Whether experiencing disability for the first time in later life or confronting the premature age-related secondary disabilities and functional limitations associated with aging with an early-onset disability, adjusting to disability in later life is a major life course transition that threatens older adults' autonomy, independence, and quality of life. There is a wealth of empirical evidence to suggest that the onset of late-onset disability among older adults is a precursor of a variety of negative life outcomes, such as hospitalization, institutionalization, and death (Horowitz & Reinhardt, 2000; Lenz et al., 2001; Schulz, Heckhausen, & O'Brien, 2000; Wetherall et al., 2004). Disability in later life has even been shown to prompt negative global psychosocial outcomes, such as decreased quality of life, happiness, subjective well-being, and life satisfaction (Dijkers, 1999; Koch, 2000; Kunzmann, Little, & Smith, 2000; Lucas, 2007).

Although the number of psychosocial studies concerning persons aging with early-onset disabilities is limited, the results of the research that does exist suggest that age-related declines in health and functional status negatively impact the quality of life in this subpopulation, as well.. For example, Gerhart, Bergstrom, Charlifue, & Menter (1993) found that persons with spinal cord injury who had age-related functional decline rated their lives as less satisfying than persons who had no such decrease in function. In 1990, a study conducted by Krause showed that life satisfaction increased as persons with early-onset disabilities aged as long as major functional changes did not occur. Similarly, Dijkers (1996) and Fuhrer, Rintala, Hart, Clearman, & Young (1992) found that the differences in life satisfaction among older adults with early-onset disabilities compared to older adults without disability could be attributed to health, mobility, and functional limitations affecting work and social life.

Rehabilitation counselors have long considered the process of psychosocial adaptation essential for enhancing and maintaining the quality of life of persons with disabilities (Crewe, 1980; Devins, 1994; Devins et al., 1983; Livneh, 1988; Livneh, Martz, & Wilson, 2001; Viney &

Westbrook, 1982; Wright, 1983). Psychosocial adaptation can be defined in general terms as the individual's adaptive response to the onset and experience of chronic illness and disability (Kendall & Buys, 1998; Livneh et al., 2001). Understanding how individuals navigate the process of adaptation and using this understanding to devise effective clinical interventions to facilitate adaptation to disability and improve the quality of life of persons with disabilities has served as the defining focus of rehabilitation counseling research for decades (Wright & Kirby, 1999). However, despite the field's increasingly important role in serving older adult populations, few studies examining the relationship between quality of life and psychosocial adaptation to disability have been conducted using older adult subjects (Groomes & Olsheski, 2002). Furthermore, no such studies have investigated the possible influence of age of disability onset on the relationship between adaptation to disability and quality of life among older adults with disabilities.

In order to assist older adults with early- and late-onset disabilities improve and maintain their quality of life as they age, it is essential for rehabilitation counselors to have a comprehensive and clinically meaningful model to understand the relationships between age of disability onset, adaptation to disability and quality of life. Over the past two decades, several rehabilitation researchers have proposed that a multidimensional model of quality of life may be appropriate for understanding both the personal impact of disability and the process by which individuals respond to this impact (Devins, 1994; Devins, Seland, Klein, Edworthy, & Saary, 1993; Livneh, 2001). Specifically, these researchers have proposed: (a) that disability-related changes can be conceived as affecting multiple domains of an individual's life; (b) that the extent of the impact of chronic illness and disability can be conceived in terms of a multidimensional framework of quality of life; and (c) that the disruption caused by these changes results in decreased quality of life. Furthermore, the individual's response to these changes may be defined as an attempt to increase or restore quality of life (Bishop, 2005).

Building on existing research pertaining to both adaptation to disability and quality of life, Bishop (2005) presented a quality of life-based model of psychosocial adaptation to chronic illness and disability termed "disability centrality." The model's central tenet rests on the premise that quality of life and adaptation to disability are directly related processes, with quality of life serving as an appropriate measure to conceive both the personal impact of disability and the process of adaptation to disability. Although the results of a preliminary

analysis of college students with disabilities supported the relationships hypothesized in the model, these findings may not generalize to older adult populations. Furthermore, Bishop's (2005) model does not consider the possible influence of age of disability onset on the relationship between quality of life and adaptation to disability. Without a theoretically sound and clinically applicable model to explain the complex relationships between age of disability onset, adaptation to disability, and quality of life, rehabilitation counselors will be at a distinct disadvantage as they face the challenge of understanding how older adult consumers navigate the process of adaptation to disability and apply this understanding in the form of effective clinical interventions.

Rehabilitation counselors serving older consumers will also require a firm grasp of the nature of aging *with* disability (early-onset) versus aging *into* disability (late-onset). Until recently, the focus of most research concerning aging and disability was placed on the increasing level of chronic illness and disability in later life. In other words, the emphasis has been placed on older adults with late-onset disabilities. However, with population estimates indicating that five to 10 million persons with early-onset disabilities are now reaching older ages (Campbell, 1996), the topic of aging with disability has emerged as a priority among rehabilitation counseling researchers. In contrast to studies of aging with late-onset disability, research concerning aging with early-onset disability refers to the study of the experience of persons who were born with or acquired disability in early to middle life (Kailes, 2006).

It has been suggested by researchers in the fields of both gerontology and rehabilitation counseling that the experience of aging with late-onset disability is fundamentally different from the experience of aging with early-onset disability based on a number of time-related factors surrounding the age of disability onset (Campbell, 1996; Krause & Adkins, 2004). This assumption is grounded in the framework of the life course perspective of sociology (Scheer & Luborsky, 1991) that posits that the life course reflects variations in the temporal structure of disability-related events, such as the age of disability onset. Surprisingly, however, there are no studies to date that examine differences in psychosocial outcomes between older adults with late-onset disabilities and older adults with early-onset disabilities. Knowledge of potential differences between persons aging *with* early-onset disabilities and persons aging *into* late-onset disabilities in regards to adaptation to disability and quality of life may open the door for

rehabilitation researchers to further examine the nature of aging with disability verses aging into disability from a life course perspective.

Theoretical Perspectives

Adaptation to Disability

Although a number of divergent models and measures of adaptation to disability have emerged in the rehabilitation counseling literature over the past forty years, a comprehensive theory and measure of this process has yet to be adopted (Frank & Elliot, 2000; Livneh & Antonak, 1997; Smart, 2001; Wright & Kirby, 1999). Furthermore, some researchers suggest that the existing theories of adaptation to disability lack the clinical utility to translate into actual counseling practice with clients with disabilities (Parker, Schaller, & Hansmann, 2003). As a result, few counselors either utilize various existing measures of adaptation in the counseling process or assess the client's level of adaptation in terms of any specific theory (Bishop, 2001; Kendall & Buys, 1998).

Several researchers from the field of rehabilitation counseling (Devins, 1994; Devins et al., 1993; Livneh 2001) have suggested that a multidimensional model of quality of life may be appropriate for understanding both the personal impact of chronic illness and disability and the process by which individuals respond to the this impact. In response to these suggestions, Bishop (2005) presented a quality of life-based model of psychosocial adaptation to chronic illness and disability termed "disability centrality." This model represents a conceptual theoretical synthesis of several existing models and theories drawn from the literature pertaining to quality of life and adaptation to disability. Several models of adaptation to disability, including Livneh's most recent conceptual framework (2001), the concept of value change associated with acceptance of loss theory (Dembo, Levitan, & Wright, 1956; Wright, 1960, 1983), and a proposed extension to Devin's illness intrusiveness theory (Devins, 1984; Devins et al., 1993) are incorporated in the model. Other concepts drawn from quality of life literature, such as domain importance (Cummin, 1997; Frisch, 1999) and response shift (Schwartz & Sprangers, 1999), are also integrated in the model.

Disability centrality model.

The disability centrality model can comprehensively be stated in terms of the following six tenets:

1. When defined as a subjective and multidimensional construct, quality of life represents an appropriate outcome measure of the adaptation to chronic illness and disability.
2. Overall quality of life represents a composite of perceived satisfaction across a set of life domains. Furthermore, overall quality of life is disproportionately influenced by the degree of perceived satisfaction within those domains that are more “central” to the individual.
3. The onset of chronic illness and disability frequently results in an initial reduction in overall quality of life. This reduction occurs to the extent that chronic illness and disability (a) reduce opportunities to experience satisfaction in centrally important areas of life, and (b) reduce feelings of personal control.
4. Because overall quality of life is disproportionately influenced by satisfaction in more important life domains, the reduction in overall quality of life depends on the degree to which more important life domains are affected.
5. People seek to achieve and maintain a personally derived set-point level of overall quality of life. This is achieved by closing perceived gaps between the present level and the desired level of quality of life.
6. When an individual experiences a reduction in quality of life as a result of the onset of chronic illness and disability, three potential responses may occur: (a) the importance of life domains is shifted so that previously central but highly affected life domains become less central, and peripheral but less affected domains become more central (importance change); (b) the impact of chronic illness and disability in important domains is reduced through processes that increase perceived control, and these domains remain central to the individual (control change); or (c) neither change situation occurs, and the individual continues to experience decreased quality of life.

Age of Disability Onset

Understanding how aging with an early-onset disability differs from aging into a late-onset disability requires an appreciation of the different dimensions of time that may be at work. The life-course perspective of sociology offers a promising framework for expanding our knowledge of aging with early-onset disability. Unlike most rehabilitation approaches which emphasize impairment and limitation, the life course perspective focuses on describing the

temporal structure of disability and examining the consequences of variables in the timing of disability events for the well-being of survivors as they age.

The life-course perspective.

In order to study and understand the experiences of persons aging with an early-onset disability, rehabilitation researchers must remain aware of five possible disability-related dimensions of time that may interact to influence each individual outcome:

1. the usual process of development and aging through childhood, middle life, and late life;
2. the number of years spent with a particular disability, also known as “duration of disability”;
3. the years of exposure to a particular medication (e.g., corticosteroids) or other therapy or environmental factor with cumulative adverse side effects;
4. the individual’s era of disability onset and initial medical treatment, which may be associated with different treatment experiences, attitudes, and opportunities;
5. the age of disability onset in relation to the individual’s developmental maturity.

Significance of the Study

As the population of the United States continues to age, older adults are experiencing increased longevity due to medical advancements and individual efforts towards maintaining a healthy lifestyle. These increases in life expectancy have given rise to a population of older adults currently constituting 33.6 million persons, and these numbers are projected to increase to 70.2 million by the year 2030, as the “Baby Boom” generation completes its transition into older adulthood (U.S. Census Bureau, 2006). Unfortunately, as the numbers of adults who successfully survive into older adulthood increase, so do the numbers of aging adults who will face the challenge of adapting to sometimes overlapping functional limitations during a time in the lifecycle when resources for coping are relatively scarce. This population of older adults with physical disabilities will not only include individuals who have acquired disability for the first time at older ages, but it will also include a new subpopulation of older adults who were born with or acquired disability early in the life span and are now experiencing new symptoms and functional limitations believed to be the result of a combination of factors related to both the aging process and the wear and tear of living with long-term disability.

In order to provide a broad range of services to older adults who are experiencing decreased quality of life and loss of independence due to aging, disability and disability-related

issues, rehabilitation counselors will need to be familiar with age-related and onset-related differences in the presentation and assessment of psychosocial adjustment to disability in both persons aging with long-term and late-onset disabilities. As rehabilitation counselors address the issues related to the psychosocial adjustment of older adults with disabilities, clients will also need to receive concurrent and explicit encouragement toward success in aging and proactive involvement in their own physical and psychological wellbeing. There is a pressing need for social sciences research to identify and validate factors that may moderate the negative impact of disability on the quality of life of older adults with early- and late-onset disabilities. A thorough understanding of the dynamic interplay among the variables that contribute to the quality of life of older adults with disabilities will provide rehabilitation counselors with the tools to implement competent and problem-focused interventions to improve this population's quality of life.

Purpose of the Study

Determining what factors influence the quality of life of older adults with physical disabilities has become a relevant topic for research as demographic shifts have resulted in unprecedented proportions of older Americans with disabilities of early- and late-onset. Empirical evidence suggests that a direct relationship exists between quality of life and adaptation to disability in young adult populations; however this relationship has not been substantiated in populations of older adults with disabilities. Furthermore, the influence of age of disability onset on this relationship is unclear. The purpose of this study was to investigate the relationships between age of disability onset, adaptation to disability, and perceived quality of life in older adults with physical disabilities. This study also sought to determine if differences exist in quality of life and adaptation to disability between older adults with early-onset disabilities and late-onset disabilities.

Research Questions

The following research questions were proposed for investigation in this study:

1. What are the relationships between age of disability onset, adaptation to disability, and quality of life among older adults with physical disabilities?
2. Are there differences in quality of life and adaptation to disability between older adults with early-onset physical disabilities and older adults with late-onset physical disabilities?

Definitions

The following definitions were utilized for the purposes of this study:

Adaptation to Disability: Adaptation to disability is defined as the process of responding to the functional, psychological, and social changes that occur with the onset and experience of living with a disability, chronic illness, or associated treatments (Bishop, 2005). For the purposes of this study, adaptation to disability was defined as the participant's total score on the Acceptance of Disability Scale-Revised (ADS-R; Linkowski, 1971, 1981; Linkowski & Groomes, 2007) which reflects the value change process associated with acceptance of loss theory (Dembo, et al., 1956; Wright, 1983) that is included in Bishop's (2005) disability centrality model.

Age of Disability Onset: Age of disability onset is defined as the age at which an individual acquires, develops, or first experiences disability (Trieschmann, 1987). For the purposes of this study, age of disability onset was defined as the earliest age indicated in response to item #5 on the Demographic Questionnaire. This item requires participants to identify any medical condition, impairment, or disability they have experienced and then indicate the age at which the medical condition, impairment or disability they identified first occurred. Age of disability onset was measured by the earliest age indicated in response to item #5 on the Demographic Questionnaire.

Early-Onset Disability: Early-onset disability is defined as impairment present at birth or acquired in childhood, adolescence, or early adulthood that persists throughout the lifespan (Campbell, 1996; Treischmann, 1987). For the purposes of this study, early-onset disability was defined as impairment that is present at birth or acquired before the age of 45 and persists throughout the lifespan. The age of 45 years was selected as the cutoff point for early-onset disability on the basis of Levinson's (1996) research on life course transitions which defines the culminating life structure for early adulthood to be between the ages of 40 and 45.

Late-Onset Disability: Late-onset disability is defined as impairment present for the first time in middle or older age (Treichmann, 1987). For the purposes of this study, late-onset disability was defined as impairment acquired for the first time at the age of 45 or thereafter, and persists throughout the lifespan. The age of 45 years was selected as the entry point for late-onset disability on the basis of Levinson's (1996) research on life course transitions which defines the entry life structure for middle adulthood to be between the ages of 45 and 50.

Quality of Life: Quality of life is defined as an individual's perception of his or her position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations and standards and concerns (The WHOQOL Group, 1995, p. 1405). For the purposes of this study, quality of life was defined as the participant's total score on the Sense of Well-Being Inventory (SWBI; Rubin, Chan, Bishop, & Miller, 2003).

Older Adults: For the purposes of this study, older adults were defined as individuals who are 55 years of age or older. The age of 55 years was selected as the entry point of older adulthood on the basis of Levinson's (1996) research on life course transitions. Levinson (1996) placed particular significance on the period of the life course occurring between the ages of 50 and 55, which he termed the "Age 50 Transition." According to Levinson (1996, p. 20), it is during this time that middle aged adults "become senior members in our own particular world."

Physical Disability: Physical disability is defined as difficulty performing physical activities in a domain of life typical for one's reference group (Verbrugge & Jette, 1994). For the purposes of this study, physical disability was defined by a score of .50 or higher on the on the Stanford Health Assessment Questionnaire – Disability Index (HAQ-DI; Fries, Spitz, & Young, 1982). The HAQ-DI assesses physical disability in eight fields: dressing and grooming, rising, reach, hygiene, eating, walking, grip and activity. The mean score of all fields constitutes the Disability Index (DI) ranging from 0.00 to 3.00.

Summary

Improvements in medicine, technology, and public policy have resulted in a dramatic increase in life expectancy in the United States. These increases in confluence with other demographic trends have made older adults the fastest growing subpopulation in American society. As disability increases in both frequency and severity with advancing age, this demographic shift toward an older population has also substantially increased the proportion of the population at risk for disability. Given the inverse relationship between disability and quality of life in older adult populations, determining what factors influence the quality of life of older adults with physical disabilities has become a relevant pursuit in rehabilitation research. Most research concerning quality of life among older adults with disability has focused solely on persons with disabilities acquired later in life, referred to in this study as persons with late-onset disabilities. However, today's older adult population contains a small, but growing

subpopulation of individuals who were born with or acquired disabilities early in the life span. Now that persons with early-onset disabilities are reaching older ages, they are experiencing the onset of new symptoms and functional limitations which further threaten their health and independence.

There are indications in the literature related to quality of life, adaptation to disability and the sociological approach known as the life course perspective that quality of life in older adult populations may be different for individuals with physical disabilities based on (a) adaptation to disability and (b) age of disability onset. Rehabilitation counseling researchers have long hypothesized a strong, positive relationship between quality of life and adaptation to disability, but this relationship has yet to be empirically tested in an older adult population. Furthermore, the effect of age of disability onset on this hypothesized relationship is unknown. The purpose of this study was two-fold: (1) to examine the relationships between age of disability onset, adaptation to disability and perceived quality of life in older adults with physical disabilities; and (2) to determine if differences exist in quality of life and adaptation to disability between older adults with early-onset disabilities and older adults with late-onset disabilities.

CHAPTER 2

REVIEW OF THE LITERATURE

Due to improvements in the medical treatment of acute and chronic diseases, along with advances in rehabilitation technology and public health policy, it is no longer beyond the realm of reality for persons with disabilities acquired in early, middle and late life to experience average life expectancies. Ironically, the same medical, technological and political progress that has allowed Americans to live longer and healthier lives has also allowed millions of older adults to live an extended number of years with one or more physical disabilities. With a considerable body of empirical evidence supporting an inverse relationship between disability and quality of life in older adult populations, researchers must now focus their investigations on factors that could possibly moderate this relationship. A review of the literature relevant to this study indicated that the concepts and concerns related to quality of life in older adult population populations may be different for individuals with physical disabilities based on (a) age of disability onset and (b) adaptation to disability.

The purpose of this chapter is to provide the reader with a comprehensive review of the literature relevant to the variables selected for analyses. Because the primary aim of this study was to examine the relationships between age of disability onset, adaptation to disability, and perceived quality of life among older adults with physical disabilities, this chapter begins with a thorough review of the literature concerning quality of life, with an emphasis on the literature specifically pertaining to older adults and persons with disabilities. The chapter continues with a synopsis of the literature related to the process of psychosocial adaptation to disability, including a thorough review of Bishop's (2005) disability centrality model which serves as the theoretical framework for adaptation to disability in this study. This literature review concludes with an examination of the issues surrounding the age of disability onset in older adult populations. A sociological approach known as life course perspective serves as the framework for understanding how the timing of a disability event may influence both the process of adaptation to disability, as well as the quality of life of older individuals with physical disabilities. Throughout this literature review, a life span developmental perspective is used to

conceptualize older adults with disabilities as capable of continual self-realization, potential growth, and fulfillment across the life span.

Quality of Life

Decreases in mortality, higher expectations for living “a good life,” and political concern for reducing public expenditure for health care have resulted in increasing interest in the topic of quality of life in older adult populations. With increases in life expectancy resulting in an average human life expectancy of 75 years, older adults are the largest and fastest growing segment of the population in the world. Although the prospect of a longer life may appeal to many people, the absolute and proportional increase of the aging population today may entail troubling medical and economical consequences for the individual and society as a whole.

In general, the risk of disability for Activities of Daily Life (ADL), which includes bathing, dressing, toileting, transfer and feeding, increases with age (Jagger, Spiers, & Clark, 2001). For the majority of older adults, disability results from a chronic condition that gradually erodes the individual’s functional capacity over a considerable amount of time. Most of the chronic illnesses associated with aging are characterized by an indolent, but progressive disease process with an unpredictable course. Although these conditions are not necessarily terminal and can usually be treated with medication and lifestyle changes, their onset often marks the beginning of a series of age-related functional declines that result in the loss of independence, and eventual death, of the affected individual. The uncertain course of these conditions, along with the time, money and energy required to manage a chronic illness not only increase health care costs for the individual and society, but they also decrease the quality of many older adults’ lives (Goodheart & Lansing, 1997).

Public policy makers are increasingly called upon to devise policies to enhance and maintain quality of life through the increasingly lengthy stage of life known as “older adulthood.” The primary aim of these policies is to implement programs that enable older adults to respond more effectively to the physical, psychological, and social challenges of older age in order to maintain their independence, thereby adding “quality” to years of life (Healthy People 2010, National Health Promotion and Disease Prevention Objectives, 1998). The emphasis of these policies on fostering independence and improving quality of life among the older adult population reflects a shift in the focus of social science research from a primarily negative paradigm of old age which emphasizes loss and decline to a more positive view of old

age as a time of continued growth and development (O'Boyle, 1997). Today the stage of life known as older adulthood is ideally viewed as a time in which one is released from a number of structured social roles and free to explore activities and interests that can provide personal fulfillment. The developmental challenge of older adulthood is to successfully adapt to age-related factors that may limit opportunities for growth and fulfillment, such as disease, disability, and loss of income, in order to maximize quality of life throughout the life span (Baltes & Baltes, 1990; Baltes & Carstensen, 1996;; Marsiski, Lang, Baltes, & Baltes, 1995).

Although improving quality of life among older adults is the primary focus of national and international aging research programs across the world, there is still no consensus on a definition of quality of life for this, or any other, population. In fact, no standard definition of the concept or widely accepted measurement instrument currently exists for older adults or any other demographic group. In the sections that follow, the literature concerning the ongoing struggle to define quality of life are presented, along with an overview of four models of quality of life. This review of the literature relevant to quality of life among older adults concludes with a synopsis of issues related to the measurement of quality of life in older adult populations.

Defining Quality of Life

The term “quality of life” refers to the evaluation of the condition of life of a person, a group or a population. Discussion about quality of life and its theoretical origins can be traced back as far as 365 B.C. to the Greek philosopher, Aristotle. He surmised that “good life” is something to live by, as well as live for (McKeon, 1941). The Aristotelian conceptualization of quality of life remains surprisingly relevant for older populations today in that “living well” is best described in terms of strategies for maintaining quality of life. Since Aristotle, a plethora of scholars have attempted to deconstruct “quality of life” in an effort to derive its true meaning and theoretical origins. Although a great deal of descriptive evidence has been garnered through the empirical study of the concept, quality of life remains theoretically undefined by the scientific community.

Quality of life is an emotionally neutral term that refers to the cognitive evaluation of the state of one’s life according to certain criteria (Efklides, Kalaitzidou, & Chankin, 2003). These criteria can include objective or subjective indicators, or a combination of both (Bowling, 1996; Bowling & Windsor, 2001; Rosenburg, 1992). Objective indicators of quality of life are based on observations that are external to the individual, such as standard of living, income,

education, health status and longevity. These criteria can also involve the quality of the physical and social environment, physical and mental health services, and available support networks (Birren & Dieckman, 1991; Boelhouwer, 2002). Conversely, subjective indicators of quality of life reflect the individual's perceptions of his or her overall quality of life based on his or her experiences and values (Arnold, 1991; Diener, 2000). Subjective criteria can include judgments of life satisfaction, as well as the individual's perceptions of his or her physical, psychological, sexual, and social functioning; financial condition; autonomy and perceived control over life circumstances; and opportunities to pursue interests and participate in recreational activity (Arnold, 1991).

How a researcher chooses to define quality of life typically varies according to the context in which the construct is being applied and the criteria chosen for measurement (Bishop, 2005). For instance, studies utilizing measurable economic "facts", such as income or unemployment figures, as indices of quality of life must necessarily define the construct in objective terms. Erickson (1993) provides a textbook example of such a definition in his writings concerning approaches to welfare research when he describes quality of life as an "individual's command over resources in the form of money, possessions, knowledge, mental and physical energy, social relations, security and so on....." (*The Quality of Life*, p. 68).

Subjective indicators of quality of life, which involve an evaluation of one's circumstances in life, essentially measure how "good" an individual considers his or her life to be. Subjective criteria are based on individual psychological responses, including life satisfaction, happiness and self ratings, and are often utilized in social science research (Diener & Suh, 1997). Because the present study is designed to measure perceived quality of life among persons aging with disabilities, quality of life is defined in subjective terms. The definition selected was proposed by the World Health Organization and defines quality of life as "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1995, p. 1405)

Today, quality of life is best understood as a complex, multidimensional concept. Both subjective and objective criteria can be used to describe quality of life, and these dimensions can theoretically cut across many life domains, including psychological well-being, social and interpersonal well-being, financial and material well-being, and functional ability (Bishop &

Feist-Price, 2002). While these major life domains are relevant to adults of all ages, they can vary in priority among persons of different age or social groups (Bowling, 1996). For example, social relationships and work may be prioritized more highly in determining quality of life among younger adults, while physical health may be the top priority among older adult populations. However, a group of older adults living in a deprived neighborhood may prioritize physical safety before physical health depending on their needs and values (Scharf & Smith, 2003).

In summary, there is no consensus on a definition for quality of life in older age, whether among healthy older adult populations or older adult populations with chronic illness or disability. Despite a plethora of research on a wide range of objective and subjective indicators of quality of life, there is also no widely accepted or supported theory of quality of life in older adult populations. Quality of life is generally conceptualized in the literature as a multi-dimensional construct, consisting of parts that affect each other as well as their sum. It is also considered to be dynamic in nature, consisting of both positive and negative experiences, affect, values and self-evaluations that may change over time in response to life and health events and experiences.

Older Adults' Perceptions of Quality of Life

During the 1980's and 1990's, quality of life among aging adults became the subject of much research and discussion in the fields of social science. Numerous studies focused specifically on the quality of life of older adults were conducted to determine how quality of life could be defined and measured in this population, as well as what factors influenced it (Arnold, 1991; Birren & Dieckman, 1991; Diener, 2000; Myers, 2000; Wood, 1996). These findings served to transform our ideas about the subject from a quasi-objective conceptualization based on normative criteria determined by experts, to more recent conceptualizations of quality of life as an individual phenomena or social construction composed of multiple dimension across multiple domains.

In an extensive review of the literature pertaining to quality of life in aging populations, Bowling (2000) found that the most frequently reported empirical associations with quality of life in older age were: (a) good health and functional ability, (b) a sense of personal adequacy or usefulness, (c) social participation, friends and social support, and (d) levels of income or other indicators of socioeconomic status (Bowling, Farquhar, & Grundy, 1996; Breeze, Grundy,

& Fletcher, 1991; Kushman & Lane, 1980; Lowenthal & Haven, 1968; Maddox, 1963; Markides & Martin, 1979; Usui, Thomas, & Durig, 1985). Bowling also noted that the data collected in these studies was obtained using a wide variety of indicators and measures based on discipline-specific concepts and/or experts' opinions, rather than those of lay people. The general lack of consistency in the data collection of these studies, coupled with the lack of empirical evidence to support the relevance of the items of most quality of life measures in aging populations motivated researchers to begin focusing their investigations on the older adults themselves to clarify previous findings and assumptions regarding quality of life in aging populations.

One of the largest studies examining older adults' perceptions regarding quality of life was conducted by Bowling, Gabriel, and Dykes (2002). In a national survey of 999 adults aged 65 and older living in Scotland and England, Bowling et al. (2002) examined older adults' perceptions of quality of life by analyzing the content of subjects' responses to open-ended questions about the construct. The main themes generated from respondents' responses concerning the constituents of a "good life" were, in order of magnitude: (1) social relationships, (2) social roles and activities, (3) solo activities, (4) health, (5) psychological well-being, (6) home and neighborhood characteristics, (7) financial circumstance, (8) independence, and (9) miscellaneous and socio-political factors. Poor health was most often mentioned by respondents as the factor that took "quality away" from their lives, followed by neighborhood characteristics.

Bowling and Gabriel (2004) furthered this preliminary investigation by comparing theoretically derived quality of life indicators from the national survey of older adults (Bowling et al., 2002) with respondents' own definitions of quality of life in an attempt to develop a conceptual framework of quality of life based solely on the views of older adults. The variables which explained most of the variance in quality of life ratings were: (1) social comparisons and expectations, (2) personality characteristics (optimism vs. pessimism), (3) health and functional status, (4) personal social capital (social activities, contact and support), (5) external neighborhood social capital (perceived safety and quality of neighborhood), and (6) socioeconomic factors. Taken together, both the theoretically derived model (Bowling et al., 2002) and the perception-based model (Bowling & Gabriel, 2004) suggest that quality of life in older adulthood is built on: (1) psychological characteristics, (2) health and functioning, (3)

social activities, (4) neighborhood characteristics, as well as (5) perceived financial circumstances and (6) independence. Furthermore, quality of life was influenced by both social comparisons and personal expectations in both models.

Models of Quality of Life

One of the major criticisms of quality of life research is the lack of consistency among the models that provide the basis for its measurement. These models range from subjective and objective indicator models to psychological models based solely on psychological constructs, such as well-being, happiness, morale, and life satisfaction. In the sections that follow, brief descriptions of three of the most widely used models of quality of life are presented, including the objective, subjective, and preference-satisfaction models.

Objective Models

Objective models hold that quality of life is influenced as much by objective social and economic circumstances as by the characteristics of the individual. While some researchers define objective indicators in terms of measurable economic “facts,” such as cost of living reports or income, others broaden this definition to include other objective data, such as social participation and education levels (Boelhouwer, 2002). A few researchers also include subjective self-evaluations of objective indicators, such as level of satisfaction with current income, although these are more commonly defined as subjective social indicators. Objective models utilize a normative approach to measurement in which norm values are often dictated by experts’ opinions. The use of objective models alone to measure quality of life has been widely criticized due to their lack of power in predicting quality of life ratings, especially in view of the paradox of well-being often cited in studies of older adults and persons with disabilities (Mroczek & Kolarz, 1998).

Subjective Models

Subjective models of quality of life are based on the premise that a “good life” is one that is experienced as such. Subjective models of quality of life define quality of life in terms indicators which require some evaluation of one’s circumstances in life. Subjective or experiential indicators are based on the model of subjective well-being as defined by the individual’s “hedonic feelings or cognitive satisfactions” (Diener & Suh, 1997). These indicators are measured using indices of life satisfaction, morale, and balance of affect. Although subjective indicators explain most of the variance found in quality of life measures

(Inglehart & Rabier, 1986), these models have been criticized due to their susceptibility to measurement biases (Veenhoven, 2002).

Preference-satisfaction Models

Preference-satisfaction models define quality of life in terms of both objective circumstances (e.g. housing, security, food) and opportunities for happiness and self-actualization. These models are reminiscent of Maslow's (1954; 1952) theory of human needs, in which needs must be satisfied according to a hierarchical order. Physiological needs for food, water, safety, and security form the base of the hierarchy and represent first-order needs. The middle portion of the hierarchy is composed of the psychological needs for love, society and belonging. Only after the physiological and psychological needs of human beings have been met can top order needs for self-actualization (e.g., ego, status, self-esteem) be satisfied.

It has been argued that human needs are the foundations for quality of life, and hence quality of life can be defined in terms of those needs and measured in terms of the individual's satisfaction with the extent to which these needs have been met. Basic needs satisfaction is, of course, particularly relevant in determining the quality of life of vulnerable groups in society, such as older adults or persons with disabilities. This model and measurement approach is commonly used in both aging and mental health research (Bowling, 2001).

Measurement of Quality of Life

Without a widely accepted theoretical framework, the definition of quality of life, by necessity, has to be considered together with its measurement. The quality of life of older adults is generally measured using scales developed for use with younger adult populations, with the exception of several domain-specific scales of physical functioning for persons with conditions that affect mobility, eyesight, hearing, or continence (Bowling, 2001). Despite increases in the prevalence of chronic illness and disability among older adults, empirical evidence suggests that many factors other than health contribute to quality of life in older adulthood. Because of the importance of such factors as social relationships and neighborhood characteristics in the lives of older adults, this population requires multidimensional assessment which respects the individual's autonomy, individuality and significance of independence (O'Boyle, 1997).

Because the period of life known as older adulthood has increased with human life expectancy to span as many as forty years, the older adult population is increasingly and uniquely heterogeneous. Today's older adult population is not only composed of many different ages, races, and ethnicities, but it is also composed of persons with a wide range of abilities, limitations, and lifestyles. This makes it unlikely that a single measure of quality of life will be suitable for administration to older adults in all situations. This is especially apparent in samples of older adults who are considered "frail" or reside in institutional settings, where issues of autonomy and control become more acute and the use of assistive devices to facilitate independence are important (Abeles, 1991; Lawton, 1991; Liberman, 1991; Wetel, 1991).

Measuring the quality of life of persons with dementia also raises important considerations for assessment. Almost all definitions of quality of life require the individual to self-evaluate the quality of his or her life in different domains. Although self-evaluations of quality of life among persons in the early-stages of dementia have been found to be good (Katsuno, 2005), the reliability of self-report measures in persons with more advanced dementia is questionable. Furthermore, the progression of dementia can affect the relative importance of certain life domains, jeopardizing the content validity of many generic measures of quality of life. For these reasons, dementia-specific measures that give primary importance to affect as a domain are recommended for evaluating quality of life in persons with dementia that has advanced beyond the early stages.

There are several important issues regarding the measurement of quality of life in populations of persons with disabilities that are also relevant to this study. Studies have shown that when quality of life is measured objectively, people with disabilities tend to have a lower quality of life than people without disabilities (Dijkers, 1997). Because the impairments of many people with disabilities impose activity restrictions and/or negatively impact cognitive or affective functioning, measures of objective indicators, such as income, education, and community involvement, tend to classify persons with disabilities as having poorer quality of life than their nondisabled counterparts. However, when subjective measures are utilized, persons with disabilities report much higher levels of life satisfaction than objective measures suggest (Dijkers, 1997; Weinburg, 1984). In fact, studies have shown that some people with disabilities rate their satisfaction with life to be no lower than people without disabilities

(Stensman, 1985). Therefore, subjective measures of quality of life are more likely to provide a valid assessment of an individual's satisfaction with his or her life situation since these measures allow for differences across individuals in what is considered an acceptable or satisfactory state in any given aspect of life (Frank-Stromberg, 1988; Noreau & Sheppard, 1995; Norstrom & Lubkin, 1990).

Psychosocial Factors Affecting Quality of Life Outcomes

Although the last stage of life is often associated with functional decline and other losses, older adulthood has also been associated with greater variation in subjective measures of psychological well-being (Stewart, Shellbourne, & Brod, 1996). The stability of life satisfaction in older adulthood in the face of declines in objective measures of wellbeing has been noted in several studies (Nyabo, Gaist, McGue, Vaupel, & Christensen, 2001). In an Italian study of quality of life among centenarians, the sample of centenarians reported greater satisfaction with life than younger age groups (Buono, Urciuou, & de Leo, 1998). They also complained less about functional limitations, took solace in religious faith, and maintained good social relationships longer than younger age groups. The results of these studies and others suggest that quality of life can be maintained in older adulthood, despite objective age-related declines in functional status, financial status, and social support.

Psychosocial adaptation is sometimes used as an explanation of how good quality of life is maintained in old age. Psychosocial adaptation is the individual's adaptive response to the onset and experience of chronic illness and disability (Kendall & Buys, 1998; Livneh et al., 2001). Over the past two decades, several rehabilitation researchers have proposed the existence of a relationship between psychosocial adaptation and quality of life (Crewe, 1980; Livneh, 1988, 2001; Livneh et al. 2001; Viney & Westbrook, 1982; Wright, 1983). However, despite decades of research committed to understanding the dynamics of psychosocial adaptation, divergent views on both the nature of the process and conceptualization of appropriate outcome measures still exists (Frank & Elliot, 2000; Livneh & Antonak, 1997; Smart, 2001; Wright & Kirby, 1999).

In the Berlin Aging Study, psychosocial adaptation is described in terms of selection, compensation and optimization (Baltes & Mayer, 1999). According to this theory, quality of life can be enhanced in older age by tapering down activities, goals, and functional domains to those which are most salient to one's life (selection); replacing losses with alternatives to

achieve goals (compensation); and maximizing the resources selected. An important mediator of this adaptation process is “response shift,” whereby internal standards and values concerning quality of life are changed to accommodate a hardship or negative circumstance. As a result of changing one’s perception of what a “good life” entails, quality of life can be maintained in the face of adversity (Sprangers & Schwartz, 1999).

The process of psychosocial adaptation has two significant implications for the measurement of quality of life in older populations. Because of the adaptive capabilities of older adults, objective pathology-based approaches to measurement often underestimate levels of health, quality of life and well-being in older adult populations. Instead, subjective self-ratings of psychological well-being and health have been found to explain more variance in the quality of life ratings of older adults than objective measures (Bowling & Windsor, 2001). Secondly, it is possible that psychosocial adaptation in some situations could be a case of “sour grapes” influencing the self-evaluation of quality of life in adverse circumstances and resulting in skewed outcomes (Elster, 1983). For example, 15% of healthy older adults who reported being consciously afraid of death considered “just being alive” to be good quality of life (Butler, 1997). Although individual survival in and of itself can reflect positive adaptation, “just being alive” in no way fulfills the definitional requirements for perceived quality of life.

Closely allied to adaptation, is the phenomena of resilience, in which persons do well against common expectations (Bartley, 2006). Resilience has been used to explain the “well-being paradox” which occurs when older persons with functional limitations still report high levels of well-being (Greve & Staudinger, 2006). Studies of resilience suggest that both social participation and social support promote resilience in older adulthood so that quality of life can be maintained despite age-related losses. A sense of mastery was suggested to play a mediating role in improving resilience among older adults (Windle & Woods, 1994).

Social comparison can also play a role in preserving quality of life in older ages as health and other circumstances deteriorate (Gibbons, 1999). Social comparison is a strategy used by many older adults to mediate a response shift. It involves making upward or downward contrasts or identifications with one’s contemporaries or peers. The predominant strategy referred to in aging and quality of life literature involves making a downward contrast in order to feel grateful and happy for one’s present circumstances in relation to others who are less fortunate (Beaumont & Kenealy, 2004).

High-quality social relations have also been shown to add to the quality of life in older adulthood by promoting resilience. According to evidence from the English Longitudinal Study on Aging, the higher the quality of one's social networks, the higher one's quality of life (Bartley, 2006). High-quality social relationships were also found to promote resilience so that a high quality of life could be maintained in the presence of functionally-limiting longstanding illness (Netuveli, Wiggins, Hildon, Montgomery, & Blane, 2006). Social support can also influence quality of life, although different types of support can have different impacts. For example, Reinhardt, Boerner, and Horowitz (2004) found that while emotional support is positively associated with quality of life, receiving instrumental support can reduce well-being by accentuating the dependence that resulted in the need for support.

Lastly, the perception of control is believed to differentially contribute to well-being among older adults. In the Berlin Aging Study, the belief that one has control over a desired outcome was shown to have a positive effect on psychological wellbeing among older adults, which in turn contributed to higher quality of life outcomes (Kunzmann, Little, & Smith, 2002). However, an opposite effect was observed for subjects who believed other persons controlled their lives. Furthermore, subjects who believed that they were responsible for negative outcomes had lower scores on emotional well-being in cross-sectional studies, but higher scores in longitudinal analysis.

Adaptation to Disability

Adaptation to disability was selected as a variable for analysis in the present study in order to realize the extent to which adapting to life with a chronic illness or physical disability influences the quality of life of aging adults with physical disabilities. Disability has a major impact on the physical, psychological and social aspects of the lives of the individuals who experience them. A number of individual and disability-related variables, including the nature of the condition, the personality of the individual, the meaning the individual assigns to the disability, and the individual's current life circumstances, interact to determine the extent of that impact. Reactions to disability also vary considerably with the individual's ability to cope with disability-related stressors, such as functional limitations, societal attitudes, and environmental challenges. Consequently, no two individuals respond in exactly the same manner to the onset of a chronic illness or physical disability.

Every chronic condition or physical disability requires some alteration or adjustment in daily life. Individuals with chronic illness or disability are often faced with the challenge of adjusting to significant changes in their social and familial roles and relationships, while concurrently coping with psychological distress, physical pain, extended medical treatment, and limitations or restrictions in the performance of daily activities (Charmaz, 1983; Livneh & Antonak, 1997). The process of responding to the functional, psychological, and social changes that occur with the onset and experience of living with a disability, chronic illness, or associated treatments is referred to as psychosocial adaptation.

Although considerable disagreement exists concerning the specific nature of the adaptation process, as well as its outcome (Livneh, 2001; Livneh & Antonak, 1997; Wright & Kirby, 1999), two points of general consensus have consistently emerged across theories. The first is that the process of adaptation to disability requires a multidimensional response. Because the onset of chronic illness and disability may potentially affect a wide range of psychological, social, environmental, and physical domains, the process of adaptation to disability must be measured multidimensionally (Jacobson et al., 1990; Livneh & Antonak, 1997; Shontz, 1965). The second point of consensus concerning adaptation to disability is that this process is highly individual and subjective in nature. Because research has consistently indicated that significant variation exists within and across individuals in the adaptation process, the only true predictor of adaptation outcome appears to be the individual's subjective analysis of his or her total situation (Kendall & Buys, 1998).

Theories of Adaptation to Disability

The process of adapting to a disability, as well as its outcome, has been conceived in variety of ways (e.g., Deloach & Grier, 1981; Kendall & Buys, 1998, Linkowski, 1971; Livneh & Antonak, 1997; Wright, 1983; Wright & Kirby, 1999). The earliest approaches to understanding the process of adaptation to disability were rooted in the medical model and emphasized a direct relationship between the condition and the degree of impairment (Elliot, 1994). These approaches advanced the idea that specific disabilities manifest specific personality characteristics or psychological disorders. As researchers increasingly observed that neither the diagnosis, nor the degree of impairment, served as significant predictors of an individual's overall adaptation to disability (Williamson, Schultz, Bridges, & Behan, 1994), these theories quickly became regarded as antiquated and were widely criticized for both their

failure to capture the complexity and individuality of the adaptation process, as well as their lack of empirical support

During the 1970's and 1980's, sequential or stage theories of adaptation gained credibility among the members of the rehabilitation research community. Stage theories describe the adaptation process in terms of an individual's movement through a predictable and limited series of stages of adjustment following the onset of chronic illness or disability. Recently, the premise of these theories has been called into question across several fronts. For example, because chronic illnesses and disabilities are not static conditions, but instead change and evolve over time, the idea of a final stage of adjustment has been largely rejected by rehabilitation theorists as unrealistic (Kendall & Buys, 1998; Parker, Schaller, & Hansmann, 2003). Furthermore, the stages incorporated by many of these theories are not universally experienced by all persons who acquire a chronic illness or disability. For instance, not all individuals experience a period of depression following the onset of disability though depression is a stage required in many stage models. Much like the early theories, stage theories have also been criticized for both their lack of predictive power (Elliot, 1994; Parker et al., 2003) and complexity to adequately represent the individual nature of the adaptation process, particularly in terms of progressive conditions (Kendall & Buys, 1998; Wortman & Silver, 1989).

More recent conceptualizations of adaptation, termed ecological or interaction models, offer a more comprehensive approach to understanding the complexity and uniqueness of the adaptation process. These models emphasize the individual's interactions with the environment in which he or she lives. For example, the conceptual framework proposed by Livneh and Antonak (1997) and Livneh (2001) suggest that four groups of variables interact to influence adaptation outcomes, including socio-demographic variables, disability-related variables, personality attributes, and physical and social environmental variables. Although ecological models have been heralded as more accurate representations of the adaptation process, they too have been criticized for being descriptive, rather than predictive. Because they fail to identify the driving force behind the movement toward adaptation (Kendall & Buys, 1998; Linkowski, 1971), these models have limited clinical utility for informing counseling interventions.

In terms of psychometric approaches to defining and measuring adaptation outcomes, the measures most commonly used in rehabilitation research have been widely criticized for their unidimensional and atheoretical nature, as well as their conceptual ambiguity (Livneh & Antonak, 1997; Wright & Kirby, 1999). Most of these measures of adaptation define adaptation to disability as a unidimensional construct measured as, for example: (a) the presence of psychopathology, (b) physical or behavioral complaints, (c) changes in productivity or performance, or (d) degree of disability acceptance (Livneh & Antonak, 1997). Such approaches fail to encompass the complex, multidimensional nature of the individual's experience. Extant measures of adaptation to disability have also been criticized for having a negatively skewed perspective (Smart, 2001; Wright & Kirby, 1999). For example, although many individuals report positive aspects of living with a disability (e.g., Smart, 2001; Wright, 1983; Wright & Kirby, 1999), most unidimensional and deficit-oriented measures of adaptation fail to capture this aspect of the experience.

Understanding how individuals navigate the process of adaptation and applying this understanding in the form of effective clinical interventions has been a defining focus of rehabilitation counseling research for decades (Wright & Kirby, 1999). However, despite a plethora of divergent models and an expansive body of literature committed to understanding the dynamics of psychosocial adaptation to disability, a comprehensive theory of adaptation to disability has not been commonly accepted (Frank & Elliot, 2000; Livneh & Antonak, 1997; Smart, 2001; Wright & Kirby). Furthermore, the clinical utility of existing theories of adaptation have increasingly been called into question, as these theories have not been translated into clinical practice (Parker et al., 2003). Studies have shown that few rehabilitation counselors either utilize various existing measures of adaptation in the counseling process or assess the client's adaptation in terms of any theory (i.e., Bishop, 2001; Kendall & Buys, 1998). Bishop (2005) suggested that the failure of rehabilitation counselors to evaluate and address adaptation in the counseling relationship could be due to a number of factors, including: (a) failure to understand the potential influence of adaptation on the rehabilitation outcome; (b) failure to recognize the clinical utility of existing theories of adaptation in the counseling relationship; (c) a lack of familiarity with, or confusion over, the many theories or models of adaptation found in the rehabilitation literature. In order to address some of these issues,

Bishop (2005) proposed a new model of adaptation to disability that integrates concepts drawn from quality of life literature with existing models of adaptation from the rehabilitation literature.

Over the last two decades rehabilitation researchers have suggested that a multi-dimensional model of quality of life may be appropriate for understanding both the personal impact of chronic illness and disability and the process by which individuals respond to the this impact (Crewe, 1980; Devins, 1994; Devins et al., 1993; Livneh, 2001; Livneh, 1988; Livneh, Martz, et al., 2001). Specifically, these researchers have suggested (a) that disability-related changes can be conceived as affecting multiple domains of an individual's life; (b) that the extent of the impact of chronic illness and disability can be conceived in terms of a multidimensional framework of quality of life; and (c) that the disruption caused by these changes results in a decreased quality of life. Furthermore, the individual's response to these changes may be defined as an attempt to increase or restore quality of life.

Disability Centrality Model

Building on research from the fields of rehabilitation and quality of life, Bishop (2005) presented a quality of life-based model of psychosocial adaptation to the onset of disability termed "disability centrality." This model represents a synthesis and extension of Devins' illness intrusiveness approach (Devins et al., 1993; Devins, 1984) and incorporates components of several models of adaptation to disability, including Livneh's recently proposed conceptual framework (2001) and the concept of value change (Dembo et al., 1956; Wright, 1960, 1983). Concepts drawn from quality of life literature, including domain importance (Cummin, 1997; Frisch, 1999) and response shift (Schwartz & Sprangers, 1999), are also integrated in the model.

Definition of Adaptation to Disability

For the purposes of the disability centrality model, Bishop (2005) defined adaptation to disability as the individual's personal and highly individual response to disability- or illness-related disruptions across a wide range of life domains. Such disruptions may be experienced in interpersonal relationships, in person-environment interactions, and as changes in psychological, emotional, and physical functioning. Because the process of adaptation is both multidimensional and subjective, Bishop (2005) suggested that quality of life, when appropriately defined, represents a measure of adaptation that (a) is sufficiently broad to

evaluate changes across multiple life domains, and (b) is able to capture the individual's subjective experience of change within those domains.

Definition of Quality of Life

Based on the consensus of rehabilitation researchers that adaptation to disability represents a subjective and multidimensional process, Bishop (2005) defined quality of life in similar terms. Specifically, quality of life is defined as the subjective and personally-derived assessment of overall well-being that results from an individual's evaluation of satisfaction with an aggregate of personally or clinically important domains. This somewhat narrow definition of quality of life has often been referred to as subjective or perceived quality of life (Cummins, McCabe, Gullone, & Romeo, 1994; Frisch, 1999). Inherent in this definition is the assumption that overall quality of life results from satisfaction across a number of life domains, the most frequently identified being physical health, emotional health, social support, employment or productive activity, and economic well-being (Bishop & Allen, 2003; Padilla, Grant, & Ferrell, 1992).

Conceptual Tenets

Although not synonymous, it is apparent that the constructs of quality of life and adaptation to disability share many of the same conceptual similarities, including their multidimensional and subjective natures. By linking these similar constructs, the disability centrality model for measuring and understanding adaptation to disability offers counselors and their clients a holistic view of the client's life and a greater understanding of the impact of chronic illness and disability in the context of the complex interactions between personal, social, and environmental domains.

According to the disability centrality model, an individual's overall quality of life represents a summative evaluation of satisfaction in a number of life domains, particularly those that are highly central to the individual (Bishop, 2005). As suggested by Devins (1994) in theory of illness intrusiveness, the onset of chronic illness or disability frequently results in an initial reduction in overall quality of life. This reduction occurs to the extent that the chronic illness or disability (a) reduces opportunities to experience satisfaction in centrally important life domains and (b) reduces feelings of personal control (Devins & Shnek, 2000). Illness intrusiveness theory suggests that this impact can be assessed in terms of quality of life domains.

One of the fundamental tenets of the disability centrality model involves an extension of Devins' theory to incorporate the recent research in the quality of life literature concerning domain satisfaction and control. Results from a number of empirical studies of quality of life suggest that an individual's overall quality of life is disproportionately influenced by satisfaction in more personally important domains (Frisch, 1999; Pavot & Diener, 1993). An important premise underlying this concept termed domain importance is that satisfaction in more personally important areas of life can in fact mitigate or compensate for dissatisfaction in less important areas (Diener & Diener, 1995; Gladis, Gosch, Dishuk, & Crits-Christoph, 1999; Michalos, 1991). Thus, the disability centrality model involves an extension of Devin's approach to include the assessment of domain importance.

The final component of the disability centrality model delineates the mechanisms by which people adapt to disability-related changes in quality of life. Based on research suggesting that a positive level of quality of life is not only normative but also adaptive, Bishop (2005) suggests that people respond to the reduction of quality of life imposed by chronic illness or disability by making adaptive changes either in terms of their external conditions or through a process of value change. Conceptually similar approaches have previously been suggested by Dembo et al., (1956), Keaney and Gluekauf,(1999), Livneh (1980, 2001), and Wright (1960, 1983).

Quality of life research with adults has revealed that most people tend to rate their quality of life relatively high across cultural groups and regardless of objective circumstances (Cummins, 1998, 2000; Diener et al., 1999). For example, Diener and associates (1999) have reported that to a great extent, person with disabilities and other disadvantaged groups report positive well-being. Diener and Diener (1995) have argued that a positive quality of life baseline is vital to adaptation in that it allows for greater opportunities for social and personal advancement, exploration, and the development of coping resources. Thus, when faced with significant life changes that reduce quality of life, people respond with adaptive changes that allow them to maintain a relatively high level of quality of life.

One form of such change is suggested in the acceptance of loss theory, initially described by Dembo et al. (1956) and further explicated by Wright (1960, 1983) and others (Keany & Gluekauf, 1999; Livneh, 1980). This theory postulates that adaptation to disability requires an adjustment of a person's value system so that his or her actual or perceived losses

attributed to disability do not negatively affect the value of his or her existing abilities. "Value change" refers to the idea that individuals respond to perceived losses in one area of life by discovering value in others. These value changes can be seen as a form of self-image reorganization in which the person with a disability has to reevaluate his self-concept in light of his or her new situation. Thus, the attitude the person with a disability adopts as a result of this reevaluation, whether positive and coping or negative and succumbing, becomes the standard by which his or her future aspirations, actions and performances are measured.

A similar mechanism of value change has been referred to in the quality of life literature as "response shift" (Rapkin & Schwartz, 2004). Response shift is defined as a change in an individual's evaluation of his or her quality of life resulting from either (a) a change in the individual's internal standards of measurement, (b) a change in the individual's values, or (c) a redefinition of quality of life (Schwartz & Sprangers, 1999). Response shift has garnered a great deal of empirical support in the quality of life literature (King et al., 2003; Rapkin & Schwartz, 2004). For example, in a study comparing persons with mobility limitations and persons without disability, Stensman (1985) found that although the two groups were similar in terms of their global quality of life ratings, the group with mobility limitations placed more emphasis on social function and interpersonal relationships and less on physiological function than the group without disabilities. In these and other findings can be seen the "awakening interest in satisfactions that are accessible" (Wright, 1983, p. 163) among persons adapting to chronic illness and disability.

Age of Disability Onset

Now that the older adult population contains individuals with both early-onset and late-onset disabilities, it is important to know if and how the timing of a disability event influences psychosocial outcomes in older adults with disabilities. Although a great deal has been learned over the past two decades concerning the physical implications of aging with an early-onset disability (e.g., Bauman & Spungen, 1996; Halstead, 1991; Murphy, Molnar, & Kankasky, 1995; Sie, Waters, Adkins, & Gellman, 1992), many questions remain unanswered concerning psychosocial outcomes in this population. Furthermore, no empirical studies to date have investigated potential differences in psychosocial outcomes between older adults with early-onset disabilities and older adults with late-onset disabilities. Now that persons with early-onset disabilities are reaching older adulthood and joining the older adult population with

disabilities of later onset, empirical research to delineate the influence of age of disability onset on the psychosocial outcomes of adaptation to disability and quality of life in older adult populations with disability is emerging as a priority in the fields of both rehabilitation and gerontology. Age of disability onset is selected as a variable for analysis in the present study in order to realize the extent to which an individual's age at the onset of disability influences the relationship between adaptation to disability and quality of life in older adults with physical disabilities.

Definition of Age of Disability Onset

“Age of disability onset” is a medical term referring to the age at which an individual acquires, develops, or first experiences a disabling condition (Trieschmann, 1987). Traditionally, the age of disability onset has been used to categorize disabling conditions as congenital, developmental, childhood-, juvenile-, or adult-onset (Falvo, 1999). However, with recent increases in life expectancy for older adults with both early- and late-onset disabilities, the term age of disability onset has recently been used to classify the disabling conditions in older adults as being either: (a) present at birth or acquired in childhood, adolescence, or early adulthood and persisting throughout the lifespan (i.e., early-onset disabilities); or (b) present for the first time in middle or older age (i.e., late-onset disabilities) (Treichmann, 1987).

When age of onset is measured in order to categorize individuals into groups, such as “early-onset” or “late onset”, the ages used to define the upper and lower limits of such categories have primarily depended on the research interests of the researcher. For instance, when Ryan and Morrow (1986) examined the relationships between gender, self-esteem, and age of disability onset in children with diabetes, subjects diagnosed with diabetes before the age of five were assigned to the early-onset group and those diagnosed at or after age five were assigned to the later-onset group. The onset age of five years was chosen to serve as both the cut-off and entry points for group assignment based on the researchers' interest in the influence of both gender and age of disability onset on short-term psychological outcomes in a sample population of children with diabetes. Consequently, when Loprest and Maag (2003) conducted a study to determine the influence of age of disability onset on educational and employment outcomes, subjects were assigned to early-onset and late-onset groups on the basis of whether they first experienced activity limitations before or after the age of 22. Because most people in the United States have at least completed their compensatory

schooling by the age of 22, this definition of age of disability onset allowed the researchers to determine if age of disability onset continues to affect employment outcomes later in life.

Age of Disability Onset as a Research Variable

Because the term “age of disability onset” was originally used to categorize disabling conditions as congenital, developmental, childhood-, juvenile-, or adult-onset, most empirical research studies have examined the influence of age of disability onset on short-term developmental and psychosocial outcomes in populations of children, teenagers, and young adults with disabilities. For instance, several studies have suggested that individuals who develop diabetes early in life are more likely to manifest serious cognitive and behavior impairments as adolescents (Rovet, Ehrlick, & Gore, 1986; Ryan, Vega, & Drash, 1985) and have lower self-esteem (Hayden, Davenport, & Campbell, 1979; Kapp, 1979; Lindemann, 1981). Many questions have also been raised about the impact of disability onset on the emotional development of adolescents; the research findings of these studies, however, have been inconclusive at best. While a number of studies support the position that adolescents with disabilities demonstrate increased rates of psychological maladjustment, behavior problems and psychiatric symptoms (Drotar & Bush, 1985; O'Malley, Koocher, Foster, & Slavin, 1979; Orr, Weller, Satterwhite, & Pless, 1984), other studies, however, have shown no differences between teenagers with disabilities and their age-matched nondisabled peers in such areas as anxiety or self-esteem (Beck, Nethercut, Crittenden, & Hewins, 1986; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980).

Although no published studies to date have examined differences in psychosocial outcomes between older adults with early-onset and late-onset disabilities, a number of empirical findings highlight the potential significance of age of disability onset as a moderating variable. Age of disability onset, as well as duration of disability, have been noted for influencing self-reported health status, a variable which is positively correlated with both adaptation to disability and quality of life (Bostrom & Ahlstrom, 2005). Rehabilitation research findings has also shown age of disability onset to be related positively related to adaptation to disability (Linkowski & Grooms, 2007), as well as quality of life and psychological and financial well-being (Chapin, Miller, Ferrin, Chan, & Rubin, 2004; Dijikers, 1999; Duggan & Dijikers, 2001). However, findings from a number of studies concerning aging with early-onset

disabilities indicate that although quality of life initially increases with duration of disability (Krause, 1990), quality of life begins to decrease significantly in persons who have had physical disabilities for 30 years or longer (Dijkers, 1996; Fuhrer et al., 1992; Gerhart et al., 1993; McColl et al., 1999).

As a group, people aging with early-onset disabilities will likely have had different life experiences with a disability than older adults who have not experienced physical impairment earlier in life. Evidence indicates that younger and middle-aged persons with physical disabilities experience a wide range of social disabilities that may have long-term effects on their physical, mental, social, and economic well-being (Bassnet, 2001; Ferguson, 2001; Gill, 2001; Kemp & Krause, 1999; Pescosolido, 2001; Schriener, 2001). However, some empirical studies suggest that late-onset chronic illness and disability may be associated with lasting changes in the subjective wellbeing of older adults with disability as well (Lucas, 2007; Dijkers, 1999). This could be due in part to the association many older adults make between late-onset disability and approaching mortality (Cohen, 1992). To better understand this conceptualization of disability, one must consider the chronological age, developmental stage and history of the individual affected. Because older adults with late-onset disabilities have lived the greater part of their lives as people without disabilities, many associate their advancing chronological age and late-onset disability as the beginning of the end of life.

Whether disability is acquired early or later in the life cycle, it is important to note that disabilities that occur as part of the aging process create unique psychosocial problems. The chronic illnesses and disabilities associated with the aging process often carry great uncertainty from day to day and definite certainty that the end of life is approaching. Older adults who are facing multiple or overlapping physical problems are often concerned about what else can, or will happen within a body that is no longer young. They may feel more threatened by the onset of chronic illness or disability due to the fact that older age is associated with vulnerability to loss. If these losses are great, it can be exceedingly difficult to face old age with courage and a sense of humor and to take pleasure in living.

Disability: A Life Course Perspective

The life course framework is a sociological approach to the study of aging that emphasizes the interaction of historical events, individual decisions and opportunities, and the effect of early life experiences in determining later life outcomes (Elder, 2006). Several

rehabilitation researchers have suggested that the life course perspective of sociology offers a promising framework for examining the cumulative effects of aging with disability (Campbell, 1996; Halstead, 1988). Building on the work of Scheer and Luborsky (1991), the impact of disability over the life course can be viewed as a complex process involving the intersection of chronological aging, social aging, and historical time, all of which are superimposed on the unique features of the individual's disability timeline. The timeline component reflects the consequences of variations in the timing of disability-related events for the well-being of individual as they age.

The onset of a chronic illness or disability is a life-changing event signifying the beginning of a continuous process of adaptation to different physical, social, and environmental changes. Therefore, each individual with a disability must be considered in the context of the life stage, chronological age, and historical period in which disability manifests, as well as the way in which the changes and limitations associated with the disability influence the attitudes, perceptions, actions, and behaviors characteristic of the individual's life stage, chronological age, and historical period. When disability is considered from a life course perspective, assessing the age of disability onset is essential for understanding how older adult clients assign meaning to and appraise the consequences of disability. In this way, age of disability onset serves as not only a guideline in assessing the older adult client's functional capacity, but also a guideline to determine potential disability-related stressors and reactions to disability-related events.

Summary

In the field of rehabilitation counseling, there is a lack of well-established research concerning the relationship between quality of life and adaptation to disability in older adult populations (Zola, 1999). This could possibly be due to the fact that neither a comprehensive theory nor measure of the adaptation process has been commonly accepted among the rehabilitation research community. Because existing theories have been criticized for their unidimensional portrayals of the adaptation construct as well as their lack of clinical utility, a new model termed disability centrality was chosen to serve as the theoretical framework for this study. This model suggests (a) that disability-related changes can be conceived as affecting multiple domains of an individual's life; (b) that the extent of the impact of chronic illness and disability can be conceived in terms of a multidimensional framework of quality of

life; and (c) that the disruption caused by these changes results in a decreased quality of life. Furthermore, the individual's response to these changes may be defined as an attempt to increase or restore quality of life.

Another variable of interest in this study is age of disability onset. Now that persons with early-onset disabilities are reaching older adulthood and joining the aging population with disabilities of later onset, empirical research to delineate the influence of age of disability onset on the relationship between adaptation and quality of life among older adults with disabilities is emerging as a priority in the field of rehabilitation counseling. Currently, no empirical studies have been conducted using age of disability onset as an independent variable to detect differences in adaptation to aging and quality of life in older adults with early- and late-onset disabilities. However, when disability is viewed from a life-course perspective, it seems reasonable to assume that the age of disability onset may serve not only as a guideline to assess the individual's functional capacity, but also a guideline to determine potential stressors and reactions to disability in aging adult populations.

CHAPTER 3

METHOD

The primary purpose of this research study was to explore the nature of the relationships between age of disability onset, adaptation to disability, and quality of life among older adults with physical disabilities. Based upon the preceding literature review, it is apparent that the concepts and concerns related to quality of life in older adult populations may be different for individuals with physical disabilities based on (a) age of disability onset and (b) adaptation to disability. For this reason, separate two-stage hierarchical regression analyses were conducted to determine: (a) the relationship between adaptation to disability and quality of life and (b) the influence of age of disability onset on this relationship. The secondary purpose of this study was to determine if differences exist in quality of life and adaptation to aging between older adults with early-onset physical disabilities (prior to age 45) and older adults with late-onset physical disabilities (post age 45). A multivariate analysis of variance (MANOVA) was conducted to detect significant differences in the dependent variables, Adaptation to Disability and Quality of Life, between the early-onset and late-onset groups that comprise the categorical independent variable, Age of Disability Onset.

Participants

The eligible participants for this research study were adults ages 55 and over whom self-identified as having one or more limitations in functioning due to a medical condition, impairment, or disability. This convenience sample of volunteers consisted of individuals living independently in the community who participate in social activity and/or social support groups for older adults and/or persons with chronic illnesses and disabilities offered at local community centers in the areas of North Florida and South Georgia. Volunteers were asked to voluntarily complete an instrument pack.

A statistical software package, GPower-3 (Faul & Erdfelder, 2007), was utilized to conduct an a priori power analysis for each proposed statistical analyses to determine sample size. Power of .95, alpha of .05, and a medium effect size were utilized in each power analysis. The minimum sample size calculated for the hierarchical regression analyses was

107. For the MANOVA analysis, a minimum sample of 65 was required. The total number of participants with complete data sets that were finally used in this study was 160.

The sample included both male and female subjects who ranged in age from 55 to more than 97 years of age. In order to minimize the inclusion of individuals whose limitations in functioning do not meet the criteria for mild, moderate, or severe physical disability, respondents with a Disability Index score lower than 0.5 on the Stanford Health Assessment Questionnaire were excluded from the study (Odding, Valkenburg, Stam, & Hoffman, 2001). Because the reliability of self-reports from individuals with moderate to severe cognitive impairments is considered questionable, this study also excluded respondents on the basis of a score of five or below on the Short Portable Mental Status Questionnaire, which indicates possible signs of moderate to severe cognitive impairment (Pfeiffer, 1975). The method for handling individuals who do not meet criteria for inclusion in the study on the basis of the results of the Short Portable Mental Status Questionnaire or the Health Assessment Questionnaire – Disability Index is described within the Research Procedures section of this chapter.

Description of the Sample

The sample consisted of 160 men and women, 55 years of age and over, recruited from social activity and/or social support groups for older adults and/or persons with chronic illnesses and disabilities offered at local community centers in the areas of North Florida and South Georgia. The sample was evenly split between participants with an early onset disability and a late onset disability. Approximately half (51.3%) of the participants were female while 48.8% were male. Most of the participants were White (91.9%) with 6.9% Blacks and 1.2% Native Americans. The most common level of education was a high school education or less (58.7%), followed by a graduate degree (22.5%), with 18.8% having a college degree.

Over half of the participants reported having two or fewer disabilities, with 18.8% having one disability and 33.8% having two disabilities. The most common type of disability was heart problems (16.9%), followed by arthritis (13.8%), kidney problems (11.3%), and diabetes (10.0%), with 21.3% of the participants indicating that they had a disability not included in the survey list. The participants ranged in age from 55 to 97 years old with a mean of 72.46 years old ($SD = 10.18$ years). The age at the onset of disability ranged from 0 to 89 years old with a mean of 43.06 years old ($SD = 23.05$ years).

Instruments

Five measures were completed by each of the subjects in this study: (1) the Short Portable Mental Status Questionnaire, (2) the Health Assessment Questionnaire – Disability Index, (3) the Acceptance of Disability Scale-Revised, (4) the Sense of Well-Being Inventory, and (5) a brief Demographic Questionnaire. A description of each instrument is presented in the sections that follow, including estimates of reliability and validity.

Short Portable Mental Status Questionnaire

The Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975) is a short mental test for assessing cognitive function. This screening tool was designed to describe the participants' capacity for memory, structured thought, and orientation. In this study, the SPMSQ was used to screen participants for possible cognitive impairment. Scores for the SPMSQ are obtained by counting the number of correct responses across 10-items evaluating short- and long-term memory, orientation to place, knowledge of current events, and the ability to perform mathematical tasks. The sum of correct answers is then interpreted as follows: 8 – 10 = cognitive function intact, 6 – 7 = cognitive function mildly impaired, 3 – 5 = cognitive function moderately impaired, 0 – 2 = cognitive function severely impaired. The 10-item SPMSQ and the interpretation of its results can be found in Appendix A.

The SPMSQ has been validated reporting a similar sensitivity and specificity to that of the widely used Mini Mental State Examination (MMSE) (Fitten, Lusky, & Hamann, 1990). Unlike the widely used 13-item MMSE (Folstein, Folstein, & McHugh, 1975) which includes drawing and manual handling of objects, the 10-items included in the SPMSQ can be administered verbally or in writing, making it ideal for use with sample populations that includes persons with physical and/or sensory impairments. In a critique of instruments and methods for detecting cognitive impairment, Smith, Breitbart, and Platt (1995) concluded that the SPMSQ is a quick and versatile screening tool of cognitive impairment. Moreover, the validity of the SPMSQ is rated as very good for memory impairment screening as well as severity-rating (Erkinjuntti, Sulkava, Wikstrom, & Autio, 1987; Fillenbaum, 1980; Fitten et al. 1990; Pfeiffer, 1975; Svensson, Stromberg, Ohlen, & Lindgren, 1996). Regarding the simplicity of the test, interrater reliability is not considered to be a problem, and the test-retest reliability has been shown to be greater than $r = .80$ (Fillenbaum, 1980). The overall conclusion drawn from

the authors of this review was that the SPMSQ is a psychometrically sound brief measure of cognitive function that has been underused in social science research (Smith, Breitbart, & Platt, 1995).

Health Assessment Questionnaire - Disability Index

The Stanford Health Assessment Questionnaire (HAQ) was originally developed under the auspices of the Stanford Arthritis Center at Stanford University to measure outcomes in persons with a wide variety of rheumatic diseases (Fries, Spitz, Kraines, & Holman, 1980). It was one of the first instruments to utilize self-reported patient outcomes to estimate functional status/disability and has become the mandated outcome measure for clinical trials in rheumatoid arthritis and other diseases. Despite its notoriety as a disease-specific measure, the HAQ is considered a generic measure of functional status that has been applied to persons with HIV/AIDS, adults and children with disabilities, and in studies of normal aging (Bruce & Fries, 2003; Hubert, Bloch, & Fries, 1993; Lubeck & Fries, 1993).

The HAQ can be used in several formats. The Full Five-Dimension HAQ is a comprehensive outcome measure that assesses a hierarchy of patient outcomes in five domains: (1) disability; (2) pain and discomfort; (3) adverse treatment effects; (4) monetary costs of treatment; and (5) death (Fries & Ramey, 1993; Fries & Spitz, 1990; Kraines & Britton, 1984; Lorig et al., 1986). It includes sections on medication side effects and medical costs, as well as supplemental sections on demographics, lifestyle and health behaviors. Alternatively, the first two domains comprising the HAQ Disability Index (HAQ-DI) and the HAQ Pain Scale can be used independently and frequently are (Hubert et al., 1993). In this study, the HAQ-DI was used alone to screen volunteers for the presence of physical disability.

The HAQ-DI has been validated in over 200 studies in numerous disciplines since its development in 1978 (Ramey, Fries, & Singh, 1996). The instrument has repeatedly demonstrated both face and content validity via comparison with other instrument in multiple disease areas. Construct validity, predictive validity and sensitivity to change have also been established with the brief instrument proving to be a strong predictor of future disability, morbidity and healthcare costs. It has also been shown to be highly sensitive to change. The HAQ-DI has also demonstrated a high level of convergent validity based on the pattern of correlations with other clinical and laboratory measure (Bruce & Fries, 2003; Fries et al. 1980; Fries, Spitz, & Young, 1982; Lorig, 1986; Ramey et al. 1996). The worldwide usage of the

HAQ-DI has resulted in the instrument's translation and/or cultural adaptation in more than 60 languages and dialects (Bruce & Fries, 2003).

The HAQ-DI assesses a participant's level of functional ability and includes questions of fine movement of the upper extremity, locomotor activities of the lower extremity, and activities that involve both upper and lower extremities. There are 20 questions in eight categories of functioning which represent a comprehensive set of personal and instrumental activities of daily living including dressing, rising, walking, hygiene, grip, and usual activities. The HAQ-DI was designed to measure a participant's usual abilities using their usual equipment during the past week. For each item, there is a four-level difficulty scale that is scored from 0 to 3, representing NO difficulty (0), SOME difficulty (1), MUCH difficulty (2), UNABLE to do (3). The highest component score in each category determines the score for that category, unless aids or devices are required. Dependence on assistive equipment or physical assistance increases a lower score to the level of two to more accurately represent underlying disability. The eight category scores are averaged into an overall HAQ-DI on a scale from zero (no disability), to three (severe disability). The scale is not truly continuous but has 25 possible values (i.e., 0, 0.125, 0.250, 0.375...3). Scores are not computed when the respondent provides answers in fewer than six categories. In this study, volunteers who scored below 0.50 on the HAQ-DI (i.e., the threshold for mild disability) were considered to be persons without disability, and their results were excluded from the data analyses.

The HAQ-DI is usually self-administered, but can also be given face-to-face in a clinical setting or in a telephone interview format by trained assessors, and has been validated in all of these settings. The questionnaire is typically mailed to respondents, who are asked to complete it without additional instructions. The instrument can be completed in approximately five minutes and is considered self-explanatory by most respondents. A copy of the HAQ-DI and instructions for its scoring and interpretation are included in Appendix B.

Adaptation to Disability Scale – Revised

The Adaptation to Disability Scale-Revised (ADS-R), a revised version of the Acceptance of Disability Scale (ADS) developed by Linkowski (1971), was used in this study to measure adaptation to disability. The ADS-R (Linkowski & Groomes, 2007) is a self-report questionnaire that measures the extent to which an individual with a physical disability has made a satisfactory adjustment to the disabling condition. This theory-based measure of

adaptation to disability is designed to reflect the value change process associated with acceptance of loss theory (Dembo et al., 1956). According to this theory, in order to successfully adapt to life with a disability, adjustments of the individual's value system must occur such that the losses attributed to disability do not negatively affect the value existing abilities. This value change process as defined by Wright (1983) pertains to four distinct shifts toward acceptance of loss: a) enlargement of scope of values, (b) subordination of physique relative to other values, (c) containment of disability effects, and (d) transformation of comparative-status values to asset values.

Linkowski (1969, 1971) developed the original Acceptance of Disability Scale (ADS) to parallel these value shifts with a theory of acceptance of disability. The original instrument is comprised of 50 self-report items assessing the degree to which individuals are able to find meaning in their circumstances, value their selfhood, and maintain positive beliefs about themselves. Participants respond to each item on a 6-point Likert scale with response categories ranging from "I disagree very much" to "I agree very much". Each item provides a single score that ranges from one (low acceptance of disability) to six (high acceptance of disability). An overall acceptance of disability score is derived by summing all items with total scores ranging from 300 to zero. High acceptance scores range from 176 to 300, while low acceptance scores range from 175 to zero (Joiner, Lovett, & Goodwin, 1989).

A variety of evidence suggests that the instrument is a valid measure of the construct, variously characterized as acceptance of loss, adjustment of disability, and adaptation to disability. After completing a split-half correlation ($r = .86$) of the scale, Linkowski (1971) reported an internal consistency coefficient of .93. These findings suggest high reliability for the scale. Construct validity was established between the ADS and Butler and Haigh's (1954) Self Ideal Q-Sort measure of self-esteem ($r = .52$). A strong correlation ($r = .64$) between the ADS and Dunn's (1967) Satisfaction with Social Relationships scale provided further evidence of construct validity (Linkowski, 1971). Moreover, a concurrent correlation coefficient of $r = .81$ (Linkowski, 1971) was attained between the ADS and the Attitudes Towards Disabled Persons scale developed by Yunker, Block, and Campbell (1960). The ADS is widely used in national and international research regarding acceptance of disability indicating that the measure is a sensitive index of adjustment among individuals with a variety of debilitating and chronic

conditions (Alston & McCowan, 1995; Bolton, 2001, 1994; Elliot, Uswatte, Lewis, & Palmatier, 2000; Livneh & Antonak, 1997).

Despite the wide and continued use of the ADS since its development in the late 1960's, the psychometric evidence used to support the validity and internal consistency of the measure was called into question in an evaluation by Keany and Gluekauf (1999). Specifically, Keany and Glueckauf (1999) examined the instrument and concluded that the ADS did not provide evidence of a systematic measure of the value change process. These researchers further asserted that the sample size utilized in the 1971 validation study precluded the use of factor analysis. In response to these criticisms and the developer's initiative to update the disability terminology used in some items to reflect sociopolitical and legislative changes, Linkowski and Groomes (2007) revised the original scale in an effort to empirically support the reliability and validity of the scale's measurement of acceptance of loss theory, as well as to increase its relevance to persons with disability in contemporary society.

Exploratory principle components analysis of 356 individual responses on the ADS yielded evidence supporting the scale's measurement of four domains that parallel the four value changes fundamental to adaptation to disability (Groomes, 2004). These data were collected across several studies that examined the relationship of acceptance of disability with variables such as stress appraisal, coping, and employment outcome. Participants were selected from three distinct rehabilitation settings: the public sector, a university office for students with disabilities, and a center for independent living. Participants were adults between the ages of 18 and 65 who met the definition of having a physical disability. Fifty-five percent of the participants were male and 45 percent were female. The racial/ethnic composition of the sample population was 73.2 percent Caucasian, 18.1 percent African American, four percent Hispanic, four percent Asian or Pacific Islander, and 0.7 percent Native American.

The responses of the participants to 50 items of the original ADS were exposed to a principal components analysis with oblique rotation, with eigenvalues for the four-component solution ranging from 12.8 to 1.8 and accounting for 42.1 percent of the variance. All items loaded on at least one component with loading coefficients ranging from .25 to .74. The highest loading for each ADS item served as the basis for component membership; furthermore the four components were named based on the items that loaded highest for that

factor. Thus, the four components were identified as: Transformation, Enlargement, Containment, and Subordination.

In addition to confirming each item's correspondence with a specific value shift process, Linkowski and Grooms (2007) were able to reduce the number of items included in the revised scale from 50 to 32, while still maintaining the psychometric integrity of the measure. After performing a reliability scale analysis with 18 items deleted, the 32-item scale maintained a relatively high to moderate internal consistency among the four components, with alpha coefficients for the four subscales as follows: .88 for Transformation, .82 for Enlargement, .88 for Containment, and .71 for Subordination (Grooms, 2004). Furthermore, the overall reliability for the 32-item ADS-R remained unchanged from the value reported for the original 50-item ADS in 1969 (Cronbach's alpha = .93), supporting the construct validity of the revised measure.

Although Linkowski and Grooms (2007) reworded several items of the ADS-R to reflect currently acceptable disability language, such as "person-first terminology", the majority of the items retained their original wording to maintain phenomenological integrity. For example, person-first language was used to change the wording in the original item number two from "non-disabled person" to "persons without disabilities." Additionally, wording that was only relevant to the provision of medical rehabilitation services was deleted. For example, the original item, "I can see the progress I am making in rehabilitation, and it makes me feel like an adequate person in spite of the limitations of my disability" was modified to, "I feel like an adequate person regardless of the limitation of my disability." Finally, after discussion with colleagues at the 2005 National Council on Rehabilitation Education, Linkowski and Grooms (2007) modified the name of the revised scale from Acceptance of Disability Scale (ADS) to Adaptation to Disability Scale – Revised (ADS-R) to reflect contemporary thinking regarding the individual's need to adapt to living with a disability to increase person-environment congruence. A copy of the ADS-R and instructions for its scoring and interpretation can be found in Appendix C.

The Adaptation to Disability Scale – Revised (ADS-R) is a 32-item scaled designed to assess an individual's level of adaptation to disability. Participants respond to each item on a four-point Likert scale with response categories ranging from 1 = Strongly Disagree to 4 = Strongly Agree, rather than the six-point scaling technique used in the original instrument. The

four-point, forced-choice Likert scale was selected so that participants completing the revised scale would be compelled to decide whether they lean more towards the agreement or disagreement end of the scale for each item (Trochim, 2006). The scale contains twenty-two items that are reversed scored, by assigning the value of 4 to the response selection of 1 (Strongly Disagree), 3 to the response selection of 2 (Disagree), and so on. Once the reverse scoring is completed for item numbers 1, 2, 4, 5, 7, 8, 9, 10, 11, 13, 14, 15, 17, 19, 20, 22, 23, 24, 26, 27, 30, and 31, the total ADS-R score may be derived by summing across all scores of the 32-items. The total score values range from 128 (highest score) to 32 (lowest score) and are interpreted according to the following scale: scores ranging from 97 to 128 = High Levels of Adaptation; scores ranging from 65 to 96 = Medium Levels of Adaptation; and scores ranging from 32 to 64 = Low Levels of Adaptation.

Subscales scores are possible for each value change component, thus depicting the multidimensionality of the revised scale. These scores can be related to external variables such as quality of life indicators, years since disability onset, self-concept and employment outcome (Linkowski & Groomes, 2007). To obtain scores for each subscale, identify the letter located in the left-hand corner of each item and sum all T's, C's, E's, and S's accordingly. The Transformation ("T") subscale represents the summative value of all items pertaining to the value change known as "Transformation of Comparative-Status Values to Asset Values"; the Containment ("C") subscale represents the summative value of all items pertaining to the value change known as "Containment of Disability Effects"; the Enlargement ("E") subscale represents the summative value of all items pertaining to the value change known as "Enlargement of Scope of Values"; and the Subordination subscale represents the summative value of all items pertaining to the value change known as "Subordination of Physique." The total score for each subscale ranges from 36 points (highest value) to 17 points (lowest value). Each totaled subscale score is interpreted according to the following scale: scores ranging from 27 to 36 = High Levels of Associated Value Change; scores ranging from 18 to 26 = Medium Levels of Associated Value Change; and scores ranging from 9 to 17 = Low Levels of Associated Value Change.

Sense of Well-Being Inventory

The Sense of Well-Being Inventory (SWBI) was developed by Rubin, Chan, Bishop & Miller (2003) to measure subjective quality of life in persons with disabilities. In this study, the

SWBI was used to measure quality of life in a population of persons with disabilities ages 55 and over. Rubin et al. (2003) developed the original 36-item self-report questionnaire in response to a number of health care and rehabilitation researchers' (Bishop & Feist-Price, 2002; Gilbride, Thome, & Stensrud, 1998; Rubin, Chan, & Thomas, 2003) recommendations to include quality of life in the framework for assessing health outcomes in rehabilitation settings. A copy of the SWBI and instructions for its scoring and interpretation can be found in Appendix D.

The development of the SWBI was based on a comprehensive review of the literature, focus group study, and Delphi process with several groups of counselors and consumer of work rehabilitation services. The rudimentary instrument developed from these processes was then refined in three instrument-refinement workshops attended by state rehabilitation agency administrators and private-sector rehabilitation managers and service providers. The refined instrument was then administered to 149 work rehabilitation clients. Factor analysis results indicated a five-factor solution to be optimal both in terms of parsimony and interpretability, providing empirical evidence for the factorial structure of the SWBI.

The original SWBI consisted of 36 items from which consumers were asked to indicate the extent to which they agreed that each item was descriptive of them using a four-point Likert type rating scale (Rating: 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). The instrument was comprised of five subscales: physical well-being and associated feelings about self, psychological well-being, family and social well-being, and medical care. The internal consistency reliability coefficients (Cronbach's alpha) were reported to be .88, .83, .79, .72, and .62, respectively. Chan, Rubin, Lee, and Pruitt (2003) correlated functional skill ratings of rehabilitation clients with subjective well-being using the SWBI and reported that clients with higher functional ability were found to have higher physical well-being and associated feelings about self, economic security, and family and social support than clients with lower functional ability. Chan and Rubin (2003) concluded that though the SWBI had great potential for use as measure of subjective well-being for persons with disabilities, the instrument should be validated with additional rehabilitation client samples and other external criteria.

To extend the validation and further refine the SWBI, researchers examined the factorial validity and concurrent validity of the instrument with a sample of community-dwelling

Canadian adults with spinal cord injuries (Chapin, Miller, Ferrin, Chan, & Rubin, 2004). After subjecting the 36 X 36 correlation matrix of the original SWBI to a principal factor analysis, a four-factor solution which accounted for 52 percent of the total variance was found to be parsimonious, have good simple structure, and, compared to the three- and five-factor solutions could be most meaningfully interpreted. Items with factor loadings of greater than .40 in one factor and less than .30 in other factors were used to define the factors, resulting in a final instrument containing 26 items. In general, the factorial structure of the SWBI in the study remained similar to the original instrument, but appeared to be more internally consistent, as supported by higher alpha coefficients.

The first factor, *Psychological Well-Being*, consists of seven items. Five of the seven items are worded to represent psychological distress (e.g., I feel lonely). These items are reversed scored so that the high score in this subscale will reflect positive psychological adjustment. The remaining two items are worded positively to represent psychological adjustment (e.g., I feel good about myself). The coefficient alpha was computed at .87, indicating high internal consistency for the items constituting this factor. The mean well-being rating for this factor was 2.68 ($SD = 0.62$). Eight items represented primarily by employment and financial security comprise the second factor, *Financial Well-Being* (e.g., I can afford medical care). A coefficient alpha of .88 indicates high internal consistency for the items constituting this factor. The mean well-being rating for this factor was 2.73 ($SD = 0.66$). The third factor, Family and Social Well-Being, consists of six items representing primarily social support (e.g., I have someone I can talk to about my problems). The coefficient alpha computed was .84, indicating moderately high internal consistency of the items constituting this factor. The mean well-being rating was 3.14 ($SD = 0.57$). The fourth and final factor, *Physical Well-Being*, consists of five items represented primarily by physical health (e.g. good physical stamina, good energy level, and good medical service). The coefficient alpha computed was .79, indicating moderate internal consistency of the items constituting this factor. The mean well-being rating for this factor was 2.70 ($SD = 0.60$).

The SWBI was correlated with the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF), a generic measure of subjective quality of life, in order to establish concurrent validity. The SWBI psychological well-being subscale correlated highly with psychological subscale of the WHOQOL-BREF ($r = .75, p < .01$); the physical well-being

subscale correlated moderately high with WHOQOL-BREF physical health subscale ($r = .63, p < .01$); the family and social well-being subscale correlated moderately with the WHOQOL-BREF social relationships scale ($r = .45; p < .01$); and the financial well-being subscale correlated with the WHOQOL-BREF environment subscale ($r = .59, p < .0001$). These results provide support for the concurrent validity of the SWBI.

Overall, this version of the SWBI supports the recommendation of health care and rehabilitation researchers to develop a measure of quality of life with psychometric properties for people with disabilities. All SWBI items were developed specifically to relate to disability and rehabilitation. Respondents utilize a four-point Likert scale (SA = Strongly Agree, A = Agree, D = Disagree, and SD = Strongly Disagree) to indicate the extent to which they agree or disagree with each item. Items 4, 5, 6, 7, 8, 11, 12, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, and 26 are scored according to the following key assigning points to the participants' indicated responses: *Strongly Agree* responses receive four points; *Agree* responses receive three points; *Disagree* responses receive two points; and *Strongly Disagree* responses receive one point. Items 1, 2, 3, 9, 10, 13, and 14 are reversed scored where: *Strongly Agree* responses receive one point; *Agree* responses receive two points; *Disagree* responses receive three points, and *Strongly Disagree* responses receive four points. Total scores may range from 104, indicating high quality of life, to 26 indicating low quality of life.

Demographic Questionnaire

This survey instrument was designed specifically for this research study. Self-report questions were used to gather information about each subject, in terms of: gender, age, race/ethnicity, educational level, number and type of chronic illnesses or disabilities, and age of onset of the primary disability. The majority of answers on this questionnaire require only a check mark. A copy of this demographic questionnaire can be found in Appendix E.

Procedures

The subjects for this study were recruited from local community centers that provide social activity and/or social support groups to older adults and/or persons with disabilities in the areas of South Georgia and North Florida. Only participants that are 55 years of age or older and living independently in the community who self-identify as having one or more limitations in functioning due to a medical condition, impairment, or disability were recruited for this study to maintain statistical generalizability of the results. Permission to sample was received from

the directors of the Blakely and Leon County Senior Centers in Blakely, Georgia and Tallahassee, Florida, respectively; the pastors of the First United Methodist Church and First Baptist Church in Blakely, Georgia; and the leaders of two support groups for persons with disabilities in Tallahassee, Florida. Upon approval, a contact person was established at each site and plans to attend upcoming groups meetings were scheduled.

After permission was granted to speak to attendees, potential volunteers were recruited according to the following method. The primary researcher conducted a brief presentation of the research project and interested volunteers were asked to fill out the research questionnaire packet after verbal instructions were given at a predetermined location within each setting. All subjects were given a packet with an informed consent form attached to the top of the packet (see Appendix F). After subjects read the anonymous consent letter stating that participation is both voluntary and confidential, participants were asked to complete the packet of questionnaires according to the directions they provided. Participants requiring assistance due to physical impairment who wished to participate in the study were accommodated by the researcher or a trained researcher assistant. These persons assisted participants on a one-on-one basis to provide the requested accommodation. Subjects were not identifiable by name, and participant confidentiality was maintained at all times by the researcher and research assistant, including subject recruitment, data collection and data storage.

Data were collected by the primary investigator and a research assistant who was a state licensed social worker from Primary Health Care in Blakely, Georgia. The research assistant was trained to administer testing by the principal researcher using verbal instructions, practice mock administrations, and observation of administration with feedback. The principal researcher was available on-site at all times to answer any questions that may arise during test administration or to arrange appropriate accommodations for participants upon request.

The questionnaire packet included: (a) the Short Portable Mental Status Questionnaire to screen for cognitive impairment, (b) the Health Assessment Questionnaire – Disability Index to screen for physical disability, (c) the Adaptation to Disability Scale-Revised to assess level of adaptation to disability, (d) the Sense of Well-Being Inventory to measure subjective quality of life, and (e) the Demographic Questionnaire. If a participant was interested in receiving the results from the study, the participant was asked to provide his or her name and address, and a summary of the study results was mailed. In addition, a summary of the study results was

mailed to the contact person established at each site. At any time during or after the study, a certified mental health counselor was available to discuss any emotional discomfort participants may have experienced during and after the completion of the research study.

During the scoring process the Short Portable Mental Status Questionnaire was scored first. If a subject was moderately to severely cognitively impaired as reflected by the SPMS test results, his or her results were excluded from the study. The Health Assessment Questionnaire – Disability Index was scored next. The results of respondents with a Disability Index lower than .50, indicating very mild to no physical disability, were also excluded from the study.

Research Design

A correlational research design was utilized in the present study. Correlational research is used to investigate relationships among variables studied. Correlations between two variables show the relationship or association between them and do not imply that one is the cause of the other (Campbell & Stanley, 1966). Correlations between variables do, however, allow for prediction in which the higher the correlation, the more accurate the prediction.

Research Question 1

The first research question posed in this study was addressed via two hierarchical regression analyses: What are the relationships between age of disability onset, adaptation to disability, and quality of life among older adults with physical disabilities? To answer this question, two specific null hypotheses were examined:

Ho1: There is no significant correlation between Adaptation to Disability and Quality of Life.

Ho2: There is no significant moderating effect of Age of Disability Onset on the relationship between Adaptation to Disability and perceived Quality of Life.

Based on previous empirical research and a review of the literature relevant to these variables, the researcher hypothesized that: (a) adaptation to disability is significantly correlated with quality of life, and (b) age of disability onset has a significant moderating effect on the relationship between adaptation to disability and quality of life. The predictor variable for the first hierarchical regression analyses was adaptation to disability. Age of disability onset served as the predictor variable in the second hierarchical analysis. Quality of life served as the criterion variable in both analyses.

Research Question 2

This research study also sought to answer a second research question: Are there differences in quality of life and adaptation to disability between older adults with early-onset physical disabilities and older adults with late-onset physical disabilities? The null hypothesis associated with this research question was:

Ho: There are no significant differences in quality of life or adaptation disability between older adults with early-onset physical disabilities and late-onset physical disabilities.

Because no previous empirical studies have examined group differences between older adults with early- and late-onset physical disabilities, a directional hypothesis was not indicated. A multivariate analysis of variance (MANOVA) was performed to detect any significant differences in the dependent variables, adaptation to disability and quality of life, between the early-onset and late-onset groups comprising the independent variable, Age of Disability Onset.

Data Analyses

All data analyses were performed using the Statistical Package for Social Sciences (SPSS 12.0) for Windows. Data were analyzed using descriptive statistics, hierarchical regression analyses, and multivariate analysis of variance (MANOVA). Frequencies, percentages, means and standard deviations were used to summarize the demographic characteristics of the participants.

Preliminary Analyses

An examination of the data was conducted in order to evaluate any violation of the assumptions of regression analysis. In order to describe the sample, the following information was provided: (a) total number of subjects, (b) percentages of male and female subjects, (c) average age and age range of the sample, (d) percentages for identified ethnicities and racial groups, (e) percentages for educational level, and (e) percentages of subjects identified as having physical disability of early-onset and late-onset. The descriptive statistics of means and standard deviations are presented for the predictor variables of age of disability onset and adaptation to disability, as well as the criterion variable quality of life. Means and standard deviations are also reported for the early-onset and late-onset groups on the dependent measures for adaptation to disability and quality of life in Chapter Four.

Cronbach alpha reliabilities were computed for the ADS-R and SWBI to examine the internal consistency of the measures. Preliminary analysis of the data included the identification of any outliers that could exert excessive influence on the results. This was accomplished by examining the scatterplots for all combinations of variables. Any violation of a multivariate normal distribution introduces bias into the estimates of the model parameters increasing the probability of Type I errors. Violations of normality were examined using measures of skewness and kurtosis. Pearson-product moment correlations between the variables were computed to assess for problems of multicollinearity with the data.

Research Question 1

Two separate hierarchical regression analyses were conducted to determine (a) the relationship between quality of life and adaptation to disability and (b) the influence of age of disability onset on this relationship. Regression analysis techniques allow for the evaluation of relationships between one dependent and several independent variables (Tabachnik & Fidell, 2001). Regression also allows for the predictor variables to be correlated with one another in addition to the criterion variable. The result of a regression analysis is an equation that represents the most accurate prediction of a criterion variable from several predictor variables.

In hierarchical regression, predictor variables are entered into the analysis in an order indicated by the researcher and based on logical or theoretical reasoning. The effect of each predictor variable is evaluated in terms of what it adds to the prediction at the point that it is entered. In the present study, the demographic variables of age, gender, race/ethnicity, education, and number of chronic illnesses or disabilities were entered as covariates in the first block of each of the regression analyses in order to control for the effects of potentially important variables of individual differences. To test the first hypothesis, the predictor variable of adaptation to disability was entered in the second block of variables.

A moderated hierarchical regression analysis was conducted to test the second null hypothesis. The interaction between age of disability onset and adaptation to disability scores was entered into the regression analysis to test the moderating effect of age of disability onset on the relationship between adaptation to disability and quality of life. This interaction term was created after centering both age of disability onset and adaptation to disability scores. Centering is the process by which the scales of these two variables are converted to have a mean of zero without affecting the standard deviation (Vogt, 1999). This hierarchical analysis

was performed by entering three blocks of variables: the five covariates were entered in the first block, followed by the predictor variables of age of disability onset and adaptation to disability in the second block, and the interaction between Age of Disability Onset and Adaptation to Disability in the third block.

Research Question 2

The second research question was tested using 2 X 2 between-subjects multivariate analysis of variance (MANOVA). Because no previous empirical studies have examined group differences between older adults with early- and late-onset physical disabilities, this research question was considered exploratory and did not include a directional hypothesis. The purpose of conducting the MANOVA was to examine the interaction effects between the two levels of the independent variable age of disability onset (Group 1 = early-onset, Group 2 = late-onset) and the two dependent variables (i.e., adaptation to disability and quality of life). The two groups for the independent variable were formed on the basis Levinson's (1996) model of transitions in adulthood which delineates the culminating life structure for early adulthood to be between the ages of 40 and 45 and the entry life structure for middle adulthood to be between the ages of 45 and 50. Therefore, the age of 45 was selected to serve as both the cutoff and entry point for each group. Persons ages 55 and older with disability present at birth or acquired before the age of 45 formed the "early-onset" group. Conversely, persons age 55 and older with disability acquired for the first time at the age of 45 or thereafter formed the "late-onset" group.

A Pearson correlation analysis was used to determine the relationship between adaptation to disability and quality of life in the two groups (early-onset, late-onset) as well as in the sample as a whole. To determine if the two groups differ on quality of life and adaptation to aging, MANOVA was performed. Adaptation to disability and quality of life (the dependent variables) were placed into a MANOVA by disability onset group (the categorical independent variable). An omnibus test was first conducted to detect any differences in either or both of the dependent variables between the early-onset and late-onset groups. Individual analysis of variance tests (ANOVA) were then conducted to determine which dependent variable(s) are different based on disability onset group. For contrast tests and intervals, simultaneous inference was utilized to control for family-wise error rate. Therefore, the results for the dependent variables were considered separately using the Tukey HSD procedure, which is

recommended when the family of tests and intervals of interest consist of all possible pair-wise comparisons of the means.

Limitations

The present study has several limitations that must be considered. Because the participants for this study consisted of a convenience sample secured by soliciting volunteers from community settings, the generalizability of the results of this study will be limited. The participants in this study were residents of North Florida and South Georgia, so the results are not generalizable to other geographic locations. The participants were also attendants of social activity and/or support groups for older adults and/or persons with disabilities offered at local community centers. Because social support is positively related to both quality of life and adaptation to disability, it is possible that results from this particular sample on the measures for quality of life and adaptation to disability are positively skewed. Furthermore, because the sample population for this study contained only thirteen non-White participants, any conclusions drawn from the results of this study cannot be generalized to non-White populations. The use of self-report instruments to obtain the data analyzed in this study constitutes another limitation to this study. Self-report assessment is noted for being susceptible to social desirability, attributional errors, distortion due to poor adjustment, and the relative self-awareness of the subjects (Groth-Marnet, 1997).

Several other potential limitations of this study are inherent within the use of regression analysis for correlational research designs. For example, regression analysis is vulnerable to capitalization on chance leading toward misinterpretation of regression coefficients (Smith & Glass, 1987). By relying on the assumption that the variable correlations are determined without error, the multiple correlation (R) of the criterion and predictor variables might lead to biased and inflated estimates of R values. Smith and Glass (1987) state that inflated R values are likely to reduce both generalizability and study replication. The data was examined to guard against other limitations that frequently hinder regression analysis. These limitations could include: (a) a violation of the assumption that the predictor variables have been reliably measured or (b) the problem of multicollinearity, defined as an increase in the size of the coefficient standard errors due to a high level of intercorrelation among predictor variables (Tate, 1996).

Finally, of particular relevance to this study, participants in the study were asked questions to subjectively evaluate the quality of their lives. Because researchers have noted a tendency for older adult subjects with and without disabilities in past studies to report high levels of quality of life (Diener & Diener, 1996; Euler, 1992), the possibility exists of obtaining skewed data. The degree of departure from the assumption of multivariate normality may bias the parameter estimates and increase the chance of committing a Type I error.

CHAPTER 4

RESULTS

The purpose of this study was to investigate the relationships between age of disability onset, adaptation to disability, and perceived quality of life in older adults with physical disabilities. This study also sought to determine if differences exist in quality of life and adaptation to disability between older adults with early-onset disabilities and late-onset disabilities. Two research questions were posed in Chapter One:

1. What are the relationships between age of disability onset, adaptation to disability, and quality of life among older adults with physical disabilities?
2. Are there differences in quality of life and adaptation to disability between older adults with early-onset physical disabilities and older adults with late-onset physical disabilities?

The current chapter presents the results of the analyses performed to answer these two questions. Initially, the sample is described in terms of demographic and background characteristics. Descriptive statistics, psychometric properties, and results related to the distributions of the composite scores and their intercorrelations are then provided. Finally, the two research questions of this study are addressed, and the chapter concludes with a summary of the research findings.

Sample Description

A total of 160 individuals participated in this study. Table 1 shows descriptive statistics for the categorical demographic and background variables. The sample was evenly split between participants with an early-onset disability and a late-onset disability. Approximately half (51.2%) of the participants were female while 48.8% were male. Most of the participants were White (91.9%) with 6.9% Blacks and 1.2% Native Americans. The most common level of education was a high school education or less (58.7%), followed by a graduate degree (22.5%), with 18.8% having a college degree.

The majority of the participants reported having two and three disabilities, with 33.8% having two disabilities and 25.0% having three disabilities. The most common type of disability was heart problems (16.9%), followed by arthritis (13.8%), kidney problems (11.3%), and

diabetes (10.0%), with 21.3% of the participants indicating that they had a disability not included in the survey list. Table 2 shows that the participants ranged in age from 55 to 97 years old with a mean of 72.46 years old ($SD = 10.18$ years). The age at the onset of disability ranged from 0 to 89 years old with a mean of 43.06 years old ($SD = 23.05$ years).

Preliminary Analysis of Composite Scores

Table 3 shows the descriptive statistics for the ten composite scores examined in this study: the four subscale scores (Transformation, Enlargement, Containment, and Subordination) and total score for the Adaptation to Disability Scale – Revised (ADS-R) and the four subscale scores (Psychological, Financial, Family/Social, and Physical) and total score for the Sense of Well-Being Inventory (SWBI). Only the total scores for the ADS-R and SWBI were used in addressing the first and second research questions. The internal consistency reliability coefficients for all ten composite scores were greater than or equal to .70 (the conventional cutoff for adequate reliability) with one exception. Specifically, the reliability of the Subordination scale was only .65. It was expected that this scale would have relatively low reliability because it is based on only five items. The low reliability for this scale is a limitation of this study that will be discussed in Chapter Five.

The next step in the analysis of the composite scores was to determine the level of normality for the distributions. Appendix G shows the frequency distribution for each of the subscales approximate normality. Table 4 shows the skewness and kurtosis of each variable, and in all cases these values were less than 1.00. A z test was used to determine if the skewness or kurtosis values were statistically significant by dividing the value by its standard error. In no case did the z value exceed 1.96, the critical value for statistical significance using a two-tailed test with an alpha level of .05. In summary, the visual examination of the histograms in Appendix G and the values of skewness and kurtosis demonstrated that the distribution of each of the ten composite scores adequately approximated normality.

Table 1

Descriptive Statistics for Demographic and Background Variables (N = 160)

	Frequency	Percentage
<hr/>		
Age of onset groups		
Early onset	80	50.0
Late onset	80	50.0
Gender		
Male	78	48.8
Female	82	51.2
Race		
Native American	2	1.2
Black	11	6.9
White	147	91.9
Education		
High school or less	94	58.7
College degree	30	18.8
Graduate degree	36	22.5

Table 1 -- Continued

	Frequency	Percentage
One	30	18.7
Two	54	33.8
Three	40	25.0
Four	22	13.7
Five or more	14	8.8
Primary type of disability		
Amputation	2	1.3
Arthritis	22	13.8
Diabetes	16	10.0
Stroke	7	4.4
Heart problems	27	16.9
Polio	7	4.4
Cancer	10	6.3
Kidney problem	18	11.3
Lung problem	10	6.3
Thyroid or endocrine problem	7	4.4
Other	34	21.3

Table 2

Descriptive Statistics for Continuous Demographic and Background Variables (N = 160)

	Min.	Max.	Mean	SD
Age	55	97	72.46	10.18
Age of disability onset	0	89	43.06	23.05

The correlations among the ten composite variables are shown in Table 5. As expected, the correlations among composite scores for the ADS-R were all positive and statistically significant ($p < .05$). Statistically significant positive correlations ($p < .05$) were also found between the composite scores of the SWBI. Participants' scores on the subscales of the SWBI and the ADS-R also tended to be strongly correlated, with the exception of the correlation of the Subordination subscale of the ADS-R and the Physical subscale of the SWBI. All other cross-correlations were statistically significant and positive ($p < .05$).

The sample was divided into two groups, those with early-onset of disability ($n = 80$) and those with late-onset of disability ($n = 80$). Participants in the early-onset group reported higher scores on the ADS-R than those for the late-onset group. The mean scores on the SWBI for the early-onset group were approximately equal to those means for those in the late-onset group. These differences will be examined for statistical significance in the analyses performed for the second research question of this study.

Table 3

Descriptive Statistics for Adaptation to Disability and Quality of Life (N = 160)

	Items	Min.	Max.	Mean	SD	α
Adaptation to Disability						
Transformation	9	14	36	28.34	4.54	.80
Enlargement	9	18	36	28.92	4.06	.82
Containment	9	14	36	27.57	4.81	.84
Subordination	5	7	20	14.23	2.91	.65
Total	32	62	128	99.06	13.65	.92
Quality of Life						
Psychological	8	11	32	23.49	3.61	.77
Financial	7	12	28	21.32	3.41	.78
Family/Social	6	13	24	19.38	2.41	.76
Physical	5	8	20	13.76	2.35	.70
Total	26	55	104	77.94	9.71	.90

Table 4

Skewness and Kurtosis for Adaptation to Disability and Quality of Life Measures (N = 160)

	Skewness	SE	z	Kurtosis	SE	z
Adaptation to Disability						
Transformation	-.27	.19	-1.40	-.59	.38	-1.56
Enlargement	-.15	.19	-.78	-.36	.38	-.95
Containment	-.22	.19	-1.15	-.38	.38	-1.01
Subordination	-.18	.19	-.94	-.49	.38	-1.28
Total	-.04	.19	-.22	-.71	.38	-1.85
Quality of Life						
Psychological	.05	.19	.28	.68	.38	1.78
Financial	-.28	.19	-1.44	.17	.38	.45
Family/Social	.12	.19	.63	-.32	.38	-.85
Physical	.35	.19	1.83	.41	.38	1.08
Total	.30	.19	1.58	.57	.38	1.50

Table 5

Pearson Correlations Among Adaptation to Disability and Quality of Life Measures (N = 160)

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
Adaptation to Disability										
1. Transformation	1.00									
2. Enlargement	.60	1.00								
3. Containment	.81	.56	1.00							
4. Subordination	.60	.38	.47	1.00						
5. Total	.93	.78	.89	.69	1.00					
Quality of Life										
6. Psychological	.55	.54	.63	.18	.61	1.00				
7. Financial	.53	.70	.55	.30	.64	.61	1.00			
8. Family/Social	.42	.58	.37	.23	.49	.48	.60	1.00		
9. Physical	.32	.47	.49	.04	.43	.68	.56	.42	1.00	
10. Total	.57	.70	.64	.24	.67	.87	.86	.74	.79	1.00

Note. All correlations are statistically significant ($p < .05$) except for the correlation between Adaptation to Disability: Subordination and Quality of Life: Physical.

Table 6

Descriptive Statistics for Adaptation to Disability and Quality of Life as a Function of Timing of Onset of Disability (N = 160)

	Early Onset (<i>n</i> = 80)		Late Onset (<i>n</i> = 80)		Total Sample (<i>N</i> = 160)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Adaptation to Disability						
Transformation	29.69	3.90	27.00	4.75	28.34	4.54
Enlargement	29.59	4.00	28.25	4.04	28.92	4.06
Containment	28.28	4.45	26.86	5.07	27.57	4.81
Subordination	15.26	2.52	13.19	2.92	14.23	2.91
Total	102.81	12.38	95.30	13.90	99.06	13.65
Quality of Life						
Psychological	23.69	3.31	23.29	3.89	23.49	3.61
Financial	21.45	3.71	21.19	3.09	21.32	3.41
Family/Social	19.56	2.14	19.20	2.65	19.38	2.41
Physical	13.45	2.52	14.06	2.13	13.76	2.35
Total	78.15	9.54	77.74	9.94	77.94	9.71

Research Question 1

Two separate hierarchical regression analyses with observed variables only were conducted to address the first research question. In these analyses, five covariates were employed: age (continuous), gender (dichotomous, coded as 0 = *male*, 1 = *female*), race/ethnicity (coded as 0 = *White*, 1 = *Other*), education (coded as 0 = *high school degree*, 1 = *college degree or graduate degree*), and number of chronic illnesses or disabilities (continuous).

The first null hypothesis for this research question was: There is no significant correlation between adaptation to disability and perceived quality of life. A hierarchical regression analysis was performed with the five covariates and adaptation to disability as predictors of quality of life. The five covariates were entered in the first step of the model and adaptation to disability in the second step. The results of this analysis are presented in Table 7. In the first block, the R^2 was .05, Adjusted $R^2 = .02$, $F(5, 154) = 1.68$, $p = .143$, indicating that the model containing only the five covariates was not statistically significant. However, one covariate, education, was statistically significant, $\beta = .20$, $p = .015$. Participants with higher levels of education tended to have higher quality of life scores.

When adaptation to disability was added in the second step of the model, the R^2 rose to .51, Adjusted $R^2 = .49$, $F(6, 153) = 26.77$, $p < .001$. Age, while not statistically significant in the first step of this model, attained statistical significance when adaptation to disability was added in the second step, $\beta = .17$, $p = .005$. This indicated that older participants tended to have higher quality of life scores. In addition, race was predictive of quality of life when adaptation to disability was added in the second step, $\beta = .12$, $p = .037$. This indicated that non-Whites tended to have higher Quality of Life scores than Whites.

The ΔR^2 with the addition of adaptation to disability was .46, $\Delta F(1, 152) = 144.44$, $p < .001$. The addition of adaptation to disability in this model was statistically significant, which was also demonstrated by the standardized regression coefficient for this variable, $\beta = .75$, $p < .001$. Therefore, the first null hypothesis for this research question was rejected: Adaptation to disability scores were positively related to quality of life scores, even when controlling for the demographic and background variables.

The second null hypothesis for this research question was: There is no significant moderating effect of age of disability onset on the relationship between adaptation to disability

and perceived quality of life. To test the second null hypothesis, a moderated hierarchical regression analysis was performed. To test the moderating effect of age of disability onset on the relationship between adaptation to disability and quality of life, the interaction between age of disability onset and adaptation to disability scores was entered into the regression analysis.

Table 7

Results of Multiple Regression Analysis Testing the Relationship between Adaptation to Disability and Quality of Life (N = 160)

Predictor	ΔR^2	β
Step 1 Control variables ^a	.05	
Step 2 Adaptation to Disability	.46***	.75***
Total R^2	.51***	
<i>n</i>	160	

^aControl variables included age, gender, race, education, and number of disabilities.

* $p < .05$. ** $p < .01$. *** $p < .001$.

This interaction term was created after centering both age of disability onset and adaptation to disability scores. Centering is the process by which the scales of these two variables are converted to have a mean of zero without affecting the standard deviation (Vogt, 1999).

This hierarchical regression analysis was performed with three steps of variables. In the first step, the five covariates were employed: age (continuous), gender (dichotomous, coded as 0 = *male*, 1 = *female*), race/ethnicity (coded as 0 = *White*, 1 = *Other*), education (coded as 0 = *high school degree*, 1 = *college degree or graduate degree*), and number of chronic illnesses or disabilities (continuous). In the second step, adaptation to disability and age of disability onset were entered. In the third step, the interaction between adaptation to disability and age of disability onset was entered. The results from this analysis are shown in Table 8.

In the first step, which is identical to the first block from the prior regression analysis, the R^2 was .05, Adjusted $R^2 = .02$, $F(5, 154) = 1.68$, $p = .143$. While this model as a whole was not statistically significant, education did have a statistically significant effect on quality of life, $\beta = .20$, $p = .015$, indicating that participants with higher levels of education tended to have higher quality of life scores. When adaptation to disability and age of disability onset were included as predictors of quality of life in the second step, the R^2 rose to .52, Adjusted $R^2 = .50$, $F(7, 152) = 23.36$, $p < .001$. The ΔR^2 for this model was .47, $\Delta F(2, 152) = 73.60$, $p < .001$, indicating that the addition of adaptation to disability and age of disability onset increased the ability of the model to predict quality of life scores. Adaptation to disability scores were positively related to quality of life scores, $\beta = .76$, $p < .001$, but age of disability onset was not. Among the covariates, education was no longer statistically significant in the second step, but race was, $\beta = .11$, $p = .046$, indicating that non-White participants tended to have higher quality of life scores than White participants.

In the third step, the interaction between adaptation to disability and age of disability onset was added to the model. The overall R^2 for this model was still .52, Adjusted $R^2 = .49$, $F(8, 151) = 20.34$, $p < .001$. The ΔR^2 was .00, $\Delta F(1, 151) = .16$, $p = .689$, indicating that the addition of the interaction term did not increase the variance explained. Race was still statistically significant in this model, $\beta = .12$, $p = .042$, indicating again that non-White participants tended to have higher quality of life scores than White participants. In addition, adaptation to disability was still statistically significant, $\beta = .76$, $p < .001$, but age of disability

onset was not, and the interaction between adaptation to disability and age of disability onset was also not statistically significant. Therefore, the second null hypothesis for the first research question was not rejected: Age of disability onset did not moderate the relationship between adaptation to disability and quality of life.

Table 8

Results of Multiple Regression Analysis Testing the Moderating Effect of Age of Disability Onset (N = 160)

Predictor	ΔR^2	β
Step 1 Control variables ^a	.05	
Step 2 Adaptation to Disability	.47***	.76***
Age of Disability Onset		.09
Step 3 Adaptation to Disability X Age of Disability Onset	.00	.02
Total R^2	.52***	
<i>n</i>	160	

^aControl variables included age, gender, race, education, and number of disabilities.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Research Question 2

A multivariate analysis of variance (MANOVA) was performed to examine differences in the quality of life and adaptation to disability between older adults with early-onset physical disabilities and older adults with late-onset physical disabilities. The results from the omnibus MANOVA were statistically significant, $F(2, 257) = 11.33, p < .001$. This indicated that the early-onset group and the late-onset group were not equivalent on the two dependent variables. One-way ANOVAs were then performed examining the two dependent variables individually. The test comparing adaptation to disability scores for the two groups was statistically significant, $F(1, 158) = 13.03, p < .001$. This indicated that participants in the early-onset group had higher scores ($M = 102.81, SD = 12.38$) than individuals in the late-onset group ($M = 95.30, SD = 13.90$). Therefore, individuals whose disability occurred earlier were more adapted to their disability than individuals whose disability occurred later.

The ANOVA performed on quality of life scores was not statistically significant, $F(1, 158) = .07, p = .789$. This indicated that there was no statistically significant difference in the mean quality of life score for individuals with an early-onset disability ($M = 78.15, SD = 9.54$) and individuals with a late-onset disability ($M = 77.74, SD = 9.94$). The age of disability onset did not affect quality of life scores.

In addition to comparing the early-onset group to the late-onset group in terms of mean scores for adaptation to disability and quality of life, the relationship between these two scores was examined separately for the early- and late-onset group. For the early-onset group, the Pearson correlation between adaptation to disability and quality of life scores was $r = .67, p < .001$. For the late-onset group, the Pearson correlation was $r = .72, p < .001$. Table 5 showed that for the total sample the correlation between adaptation to disability and quality of life scores was $r = .67, p < .001$. Thus, based on the correlational analysis, it appears that age of disability onset does not affect the relationship between the adaptation to disability and quality of life.

Summary of Findings

This chapter presented the results of the analyses performed to investigate the relationships between age of disability onset, adaptation to disability, and perceived quality of life in older adults with physical disabilities. The first research question of this study was: What are the relationships between age of disability onset, adaptation to disability, and quality of life

among older adults with physical disabilities? The first null hypothesis for this research question was: There is no significant correlation between adaptation to disability and quality of life. This null hypothesis was rejected, and it was concluded that individuals with better adaptation to their disabilities tended to have higher scores on the quality of life scale.

The second null hypothesis for this research question was: There is no significant moderating effect of age of disability onset on the relationship between adaptation to disability and perceived quality of life. The results from the moderated hierarchical regression analysis indicated that this null hypothesis was not rejected: Age of disability onset did not moderate the relationship between adaptation to disability and quality of life. Additional findings from the first research question indicated that in various regression models, older participants tended to have higher quality of life scores, non-White individuals tended to have higher quality of life scores, and more educated individuals tended to have higher quality of life scores.

The second research question was: Are there differences in quality of life and adaptation to disability between older adults with early-onset physical disabilities and older adults with late-onset physical disabilities? The corresponding null hypothesis was: There are no significant differences in quality of life or adaptation disability between older adults with early-onset physical disabilities and late-onset physical disabilities. Results showed that participants in the early onset group had higher adaptation to disability scores than individuals in the late onset group, but that there were no differences between the groups in terms of quality of life scores. Therefore, this null hypothesis was rejected for adaptation to disability scores but not rejected for quality of life scores.

Additional analyses performed for the second research question supported the findings from the first research question in that age of onset of the disability did not affect the relationship between the adaptation to disability and quality of life scores. The next chapter presents a discussion of these findings as well as recommendations for future research and clinical practice.

CHAPTER 5

DISCUSSION

Determining what factors influence the quality of life of older adults with physical disabilities has become a relevant topic for research as demographic shifts have resulted in unprecedented proportions of older Americans with disabilities of early- and late-onset. Rehabilitation counseling researchers have long hypothesized a strong, positive relationship between quality of life and the process of adaptation to disability. However, most of the studies examining this relationship have been conducted in younger adult populations, resulting in findings that may not generalize to older adults. Furthermore, no such studies have investigated the possible influence of age of disability onset on the relationship between adaptation to disability and quality of life among older adults with disabilities.

Until recently, the focus of most research concerning aging and disability was placed on persons with late-onset disabilities. However, for the first time in this nation's history, there are growing numbers of individuals who were born with or acquired a disability early in the life span that are reaching old age and experiencing premature or atypical aging related to their condition, its management, and other environmental factors. Older adults with early-onset disabilities are hypothesized to be different from those with late-onset disabilities due to a number of factors related to the timing of the disability event. Despite the likelihood of finding empirical evidence to support this assumption, there are no empirical studies to date that examine differences in psychosocial outcomes between persons aging with late-onset disability and persons aging with early-onset disability. This study utilized a convenience sample of 160 community-dwelling older adults aged 55 and over with physical disabilities to: (1) examine the relationships between age of disability onset, adaptation to disability, and quality of life among older adults with physical disabilities and (2) determine if differences exist in adaptation to disability and quality of life between older adults with early-onset physical disabilities and late-onset physical disabilities.

Age of Disability Onset, Adaptation to Disability, and Quality of Life

Based on previous empirical research and a review of the relevant literature, two null hypotheses specifying the relationships between age of disability onset, adaptation to

disability, and quality of life were formulated and analyzed in this study: (a) there is no a significant correlation between adaptation to disability and quality of life and (b) there is no significant moderating effect of age of disability onset on the relationship between adaptation to disability and quality of life. To test the first hypothesis, a hierarchical regression analyses was conducted using the demographic variables of age, gender, race/ethnicity, education, and number of disabilities as control variables.

The results of this analysis indicated that adaptation to disability is positively related to quality of life among older adults with physical disabilities. This result is consistent with the results of previous studies conducted in younger adult populations that have concluded that individuals with better adaptation to their disabilities tend to have a higher quality of life (Crew, 1980; Devins, 1994; Devins et al., 1993; Livneh, 2001; Livneh, 1988; Livneh et al., 2001). This finding also adds evidence for Bishop's (2005) disability centrality model, which rests on the premise that when defined as a subjective and multidimensional construct, quality of life represents an appropriate outcome measure of the adaptation to chronic illness and disability.

To test the second hypothesis, a moderated hierarchical regression analysis was conducted in which the interaction between age of disability onset and adaptation to disability was entered into the regression analysis to test the moderating effect of age of disability onset on the relationship between adaptation to disability and quality of life. Similar to the previous analysis, the demographic variables of age, gender, race/ethnicity, education, and number of disabilities were entered as control variables. Based on the results of this analysis, age of disability onset did not moderate the relationship between adaptation to disability and quality of life. These results are inconsistent with the literature related to life course theory, as well as previous empirical studies.

A number of empirical findings highlight the potential significance of age of disability onset as a moderating variable. Bostron, & Ahlstrom (2005) found that age of disability onset, as well as duration of disability, had a significant influence on self-reported health status, a variable which is positively correlated with both adaptation to disability and quality of life. Age of disability onset was also found to be positively related to adaptation to disability in the validation study of the ADS-R (Linkowski & Groomes, 2007). Other significant relationships between age of disability onset and psychosocial outcomes include quality of life and psychological and financial well-being (Chapin et al., 2004; Dijikers, 1999; Duggan & Dijikers,

2001). The inconsistent finding in this study may be explained by characteristics of the sample population.

When an individual acquires a physical disability, his or her reaction to the impairment depends on a number of individual variables that influence the extent of the disability's impact on his or her quality of life. Some of these variables include: the mode of disability onset, the nature of the condition, the individual's pre-disability personality, the meaning of the disability to the individual, the current life circumstances of the individual, the degree of family and social support, and the individual's age at the time of disability onset (Kendall & Buys, 1998). Because causation cannot be inferred from correlational research designs, it is possible that one or more of these individual factors that was not controlled for in this study may have influenced the study's outcome. Take, for example, the individual variable of family and social support. Social support has consistently demonstrated a strong, positive relationship with both adaptation to disability and quality of life (Bartley, 2006; Bowling et al., 2002; Bowling & Gabriel, 2004; Netuveli et al., 2006). Because all of the participants in this study participate in one or more social support and/or activity groups designed for persons who are 55 and over or persons coping with similar disabilities, it is possible that this sample's level of social support diminishes the moderating effect of age of disability onset on the relationship between quality of life and adaptation to disability.

Other individual variables of interest concern disability-related factors that may be specific to this sample population. Most of the previous research concerning aging with early-onset disability has focused solely on participants that are aging with particular types of chronic illnesses and disabilities, namely post-polio, spinal cord injury, traumatic brain injury, cerebral palsy, and rheumatoid arthritis (Fuhrer et al., 1993; Kailes, 2001; Kemp et al., 1997; McColl & Rosenthal, 1994; Reinhardt, 1996; Tate, et al., 1994). For most individuals with these disabling conditions, a chronic and severe disability/disease course can be expected. Furthermore, all of these conditions share an abrupt mode of onset. The mode of onset of a condition or impairment has a marked effect on the response to the intrusion of this disability. The sudden onset of disability, as in the case of spinal cord injury, catapults an individual into a radical change immediately; whereas, the gradual onset of such conditions as diabetes or hypertension, may make itself felt as a more insidious process (Wright, 1983; Falvo, 1999; Goodheart & Lansing, 2002).

The present study examined age of disability onset from a wider disability scope than these studies by including participants with a variety of physical disabilities. For instance, the sample in this study consisted primarily of individuals with physical disabilities resulting from heart problems (16.9%), arthritis (13.8%), and kidney problems (11.3%). There were also a substantial percentage of participants (21.3%) who identified physical disabilities that were not listed on the demographic questionnaire, such as lower back pain and fibromyalgia. Although these conditions can vary according to individual case, the types of disabilities that were most prevalent in this sample population, in general, share a more gradual onset and stable disability course. Such disability-related factors as disability course and mode of onset may have offset the moderating influence of age of disability onset, suggesting that age of disability onset may only serve to moderate the relationship between adaptation to disability and quality of life among older adults with physical disabilities that share certain disease/disability characteristics

Demographic Variables

Additional findings from the first research question regarding the significance of certain demographic variables were indicated in various regression models. For instance, age was significantly correlated with quality of life in the first regression analysis, indicating that older participants tended to have higher quality of life scores. Although the last stage of life is often associated with functional decline and other losses, older adulthood has also been associated with greater variation in subjective measures of psychological well-being (Stewart, Shellbourne, & Brod, 1996). The stability of life satisfaction in older adulthood in the face of declines in objective measures of wellbeing has been noted in several studies (Buono, Urciuou & de Leo, 1998; Nyabo, Gaist, McGue, Vaupel, & Christensen, 2001). The results of these studies and others suggest that quality of life can be maintained in older adulthood, despite objective age-related declines in functional status, financial status, and social support.

Education was also found to be predictive of quality of life in these analyses, indicating that participants with higher levels of education tended to have higher quality of life scores. This finding is also consistent with previous empirical research that supports that the higher the level of education, the higher the subjective rating of quality of life (Chapman, Duberstein, & Lyness, 2007; Kempen, Brilman, Ranchor, & Ormel, 1999; Ranchor, Bouma, & Sanderman, 1996; Ormel et al., 1998). Ranchor et al. (1996) reported that higher educational levels (i.e.,

graduate level) were significantly associated with a range of psychosocial coping resources, such as personality and social support, which may positively influence quality of life in older adults. In accordance with this finding, the sample in this study had an unusually high percentage of participants who reported having exceeded a high school education or less with a college (18.8%) or graduate (22.5%) degree.

Finally, the demographic factor of race was found to be predictive of quality of life in this study, with non-white individuals tending to have higher quality of life scores than whites. Very little information exists on racial differences in quality of life among older adults (Wolinsky, Miller, Andresen, Malmstrom, & Miller, 2004). However, the studies that have been conducted overwhelmingly indicate lower quality of life among non-whites than whites in older adult populations (Hughes & Thomas, 2007, 1998; Ibrahim, Burant, Siminoff, Stoller, & Kwoh, 2002; Jackson-Triche et al., 2000; Sharupski et al., 2007). Furthermore, the majority of these studies were conducted using extensive amounts of data collected from national or state-wide surveys of older adults in the United States. Any results concerning race from this study should be interpreted with extreme caution due to the small percentage of data obtained from non-white participants (8.1 %) versus white participants (91.9%).

Differences between Older Adults with Early- and Late-Onset Disabilities

For the second research question, a MANOVA analysis was conducted to determine if differences existed in adaptation to disability and quality of life between older adults with early-onset and late-onset disabilities. The results of this analysis showed that participants in the early-onset group had higher adaptation to disability scores ($M = 102.81$, $SD = 12.38$) than individuals in the late-onset group ($M = 95.30$, $SD = 13.90$). The mean ADS-R score for the early-onset group reflected high levels of disability acceptance, while the mean ADS-R score for the late-onset group reflected only medium levels of disability acceptance. Therefore, individuals whose disability occurred earlier were more adapted to their disability than individuals whose disability occurred later. This finding is consistent with the results from the ADS-R validation study (Linkowski & Groomes, 2005) which reported a positive relationship between age of disability onset and ADS-R scores.

Conversely, a statistically significant difference in the mean quality of life scores for individuals with early-onset disabilities ($M = 78.15$, $SD = 9.54$) and individuals with late-onset disabilities ($M = 77.74$, $SD = 9.94$) was not found in this study, indicating that age of disability

onset did not affect Quality of Life scores. The insignificant results of this analysis could be attributed to several factors. Although no published studies to date have examined differences in psychosocial outcomes between older adults with early-onset and late-onset disabilities, findings from a number of studies concerning aging with early-onset disabilities indicate that although quality of life initially increases with duration of disability (Krause, 1990), it begins to decrease significantly in persons who have had physical disabilities for 30 years or longer (Dijkers, 1996; Fuhrer et al., 1992; Gerhart et al., 1993; McColl et al., 1999). The age criteria used in each of these studies to exclude participation, as well as to define the limits for early-onset disability, ensured that all participants had lived with a disability for 20 years or more. According to the age criteria used in this study, it was possible for participants in the early-onset group to have lived with a disability a minimum of ten years.

In previous studies when age of onset has been measured in order to categorize individuals into groups, such as “early-onset” or “late onset”, the ages used to define the upper and lower limits of such categories have primarily depended on the particular interests of the researcher. For instance, when Ryan and Morrow (1986) examined the relationships between gender, self-esteem, and age of disability onset in children with diabetes, subjects diagnosed with diabetes before the age of five were assigned to the early-onset group and those diagnosed at or after age five were assigned to the later-onset group. The onset age of five years was chosen to serve as both the cut-off and entry points for group assignment based on the researchers’ interest in the influence of both gender and age of disability onset on short-term psychological outcomes in a sample population of children with diabetes. Consequently, when Loprest and Maag (2003) conducted a study to determine the influence of age of disability onset on educational and employment outcomes, subjects were assigned to early-onset and late-onset groups on the basis of whether they first experienced activity limitations before or after the age of 22. Because most people in the United States have at least completed their compensatory schooling by the age of 22, this definition of age of disability onset allowed the researchers to determine if age of disability onset continues to affect employment outcomes later in life.

In this study, early-onset disability was defined as impairment that is present at birth or acquired before the age of 45 and persists throughout the lifespan. Late-onset disability was defined as impairment acquired for the first time at the age of 45 or thereafter, and persists

throughout the lifespan. The age of 45 years was selected as the cutoff point for early-onset disability and the entry point for late-onset disability on the basis of Levinson's (1996) research on life course transitions which defines the culminating life structure for early adulthood to be between the ages of 40 and 45. It is possible that adopting stricter age criteria to define these groups could produce a significant result. For instance, the mean age of disability onset for the early-onset group in this study was 23.6 years, while it was 11.9 years in one of the largest studies of life satisfaction among persons aging with post-polio ever conducted (Ranchos Los Amigos Medical Center, 1993).

Evidence from other studies indicate that younger and middle-aged persons with physical disabilities experience a wide range of social disabilities that may have long-term effects on their physical, mental, social, and economic well-being (Furher et al., 1992; Kemp & Krause, 1999; McColl & Rosenthal, 1994). It is likely that, as a group, people aging with early-onset disabilities will likely have had different life experiences with a disability than older adults who have not experienced physical impairment earlier in life. However, the sample populations in the previously cited studies consisted of participants with lower average educational levels than were found in the present study. For example, in Kemp & Krause's (1990) study of life satisfaction among persons aging with early-onset spinal cord injury, participants had an average of 10.4 years of education. Of the participants in the early-onset group (n = 80) in this study, 18.75% had obtained a college degree, while 31.25% had furthered their education to the graduate level. Because educational level has been recognized for having a significant effect on quality of life in this study and others, it is possible that the higher educational levels found among sample population in this study served to bolster their quality of life scores.

Limitations of the Study

Several limitations of the current study should be acknowledged and addressed, including the homogeneity of the sample, which limits the conclusions that can be drawn. Most of the participants in this study were Whites (91.9%) who lived in communities in South Georgia and North Florida. Thus, findings from this study cannot be applied to those with other characteristics. Furthermore, the participants in this study were already actively engaged in social activities designed to foster social support, which is positively related to both adaptation to disability and quality of life. It is possible that people who participate in such activities are naturally "high adaptors" who find ways to maintain a high quality of life despite

negative life circumstances, such as the onset of disability. If the sample in this study was composed of a group of exceptionally adaptive individuals, the results from this study are not generalizable to the larger adult population ages 55 and over with physical disabilities.

The use of self-report instruments to obtain the data analyzed in this study constitutes another limitation to this study. Self-report assessment is noted for being susceptible to social desirability, attributional errors, distortion due to poor adjustment, and the relative self-awareness of the subjects (Groth-Marnet, 1997). Of particular relevance to this study, participants were asked questions to subjectively evaluate the quality of their lives. Because researchers have noted a tendency for older adult subjects with and without disabilities in past studies to report high levels of quality of life (Diener & Diener, 1996; Euler, 1992), the possibility exists of obtaining skewed data. The degree of departure from the assumption of multivariate normality may bias the parameter estimates and increase the chance of committing a Type I error.

Several other potential limitations of this study are inherent within the use of regression analysis for correlational research designs. For example, regression analysis is vulnerable to capitalization on chance leading toward misinterpretation of regression coefficients (Smith & Glass, 1987). By relying on the assumption that the variable correlations are determined without error, the multiple correlation (R) of the criterion and predictor variables might lead to biased and inflated estimates of R values. Smith and Glass (1987) state that inflated R values are likely to reduce both generalizability and study replication.

The low reliability for the Subordination subscale of the ADS-R is another limitation of this study that warrants discussion. The internal consistency reliability coefficients for all ten composite scores for the ADS-R and SWBI were greater than or equal to .70 (the conventional cutoff for adequate reliability) with the exception of the Subordination subscale of the ADS-R. Specifically, the reliability of the Subordination scale was only .65. Although it was expected that this scale would have relatively low reliability because it is based on only five items, the low reliability of this scale represents a limitation to this study.

Future Research Recommendations

To replicate the significant findings in this study, it is important to acquire additional data sets. Therefore, research to duplicate the initial significant findings is suggested. To increase the number of significant findings in this study, the following recommendations are offered.

Repeating this study using more precise criteria and definitions for the terms related to age of disability onset (i.e., early-onset, late-onset) would increase the likelihood of finding a statistically significant results for the age of disability of onset variable. Furthermore, narrowing the criteria for inclusion in the sample in regards to such disability-related variables as disability type and mode of onset is advised. Stratifying the sample by educational level and controlling for other individual variables may affect rehabilitation outcomes, should be attempted as well. Finally, repeating this study using a different instrument to measure adaptation to disability may be warranted due to the low reliability evidenced by the Subordination subscale of the ADS-R.

Implications for Practice

Whether an aging individual is born with a disability, achieves disability in old age, or acquires a disability some time in between, more older adults than ever before are facing the challenge of preserving their quality of life in the face of increasing, and sometimes overlapping, functional limitations that characterize disability. The onset of disability has a major impact on the physical, psychological and social aspects of the lives of the individuals who experience them. Many individual and disability-related factors, including the age of disability onset, the nature of the condition, the personality of the individual, the meaning the individual assigns to the disability, and the individual's current life circumstances interact to influence the extent of that impact. Reactions to disability also vary considerably with the individual's ability to cope with disability-related stressors, such as functional limitation, societal attitudes, and environmental challenges. Consequently, disability must be considered in the context of the impact it makes on the quality of all aspects of the individual's life.

Rehabilitation counselors' perspective on the process of adaptation to disability plays a significant role in guiding both rehabilitation service delivery and outcome expectations. Yet despite the decades of research committed to understanding the dynamics of psychosocial adaptation, the rehabilitation counseling literature reveals a surprising lack of consensus about the nature of the adaptation process or the appropriate conceptualization of its measurement. Furthermore, there is little evidence that adaptation theory has effectively translated into clinical practice (Parker, Schaller, & Hansmann, 2003), with few rehabilitation counselors either utilizing existing measures of adaptation in the counseling process or assessing the client's adaptation to disability in terms of any extant theory (Bishop, 2001; Kendell & Buys, 1998).

Rather, outside the research context, measures of adaptation to disability rarely play a significant role in rehabilitation counseling, assessment, or planning. The failure of rehabilitation counselors to assess and address psychosocial adaptation in the counseling relationship most likely results from such factors as: (a) failure to understand the influence of adaptation on the counseling outcome; (b) failure to recognize the clinical utility of existing theories of adaptation in the counseling relationship; and (c) a lack of familiarity with, or confusion over, the many contradictory theories or models of adaptation in the rehabilitation counseling literature (Bishop, 2005).

As opposed to traditional unidimensional measures of adaptation, the multidimensional quality of life-based framework of Bishop's (2005) disability centrality model offers rehabilitation counselors and their clients the opportunity to view the client's life holistically and understand the impact of disability in the context of the complex interactions between different life domains. This approach also presents rehabilitation counselors with a means of understanding and exploring adaptation with their clients that has significant potential for furthering the understanding of individual differences in the response to disability. For example, analyzing the impact of disability on quality of life in terms of the unique values that may emerge from age/generational differences, background differences, and different disability types may lead to the development of more effective interventions based on these differences. Assessing adaptation across quality of life domains may also help counselors distinguish between positive and negative experiences in response to disability, addressing the previously identified limitation of adaptation measures that assess only the negative aspects of disability.

Whether an older adult is experiencing disability for the first time in later life or confronting the onset of secondary disabilities and increasing functional limitations associated with aging with early-onset disability, the process of psychosocial adaptation is essential to enhancing and maintaining quality of life (Livneh, 2001). Rehabilitation counselors should have a workable framework for exploring the client's experiences in the domains of psychological health, physical health, social/family relationships, and economic stability and organizing this information in a way that allows for the prioritizing of interventions. This knowledge could be critical for counselors serving older adult clients with disabilities as they face the challenge of understanding how older adult clients navigate the process of adaptation and apply this understanding in the form of effective clinical interventions.

APPENDIX A

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE

The SPMSQ (Pfeiffer, 1975)

1. What is the date today?
2. What day of the week is it?
3. What is the name of this place?
4. What is your telephone number or street address?
5. How old are you?
6. When were you born?
7. Who is the President of the United States now?
8. Who was the President of the United States before him/her?
9. What was your mother's maiden name?
10. Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down.

8-10 correct answers = cognitive function intact

6-7 correct answers = cognitive function mildly impaired

3-5 correct answers = cognitive function moderately impaired

0-2 correct answers = cognitive function severely impaired

APPENDIX B

HEALTH ASSESSMENT QUESTIONNAIRE – DISABILITY INDEX

Copyright laws prevent the reproduction of the Health Assessment Questionnaire.

APPENDIX C

ADAPTATION TO DISABILITY SCALE – REVISED

Read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.				
	Strongly Disagree	Disagree	Agree	Strongly Agree
C 1. With my disability, all areas of my life are affected in some major way.	1	2	3	4
T 2. Having my disability, I am unable to do things like people without disabilities do.	1	2	3	4
E 3. Disability or not, I am going to make good in life.	1	2	3	4
T 4. Because of my disability, I have little to offer other people.	1	2	3	4
S 5. Good physical appearance and physical ability are the most important things in life.	1	2	3	4
E 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
T 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
C 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
S 9. The most important thing in this world is to be physically capable.	1	2	3	4
T 10. Because of my disability, other people's lives have more meaning than my own.	1	2	3	4
C 11. Because of my disability, I feel miserable much of the time.	1	2	3	4

Read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
E 12. Though I have a disability, my life is full.	1	2	3	4
T 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
S 14. A physical disability affects a person's mental ability.	1	2	3	4
C 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
E 16. There are many things a person with my disability is able to do.	1	2	3	4
C 17. My disability in itself affects me more than any other characteristic about me.	1	2	3	4
E 18. There are many more important things in life than physical ability and appearance.	1	2	3	4
T 19. Almost every area of life is closed to me.	1	2	3	4
C 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

Read each statement below and circle the number that indicates to what extent you agree or disagree with the statement.

	Strongly Disagree	Disagree	Agree	Strongly Agree
C 21. My disability affects those aspects of life that I care most about.	1	2	3	4
T 22. A disability such as mine is the worst possible thing that can happen to a person.	1	2	3	4
S 23. You need a good and whole body to have a good mind.	1	2	3	4
E 24. There are times that I completely forget that I have a disability.	1	2	3	4
T 25. If I didn't have my disability, I think I would be a much better person.	1	2	3	4
C 26. 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
T 27. People with disabilities are able to do well in many ways.	1	2	3	4
E 28. I feel satisfied with my abilities and my disability does not bother me too much.	1	2	3	4
C 29. In just about everything, my disability is annoying to me so that I can't enjoy anything.	1	2	3	4
S 30. Physical wholeness and appearance make a person who s/he is.	1	2	3	4
E 31. 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

Scoring of the AD Scale-Revised

Twenty-two items on the ADS-R are reversed scored. Assign the reverse score on the Likert scale to item numbers: 1, 2, 4, 5, 7, 8, 9, 10, 11, 13, 14, 15, 17, 19, 20, 22, 23, 24, 26, 27, 30, 31 before summing across all scores of the 32-item scale. Thus for each of these items, a score of “1” becomes a “4”, a score of “2” becomes a “3”, a score of “3” becomes a “2” and a score of “4” becomes a “1”. The graphic below illustrates an example of reverse scoring when a respondent circled the number “4”, strongly agree, on question # 1.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. With my disability, all areas of my life are affected in some major way.	1	2	3	4
	↑			↓

Once reverse scoring is complete, derive the total ADS-R score by summing across all scores of the 32-items. A total score possible is 128 points:

97-128	High Levels of Acceptance
65-96	Medium Levels of Acceptance
32-64	Low Levels of Acceptance

There are four subscale scores: In the lower left-hand corner of each item, there is a small letter T, C, E, or S. Add up all Ts, Cs, Es, and Ss accordingly.

T (36 points)

- 27-36 High Levels of Transformation from Comparative Status to Asset Values
- 18-26 Medium Levels of Transformation from Comparative Status to Asset Values
- 9-17 Low Levels of Transformation from Comparative Status to Asset Values

C (36 points)

- 27-36 High Levels of Containment of Disability
- 18-26 Medium Levels of Containment of Disability
- 9-17 Low Levels of Containment of Disability

E (36 points)

- 27-36 High Levels of Enlargement of Scope of Values
- 18-26 Medium Levels of Enlargement of Scope of Values
- 9-17 Low Levels of Enlargement of Scope of Values

S (20 points)

- 16-20 High Levels of Subordination of Physique
- 11-15 Medium Levels of Subordination of Physique
- 5-10 Low Levels of Subordination of Physique

APPENDIX D

SENSE OF WELL-BEING INVENTORY

The SWBI (Rubin, Chan, Bishop, & Miller, 2003)

Please use the following 4-point scale to indicate the extent to which you agree or disagree that each of the following items are descriptive of you:

SA = Strongly Agree A = Agree D = Disagree SD = Strongly Disagree

1. I get frustrated about my disability.	SA	A	D	SD
2. I feel lonely.	SA	A	D	SD
3. I frequently feel down.	SA	A	D	SD
4. I am an important member of my family.	SA	A	D	SD
5. I am happy with my employment situation.	SA	A	D	SD
6. I can afford the medical services I need.	SA	A	D	SD
7. I can afford to go to the movies or out to eat.	SA	A	D	SD
8. I am happy with my job choices.	SA	A	D	SD
9. I am well adjusted to my disability.	SA	A	D	SD
10. I frequently worry about money.	SA	A	D	SD
11. I feel people view me differently because of my disability.	SA	A	D	SD
12. I am in control of my life.	SA	A	D	SD
13. I am happy with my job skills.	SA	A	D	SD

14. People take advantage of me.	SA	A	D	SD
15. I frequently feel nervous.	SA	A	D	SD
16. People like being with me.	SA	A	D	SD
17. I have someone that I can talk to about my problems.	SA	A	D	SD
18. I feel good about my physical stamina.	SA	A	D	SD
19. My health is good.	SA	A	D	SD
20. I feel good about myself.	SA	A	D	SD
21. I am satisfied with my physical appearance.	SA	A	D	SD
22. I receive emotional support from my family.	SA	A	D	SD
23. I have friend who cares about me.	SA	A	D	SD
24. I have adequate energy.	SA	A	D	SD
25. I have job advancement opportunities.	SA	A	D	SD
26. I have good medical services.	SA	A	D	SD

Scoring Procedures for the Sense of Well-Being Inventory

Items 4, 5, 6, 7, 8, 9, 12, 13, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, and 26 are scored as:

SA = 4 points A = 3 points D = 2 points SD = 1 point

Items 1, 2, 3, 10, 11, 14, and 15 are reversed scored as:

SA = 1 points A = 2 points D = 3 points SD = 4 point

Total scores may range from 104, indicating *high* quality of life, to 26 indicating *low* quality of life.

APPENDIX E

DEMOGRAPHIC QUESTIONNAIRE

Please answer all of the questions and place an "x" in the box that applies.

- 1. Gender: Male Female
- 2. Age: _____
- 3. Race/ethnicity (please place an "x" in the box that applies to you):
 - American Indian Black or African-American
 - Asian White
 - Hispanic or Latino Other: _____
- 4. Indicate the number of years of school completed: _____

Indicate the highest degree earned:
 High School Diploma or less
 College Degree
 Graduate Degree

- 5. During your lifetime, have you had any of the following medical conditions, impairments, or disabilities? If yes, please indicate the age at which the condition, impairment or disability first occurred.
 - Amputation Age at occurrence: _____
 - Arthritis Age at occurrence: _____
 - Diabetes Age at occurrence: _____
 - Stroke Age at occurrence: _____
 - Heart problems Age at occurrence: _____
 - Polio Virus Age at occurrence: _____
 - Spinal Cord Injury Age at occurrence: _____
 - Brain Injury Age at occurrence: _____
 - Cancer Age at occurrence: _____
 - Kidney problems Age at occurrence: _____
 - Liver problems Age at occurrence: _____
 - Lung problems Age at occurrence: _____
 - Thyroid or Endocrine problems Age at occurrence: _____
 - Other: _____ Age at occurrence: _____

APPENDIX F

PARTICIPANT CONSENT FORM

CONSENT TO PARTICIPATE IN A REHABILITATION RESEARCH STUDY

PRINCIPAL INVESTIGATOR: Virginia L. Grist, M.S., Ed.S., NCC, LAPC, doctoral candidate in the Rehabilitation Counseling program, Florida State University

STUDY TITLE: The Relationships Between Adaptation to Disability, Age of Disability Onset, and Quality of Life in Older Adults with Physical Disabilities

INTRODUCTION

We invite you to take part in a research study. It is important that you read and understand several principles that apply to all who take part in this study: (a) taking part in the study is entirely voluntary; (b) personal benefits to you may or may not result from taking part in this study, but knowledge gained from your participation may benefit others; (c) you may withdraw from the study at any time without penalty or loss of any benefits to which you are otherwise entitled. The nature of the study, the benefits, risks, discomfort, and other information about the study are discussed below.

Explanation of Research Study:

The purpose of this study is to develop further understanding of the factors that influence quality of life in aging persons with physical disabilities.

Several measures will be administered which measure quality of life, level of adaptation to disability, functional ability, and cognitive functioning. Brief demographic information will also be collected. Potential risks for participating in this study may include fatigue or frustration, or the highlighting of potentially unfavorable life circumstances of the participant. In order to minimize these risks, the participants will be allowed to complete the four measures and demographic questionnaire at their own pace, taking breaks whenever needed. In addition, a certified mental health or rehabilitation counselor will be present during the administration of the measures in order to help the individual cope with any possible negative reactions that may occur in response to a questionnaire. Potential benefits from participating in this study may include increasing your awareness of your own quality of life in relation to level of adaptation to disability and providing rehabilitation counselors with insight into the factors that influence quality of life in older adults with disabilities.

Administration times are as follows: (a) 5 minutes to complete the measure of cognitive functioning, (b) 5 minutes to complete the measure of functional ability, (c) 10 minutes to complete the measure of adaptation to disability, (d) 10 minutes to complete the measure of quality of life, and (e) 5 minutes to complete the demographic questionnaire. The total length of time for subject participation should not exceed one hour. Meeting times will be arranged at the individual's convenience by the researcher.

OTHER PERTINENT INFORMATION

Confidentiality: Any input provided by you for this project will be confidential to the extent allowed by law. The identity of participants will not be revealed in any report produced from this study. The written information will be treated confidentially and will be stored in a locked file cabinet. **There will be no identifying names on the material.** Written information will be identified using a subject code number. All material will be destroyed at the end of seven years.

Problems or Questions: If any problems or questions arise with regard to this study you should contact the principal investigator: Virginia L. Grist at (229) 208-2133, or her supervising professor: Dr. Deborah Ebener at Florida State University, 215 Stone Building at (850) 645-1789. If you have any questions about your rights as a research participant, please contact the FSU Institutional Review Board at (850) 644-7900.

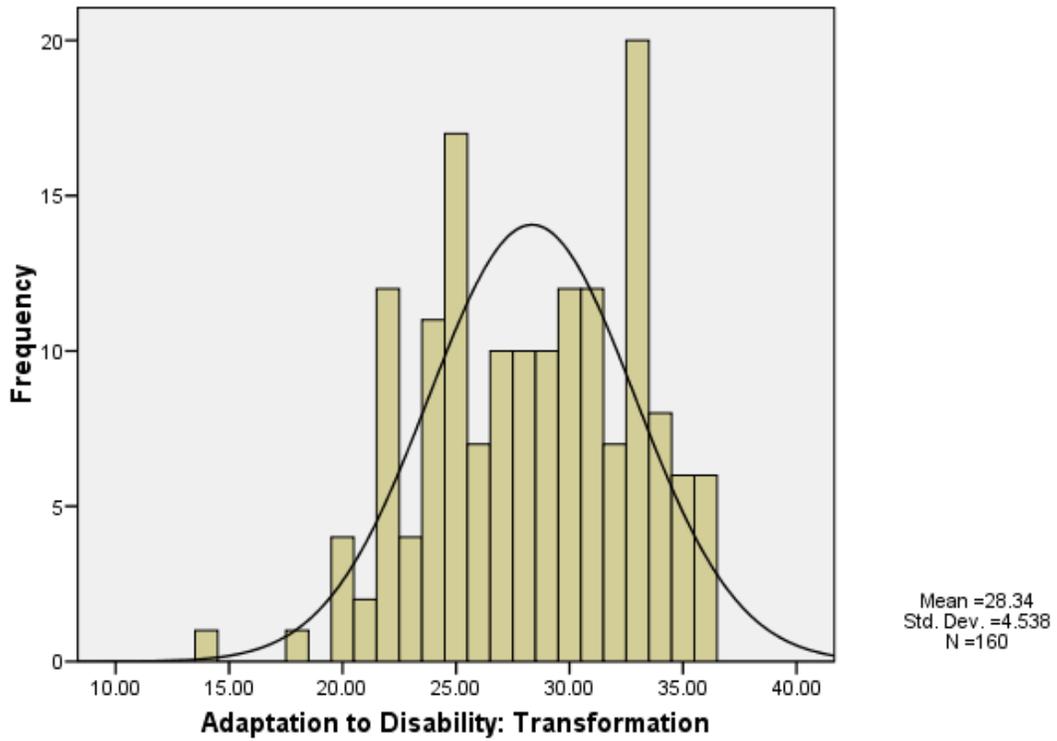
Authorization: "I, _____, have read the above and decided to participate in the research project described above. My signature also indicates that I have received a copy of this consent form."

Signature of Participant: _____ Date: _____

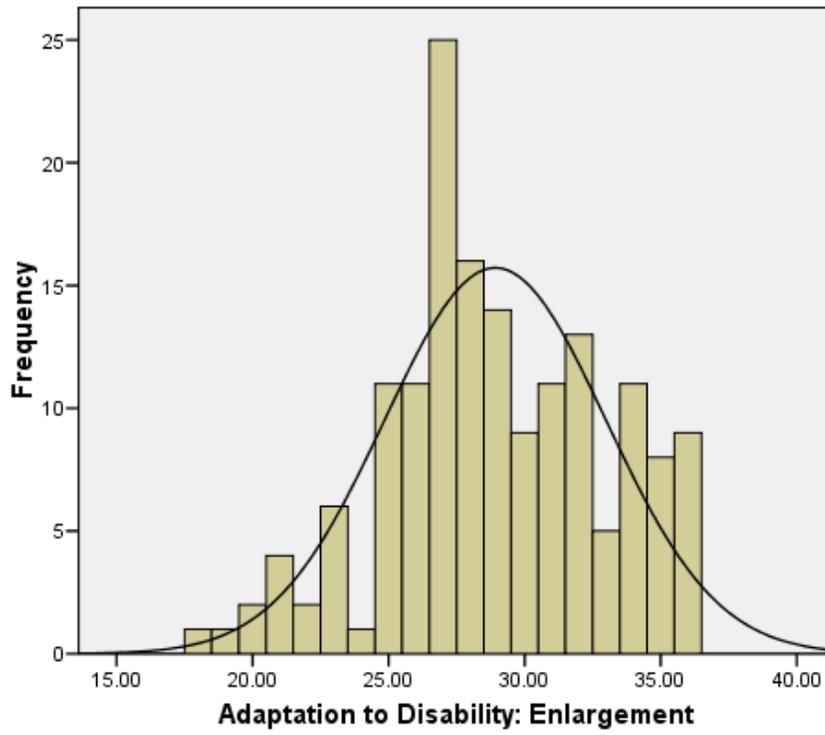
APPENDIX G

HISTOGRAMS FOR ADAPTATION TO DISABILITY AND QUALITY OF LIFE MEASURES

Adaptation to Disability: Transformation

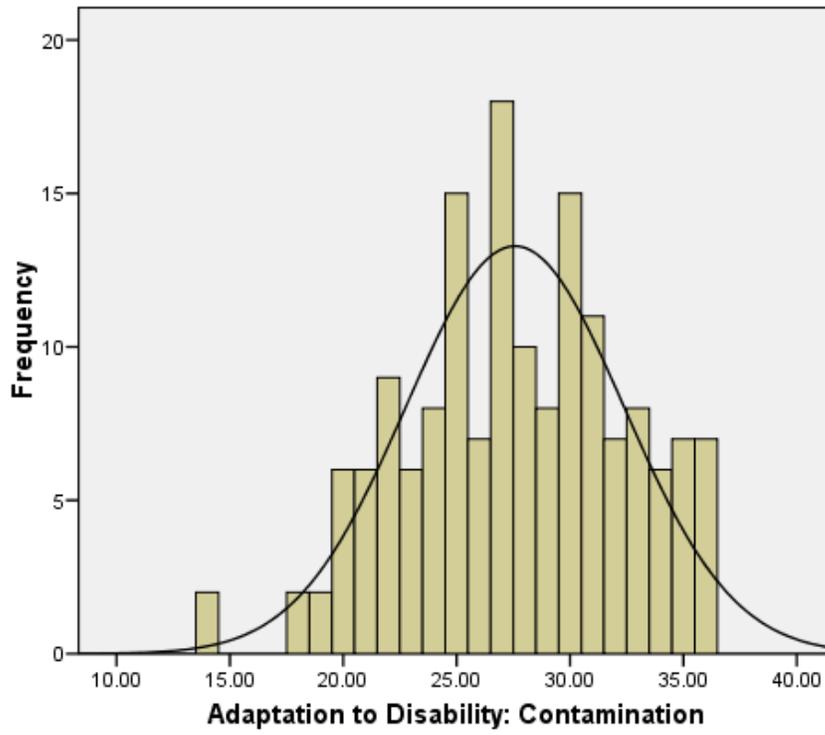


Adaptation to Disability: Enlargement



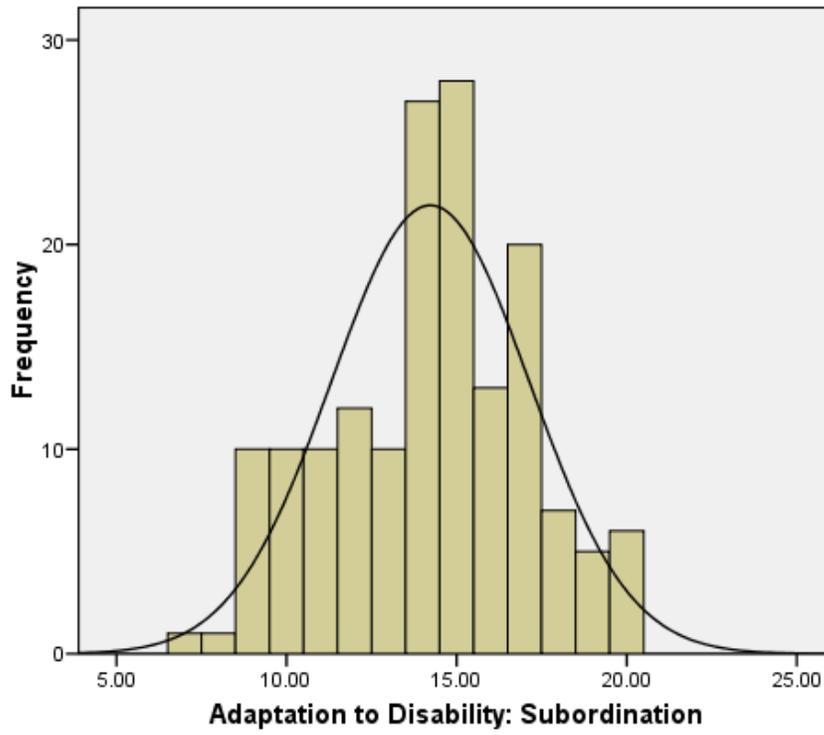
Mean =28.92
Std. Dev. =4.061
N =160

Adaptation to Disability: Contamination



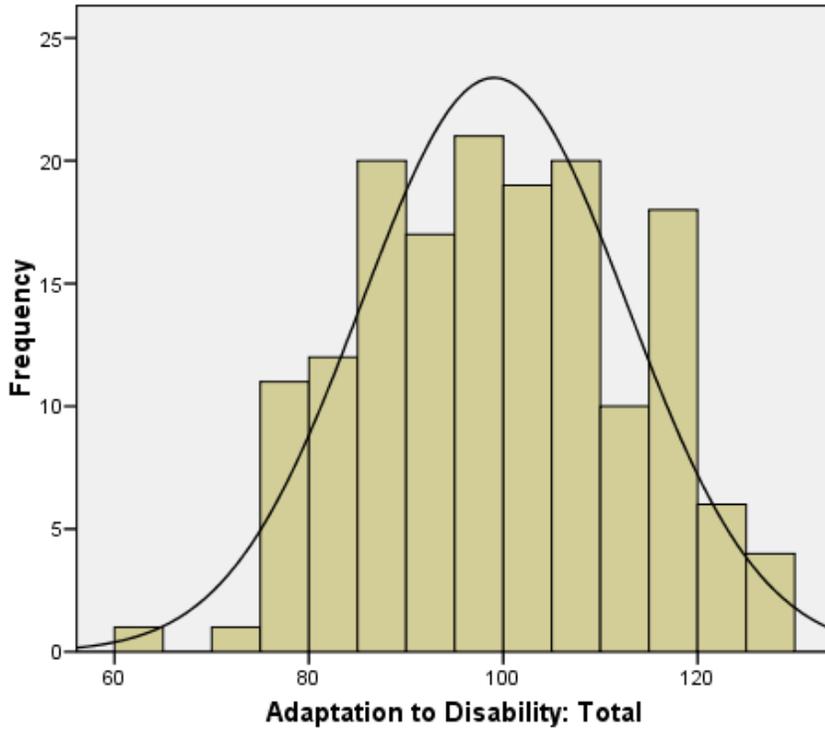
Mean = 27.57
Std. Dev. = 4.805
N = 160

Adaptation to Disability: Subordination



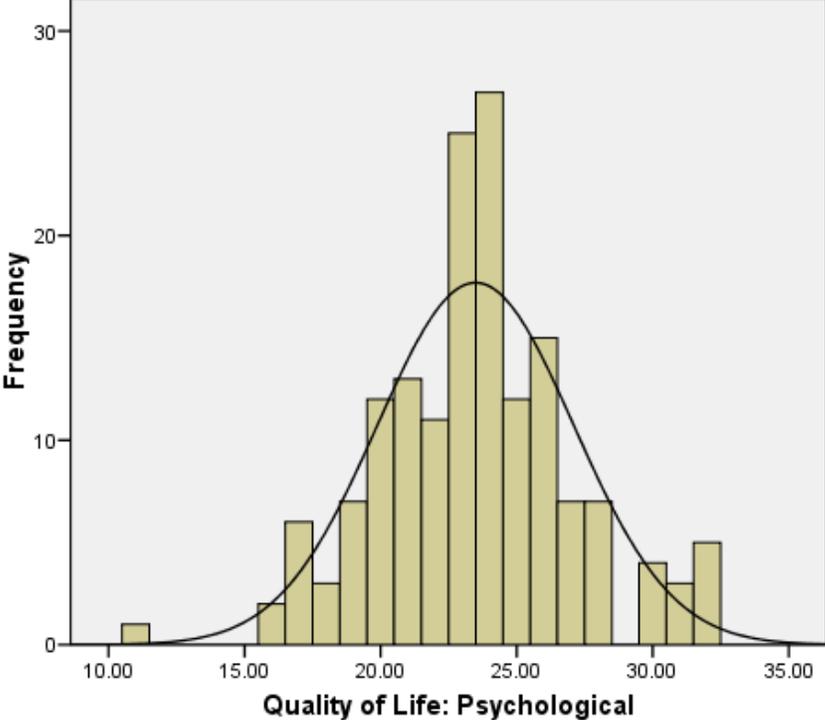
Mean =14.22
Std. Dev. =2.912
N =160

Adaptation to Disability: Total



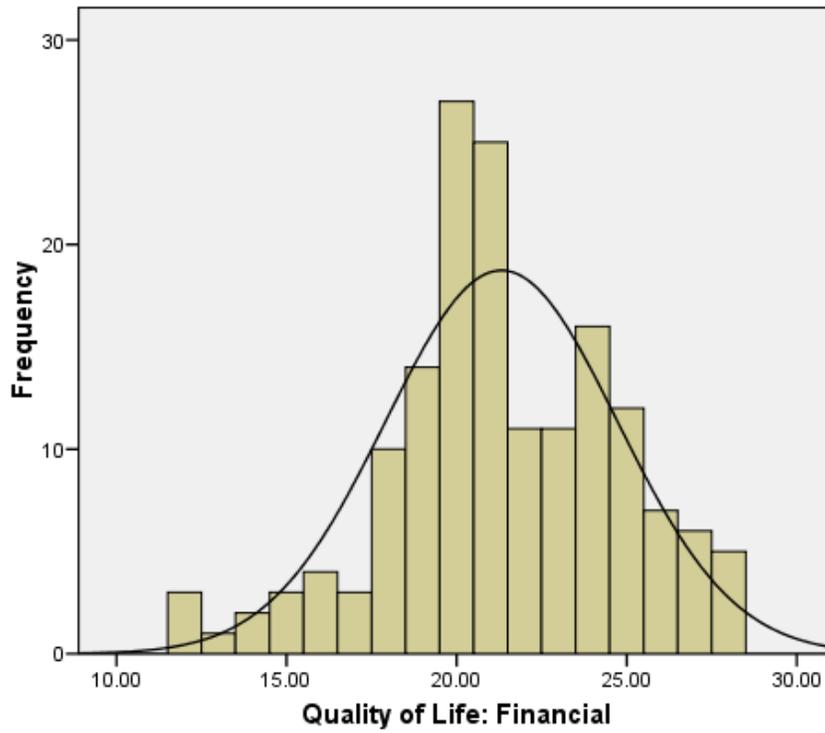
Mean =99.06
Std. Dev. =13.652
N =160

Quality of Life: Psychological



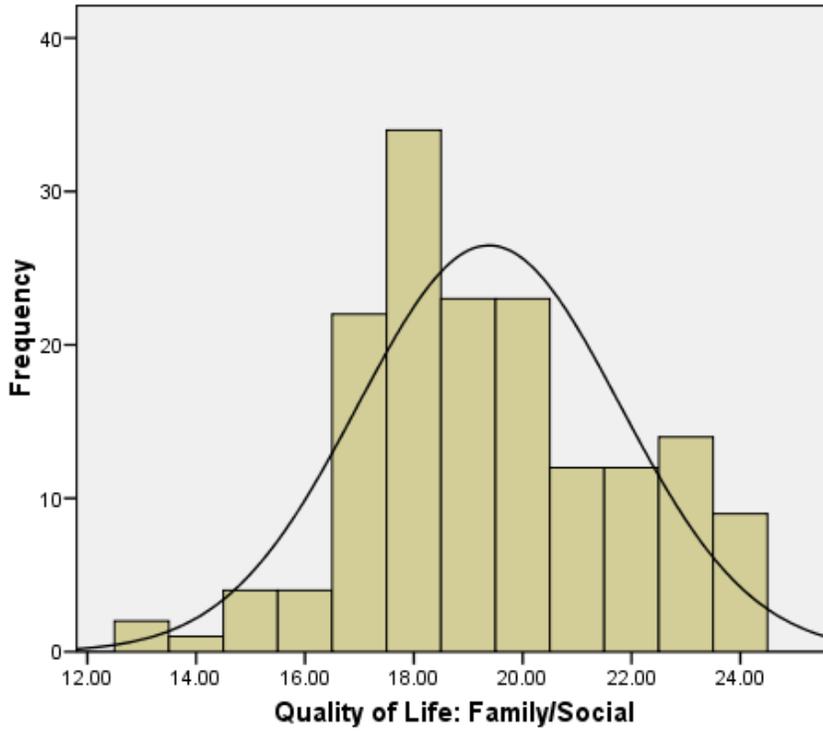
Mean =23.49
Std. Dev. =3.606
N =160

Quality of Life: Financial



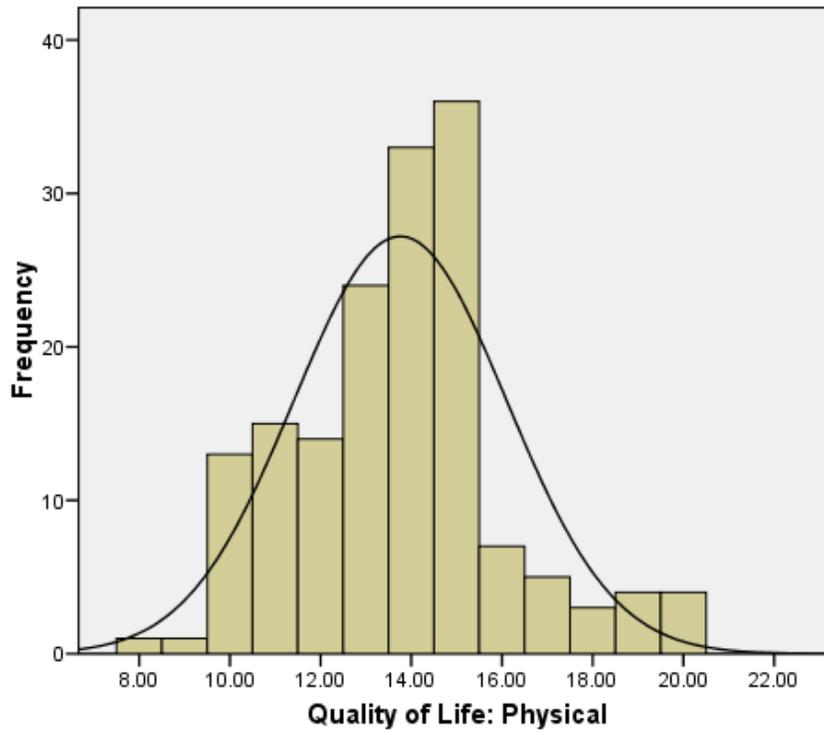
Mean =21.32
Std. Dev. =3.406
N =160

Quality of Life: Family/Social



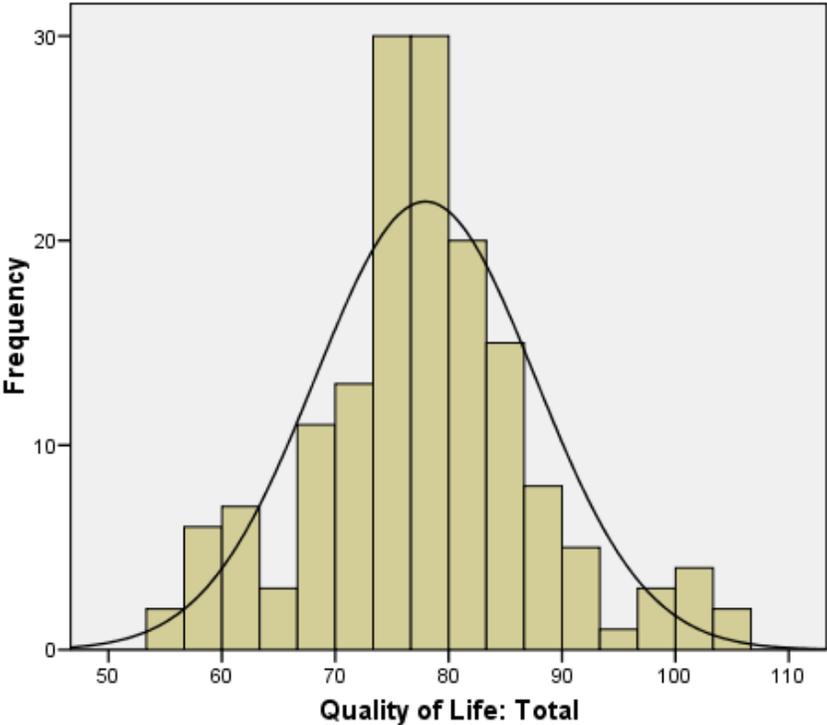
Mean =19.38
Std. Dev. =2.41
N =160

Quality of Life: Physical



Mean =13.76
Std. Dev. =2.347
N =160

Quality of Life: Total



Mean =77.94
Std. Dev. =9.712
N =160

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BIOGRAPHICAL SKETCH

In the spring of 1996, Virginia Grist completed her Bachelors degree in Psychology at The Florida State University. She obtained her Master's and Educational Specialist degrees in the spring of 1998 in Mental Health Counseling from the Department of Human Services and Studies also at The Florida State University. Under the direction of Dr. Deborah J. Ebener, she began her dissertation research to fulfill the requirements for the degree of Doctor of Philosophy in Rehabilitation Counseling in the spring of 2008.