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Walden University

COLLEGE OF SOCIAL AND BEHAVIORAL SCIENCES

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Delinda Stinnette

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Walden University 2009

ABSTRACT

Locus of Control and Adjustment to Vision Loss among People with Age Related

Macular Degeneration

By

Delinda Stinnette

M.A., College of Mount Saint Joseph, 1999 B.A., College of Mount Saint Joseph, 1993

Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy Psychology

> Walden University November 2009

ABSTRACT

People aged 65 and older account for 12.8% of the population and for 30% of all visually impaired individuals. Age-related Macular Degeneration (ARMD) has been identified as a significant public health issue, with a potential 8 million Americans at risk. While the literature supports a connection between LOC and adaptation to ARMD, there is a gap in the current literature supporting this relationship even when other factors are controlled (i.e. age, sex, education, type of ARMD, when diagnosed, the use of medical treatments, the use of visual assistance devices, participant engagement in rehabilitation, and depression). The present survey study used hierarchical regression to examine the relationship between LOC and adjustment to ARMD while controlling for these factors. A sample of 75 adults aged 60 and older diagnosed with ARMD for at least 6 months completed the Multidimensional Health Locus of Control Scale-Form C (MHLC), the Adaptation to Age-Related Vision Loss Scale (AVL) and the Geriatric Depression Scale-Short Form (GDS). LOC accounted for 30% of the variance in adjustment beyond what was explained by the control variables, with higher internal LOC being associated with greater adaptation to loss. The present results add to the existing literature and enhance social change initiatives by guiding the development of interventions to mitigate the difficulties experienced by people with ARMD, reduce their dependency on others, and improve their ability to maintain their quality of life.

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DEDICATION

This study is dedicated to my family, who always stands in support of my endeavors. My family includes not only my sons, Tommy and Chris, Tommy's wife Lynda, and my grandson Eric, but also my closest friend, Barbara O'Toole. Barb has been a positive and motivating factor and has been there every step of the way, offering both intellectual and common-sense advice. I also dedicate this to two of the most devoted Walden companions with whom one could travel this road, Kathy Kline and Mary Hollingsworth. We have been together from the very first AYR and continue to support, encourage, and care about one another. I would be remiss if I neglected to thank the rest of my family, Doc, Samantha, and Sweetie the Golden Retrievers; Jefferson the Shih Tzu; and Lilith, Dudley, and Elsie (Fat Cat), the felines in my world. I am truly blessed and grateful to share my life with each of those named above. And lastly I dedicate this work to all of those with Age Related Macular Degeneration in the hope that in some way this will ease their way and that we all may see everything very clearly again.

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CHAPTER 1:

INTRODUCTION TO THE STUDY

Introduction

The elderly are disproportionately affected by sensory impairments, including loss of vision, hearing, and balance (Desai, Pratt, Lentzner, & Robinson, 2001; Heine & Browning, 2002). Vision loss is the third most common chronic condition (after arthritis and heart disease) that forces the elderly to require assistance with activities of daily living (Lupsakko, Mantyjarvi, Kautianinen, & Sulkava, 2003), thereby contributing to a loss of independence and a poorer quality of life (Casten & Rovner, 2006, p. 1). For example, those with severe visual impairment have been found to be more than five times as likely (39% compared with 7%) as those with 20/40 vision to be limited in their activities of daily living and more than twice as likely (70% compared with 29%) to have mobility limitations (Guralnik, Alecxih, Branch, & Wiener, 1999, p. 13).

People aged 65 and older account for 12.8% of the population and about 30% of all visually impaired individuals (Desai et al., 2001). Concomitant with the aging of the population, vision loss, in particular, has been identified as "a public health issue for the future as well as today" (Ferris & Tielsch, 2004, p. 451; National Alliance for Eye and Vision Research [NAEVR], n.d.). With the aging of the population, referred to as "a demographic revolution" (Guralnik et al., 1999, p. 6), the number of people with visual impairment is expected to increase significantly by 2020 (Alliance for Aging Research (AAR), 2008; NAEVR & National Eye Institute (NEI), 2006).

Age-related eye diseases (AREDs) are the leading cause of vision impairment, both age-related low vision (AVL) and blindness. AREDs include macular degeneration (MD), cataracts, diabetic retinopathy, glaucoma, and other age-related physiologic changes such as presbyopia (loss of near focus) and incipient cataract formation (Mitchell & Bradley, 2006; NAEVR & AAR, 2008). Overall, more than 38 million Americans age 40 or older are blind, visually impaired, or have an age-related eye disease (NAEVR & AAR, 2008).

Age-related macular degeneration (ARMD), the focus of the present study, is a "debilitating" (Bourla & Young, 2006, p. 1134), "chronic," "progressive" (Mitchell & Bradley, 2006, p. 5), and, in most cases, "untreatable" (p. 2) eye disorder. Though "the least understood," it is the "leading cause" of irreversible blindness and loss of vision in those over age 65 (Guralnik et al., 1999, p. 12).

ARMD, a gradual degeneration of the macula, or central portion of the retina, rarely affects those under age 50 (NEI, 2002, p. 18). An estimated 7 million (Friedman et al., 2004) to 8 million Americans (National Institutes of Health [NIH], n.d.) are at high risk for developing ARMD. About 1.8 million Americans currently have advanced ARMD; by 2020, the number will reach 3 million. Each year, 200,000 Americans develop advanced ARMD, a number that will also double by 2020 (NAEVR, n.d.).

Background of the Problem

Vision has been identified as perhaps the most valued sense (Zullo, n.d.), and for the past four decades public opinion polls have reported fear of vision loss as second only to the fear of cancer (NAEVR & Harvard Health, 2007). Because of the value placed on sight, the visually impaired person "mourns the loss of the sighted self" (Zullo, n.d., p. 3). This emotional impact means that ophthalmologists (and other health care providers) must take into account not only the medical symptoms of ARMD but also how these symptoms affect patients' lives, an often neglected component of care. Simply stated, they must treat the whole patient (Tasman & Rovner, 2004). According to Casten and Rovner (2006), the emotional and functional consequences of sensory impairment in the elderly have not been adequately studied despite the fact that vision loss, a major obstacle to independence and quality of life, has been increasing among this population group. Horowitz and Reinhardt (1998) also noted the lack of empirical data on functional and bio-psychosocial adjustment to visual impairment among the elderly emphasizing the profoundness of vision loss for those who have been fully sighted for most of their lives. The profound impact of late-onset vision impairment is evidenced by the insight of congenitally blind students, who considered themselves fortunate to have been born blind rather than lose their vision later in life because they "had no idea that they were missing anything"; that is, they "had no idea what it actually meant to see," as noted by Schinazi, (2007, p. 2).

A qualitative interview study of 15 Australian patients with ARMD (with an average age of 77 years) was conducted by Wong, Guymer, Hassell and Keefe (2004) to gain a better understanding of the effect of ARMD on the patient's life in terms of quality of life, social interaction, and psychological changes. According to the authors, such information would contribute to the development of targeted and appropriate rehabilitative interventions. Overall, participants expressed feeling powerless, debilitated,

and despondent because of the progressive nature of the disease, coupled with a sense of frustration at medical providers who have little to offer in the way of treatment and support.

ARMD as a Chronic Illness

Consistent with the chronic and degenerative course of ARMD, adjustment to having the disorder may be viewed within the context of chronic illness (Charmaz, 1995; Gordon, Feldman, & Crose, 1998; Schiaffino, Shawaryn, & Blum, 1998; Sidell, 1997). As with many chronic illnesses, consequences of ARMD for the patient include: mortality and morbidity (Cugati et al., 2007); comorbid conditions (Crews, Jones, & Kim, 2006); falls and fractures (de Rekeneire et al., 2003; Ivers, Cumming, & Mitchell, 2002; Ivers, Norton, Cumming, Butler, & Campbell, 2000; Lord, 2003); personal safety (Bozeman, 2004); employment (La Grow, 2004); cognitive impairment (Bylsma & Doninger, 2004; Pham, Kifley, Mitchell, & Wang, 2006); activities of daily living (Schmier & Covert, 2006; Ryan, Anas, Beamer, & Bajorek, 2003); change in leisure activities (Stevens-Ratchford & Krause, 2004); poor psychosocial adjustment (Davis & Lovie-Kitchin, 1995; Horowitz & Reinhardt, 1998; Wahl, Kammerer, et al., 2006; Wong, 2006); stress (Lee & Brennan, 2006); and depression (Casten & Rovner, 2006; Casten, Rovner, & Edmonds, 2002; Rovner & Casten, 2002; Rovner, Casten, Hegel, Hauck, & Tasman, 2007; Tasman & Rovner, 2004).

Factors Related to Coping with ARMD

A number of factors may influence people's ability to cope with loss of visual acuity and ultimate vision loss. These may be broadly categorized as internal and external factors. Rehabilitative programs may be considered external in that they are external to the individual. To facilitate successful adaptation, ARMD patients often participate in rehabilitation and training that is both compensatory (Rovner et al., 2007) and/or rehabilitative (Casten, Maloney, & Rovner, 2005). Programs and services for people with ARMD include low vision rehabilitation (Lamoureaux et al., 2007; Reeves, Harper, & Russell, 2004; Scanlon & Cuddeford, 2004); instructional classes (Van Tol, 2002); selfmanagement programs (Brody et al., 2002; Brody, Roch-Levecq, Kaplan, Moutier, & Brown, 2006); low vision services/aids (Scilley, DeCarlo, Wells, & Owsley, 2004); peer support (Milner, 2002); and support groups for partners (Cimarolli, Sussman-Skalka, & Goodman, 2004).

Demographic characteristics may be considered internal to the individual and have been explored by researchers as well (e.g., Casten & Rovner, 2006; Grunwald, 2003; Horowitz & Reinhardt, 1998; Wong et al., 2004; Zullo, n.d.). Population demographics include household characteristics (Administration on Aging, 2004; 2008; Federal Interagency Forum, 2000; 2008; Guralnik et al., 1999; He, Sengupta, Velkoff, & DeBarros, 2005); family structure (He et al., 2005; Tennstedt, 1999; Yagoda, 2004); and suburbanization (Fein, 1994; Frey, 1999).

Another factor internal to the individual that has received only slight attention from researchers is locus of control, defined as an individual's belief system regarding the causes of his or her experiences and the factors to which the person attributes success or failure in controlling his or her life (Neill, 2006). Locus of control has been identified as a theoretical framework for examining how patients with ARMD respond to the disease (Pilisuk, Montgomery, Parks, & Acredolo, 1993; Kunzmann, Little, & Smith,

2002), including a test case of the theory (Wahl, Becker, Burmedi, & Schilling, 2004).

Statement of the Problem

Despite the growing prevalence of ARMD, the emotional and functional consequences of sensory impairment in the elderly have not been adequately studied (Casten & Rovner, 2006). Horowitz and Reinhardt (1998) also noted the lack of empirical data on functional and bio-psychosocial adjustment to visual impairment among the elderly and emphasized the profound effects of vision loss on those who have been fully sighted for most of their lives. The proposed research will address this gap by focusing on the role that locus of control, the independent variable, may play in people's adaptation to age-related vision loss, the dependent variable, when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual devices, rehabilitation training, and depression.

Purpose of the Study

The purpose of this study is to evaluate the relationship between locus of control and adjustment to vision loss in older adults with ARMD while controlling for demographic factors relating to vision loss and depression in the study population. The demographic factors include age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, the use of medical treatments, the use of visual assistance devices, and engagement in rehabilitation training. Because depression is a significant complication of chronic illness, it was also included as a variable in the study. It is the researcher's goal that this study will help to raise awareness of the ways in which locus of control can affect the ability of older people with ARMD to develop the skills necessary to adapt to their loss and maintain their overall quality of life. In addition, this study is intended to support the development of specific interventions to mitigate the difficulties experienced by people with ARMD, reduce their dependency on others by becoming more selfsufficient, and improve their ability to maintain their quality of life. In this way, people with ARMD may become less vulnerable to a range of negative complications of their illness. There is the fervent belief and hope that through this study important contributions will be made not only to the body of information regarding those with ARMD but to positive social change associated with this population.

Theoretical Framework

The theoretical framework used in the present study is locus of control. As people age, they tend to be characterized more by an internal locus of control (Neill, 2006), a characteristic that may enable them to "maintain an optimistic outlook despite the presence of symptoms or the beginning of diminished capacities" (Pilisuk et al., 1993, p. 3). According to Pilisuk et al., individuals with an internal locus of control have "a sense of mastery" over their lives (p. 3) and are associated with better self-reported health status. On the other hand, among elderly people with a mean age of 85 years, perceived external control was found to be "an emotional risk factor" (Kunzmannn, Little, & Smith, 2002, p. 484).

Nature of the Study

The proposed correlational survey study will examine the relationship between locus of control and adjustment to vision loss in a sample of older adults, controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression. See chapter 3 of this proposal for a detailed discussion of the research design and methods.

Hypotheses

There are two research questions in this study. The first research question is, "Do age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training and depression predict adjustment to vision loss?" This gives rise to the following null hypothesis:

H0₁: Age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression are not predictors of adjustment to vision loss.

The corresponding research hypothesis is:

H1₁: Age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistive devices, rehabilitation training, and depression are predictors of adjustment to vision loss.

The second research question of this study is, "Does internal locus of control predict positive adjustment to vision loss in older adults when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression?" The null hypothesis for this research question is:

H0₂: Internal locus of control is not predictive of positive adjustment to vision loss when controlling for age, sex, education, ARMD in one or both eyes, wet or

dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression.

The corresponding research hypothesis is:

H1₂: Internal locus of control is predictive of positive adjustment to vision loss when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression.

Operational Definitions

Age-related Macular Degeneration is a progressive disease of the retina in which the light-sensing cells in the macula, or central area of vision, cease working and ultimately die (Bourla & Young, 2006).

Locus of control. "Locus of Control Reinforcement," a construct developed by Rotter in the 1950s, "refers to an individual's perception about the underlying main causes of events in his/her life." Locus of control is conceptualized as a continuum ranging from "internal control" (i.e., "what we do") to "external control" (i.e., what outside forces such as "god or powerful others" do) (Neill, 2006, p. 1). People with an internal locus of control believe that what happens to them is a function of their own "behavior, capacities, or attributes" (Pilisuk et al., 1993, p. 1). Generally, an internal locus of control is considered more desirable than an external locus of control (Neill, 2006).

Adaptation to vision loss. For the purposes of this study, adjustment to vision loss, the dependent variable, will be defined as participant score on the Adaptation to Age-

Related Vision Loss (AVL) Scale (Horowitz & Rinehardt, 1998), a 24-item self-report instrument that asks respondents to indicate their agreement or disagreement with statements regarding the impact of vision loss on their lives.

Visual-assistive devices refers to devices designed to promote independence and improve day-to-day functioning, such as magnifiers, large-print books and other materials (e.g., clocks, and calculators), audio books/magazines, electronic reading devices, and speech-output systems (Casten et al., 2005); high-powered reading lenses, glasses with prisms, bifocals, monocular or binocular telescopes, and closed-circuit television (Silbersweig & Garvey, 2007).

Rehabilitative training. Rehabilitative training for people with ARMD includes low vision rehabilitation, occupational therapy, social support programs, and orientation/mobility training (Rovner et al., 2007, p. 720).

Assumptions, Delimitations, and Limitations of the Study
Assumptions

First, it is assumed that the instruments chosen to measure adaptation to vision loss and locus of control are reliable measures of the constructs. Second, it is assumed that participants will give honest and accurate answers to survey questions.

Delimitations

The study is delimited to older adults. For the purpose of this research, "older" is defined as being aged 60 and over. This wide age range will permit the researcher to examine the impact of specific age groups on the dependent variable of adaptation to vision loss.

The population of the present study is delimited to a population from support groups associated with agencies that provide services to vision-impaired people in Ohio. Random selection was used and all necessary signed releases were obtained.

Limitations

The first limitation of the research is that, due to the geographically limited sampling frame, it was not known how representative the participants would be of older adults with ARMD more generally.

A final limitation has to do with the use of self-report surveys. Although the researcher assumed that participants would answer the questions honestly and accurately, there could be no guarantee that they would do so. A trained Research Assistant was available to administer the survey to any participant who had difficulty reading the instruments.

Significance of the Study

ARMD is the most common cause of irreversible blindness and vision impairment in Americans aged 60 and over. More than 1.6 million Americans over age 60 now have advanced ARMD, according to the U.S. Department of Health and Human Services (DHHS), National Institutes of Health (NIH), and the NEI (2005). By the year 2050, it is estimated that the number of persons over age 65 will double to 80 million and by 2030 one in eight persons living in the United Sates will be over age 65 (U.S. Bureau of the Census, 2000). These numbers, added to the knowledge that age is very much related to the onset of ARMD, indicate the overall significance of the study. Despite the extent of this illness, little is known about the bio-psychosocial aspects of adaptation to vision loss in this population. In the effort to produce positive social change that will result in positive outcomes it is the hope that the results of the study enable professionals who help patients with ARMD and researchers in the field to develop better support for this population. This will contribute in a positive way to social change as well as to the body of research on adaptation to vision loss.

Summary

This study investigated the relationship between locus of control and the adaptation to vision loss within the population of older adults with ARMD. The purpose of the study is to provide information for use in designing programs and interventions to help these people.

Chapter 1 introduced the study by explaining the background of the study, research questions and hypotheses, and research methods. It also laid out the objectives and significance of this study, which is to provide information on the relationship between locus of control and adaptation to vision loss among the study population, for use in designing appropriate interventions.

Chapter 2 reviews relevant literature in this area, focusing on research into the demographic factors related to ARMD, and on the factors that provide resilience against ARMD, such as locus of control.

Chapter 3 describes the proposed research design, instruments, and data collection and analysis procedures for investigating the relationship between the study variables. The methodological limitations are also noted.

CHAPTER 2:

LITERATURE REVIEW

Introduction

The previous chapter of proposed study explained the research problem, which is the lack of empirical data relating to factors affecting the bio-psychosocial adjustment to ARMD, particularly locus of control. In the current chapter, a review of literature concerning the variables and theoretical framework of the present study is presented. The chapter begins with an overview of the method used to gather material covered in the review. This section is followed by an explanation of complications and consequences of ARMD that necessitate an adjustment process on the part of the patient. Following this section, discussions of the independent, control, and dependent variables of the study-locus of control, depression, and adjustment to vision loss, respectively--are presented. The chapter concludes with a summary.

Literature Review: Method and Overview

This review is based on a search of the relevant literature using Google, Google Scholar, and Yahoo Search engines as well as the following databases: Academic Search Premier; Education Full Text; Cumulative Index of Nursing and Allied Health Literature (CINHAL); ERIC (Educational Resource Information Center); Gale Directory of Databases; Health Source: Consumer Edition; Health Source: Nursing/Academic Edition; Lexis Nexus Academic; MasterFILE Premier; MasterFILE Select; MEDLINE; Newspaper Source; Professional Development Collection; PsycARTICLES; PsycINFO; Psychology and Behavioral Sciences Collection; SAGE Fulltext; Social Sciences Abstracts; Social Services Abstracts; Sociological Abstracts; and Social Work Abstracts. The Indiana University Library System, University of Cincinnati Library and College of Mount Saint Joseph Library gave additional sources to find articles not located online. Web sites for the following associations and agencies were also searched: Administration on Aging (AOA), AAR, American Foundation for the Blind (AFB), Census Bureau, Centers for Disease Control (CDC), Lighthouse International, NAEVR, NEI, and NIH.

Keywords used alone or in combination included: activities of daily living; adaptive/assistive devices/technology; advanced ARMD; age-related eye diseases (AREDS); age-related macular degeneration (ARMD); aging; blindness; caregivers; chronic illness/disease; cognition; comorbid conditions; depression; dry ARMD; elderly; instrumental activities of daily living; locus of control; low vision training/rehabilitation; macular degeneration; mortality; morbidity; treatment for ARMD; vision impairment; vision loss; and wet ARMD.

Complications and Consequences of Age-Related Macular Degeneration

As noted in chapter 1, the degenerative course of ARMD brings with it a series of consequences and complications that significantly impinge upon the quality of life of the affected individual. These are summarized in this section,

Complications of ARMD

Complications of ARMD include mortality, falls and fractures, cognitive impairment, and impaired personal safety. Researchers in Australia found that ARMD predicted mortality of patients aged 49 to 74 years. At baseline, 6.9% of participants had ARMD (4.8% with early ARMD and 2% with late ARMD). Findings showed that those

with ARMD as compared with those without ARMD showed higher 11-year mortality (55.8% vs. 25.9%, respectively) (Cugati et al., 2007). The increase in mortality is likely related to the presence of comorbid conditions (Crews et al., 2006, p. 825), including falls and hip fracture, cognitive decline, and loss of personal safety, all or each of which can adversely impact functioning and health status. Crews et al. found that older, visually impaired adults often experienced comorbid conditions that were associated with limitations and/or difficulties in physical functioning (walking, stair climbing) and participation (shopping and socializing), and greater than expected declines in health.

Falls and fractures. Vision problems have been associated with falls, fear of falling, serious injuries (especially hip fractures), physical deterioration, hospitalization, institutionalization, and death (see, for example, de Rekeneire et al., 2003; Ivers et al., 2002; Ivers et al., 2000). Crews and Campbell (2004) found that community-dwelling elderly (age 70 and older) with impaired vision were almost twice as likely as unimpaired individuals to experience a fall or broken hip. Visual risk factors highlighted by Ivers et al. (2002) include "reduced visual acuity, reduced contrast sensitivity, poor depth perception, self-reported poor vision, and visual field loss (p. 2).

Cognitive impairment. ARMD and cognitive impairment are two key causes of age-related disability, although the reasons for the association of these conditions are not well understood (Pham et al., 2006). To examine the link between ARMD and cognitive impairment, the authors analyzed data from the Blue Mountain Eye Study, a survey of "vision, common eye disease, and other health conditions" in a community-based population (aged 49 or older) in Sydney, Australia (N = 3,509). Data showed a higher

rate of cognitive impairment in participants with late ARMD than those with early ARMD or without ARMD that was independent of visual impairment.

Personal safety. Bozeman (2004) addressed the issue of personal , such as the chance of being a crime victim, and revealed a startling statistic: "Three out of every four visually impaired people will be, or have been, assaulted in their lifetimes," a figure that is 15 times greater than that for the population at-large (p. 1). The author stressed the importance of rehabilitative training that included both environmental and personal safety.

Consequences of ARMD

ARMD has numerous consequences directly related to loss of vision. These include reduced ability to read, reduced or changed leisure activities, and psychosocial problems. These consequences can become more severe as the disease progresses and, therefore, demand greater coping efforts on the part of the patient.

Reading. One of the main activities impeded by vision impairment is reading, a task required for many instrumental activities of daily living. Ryan et al. (2003) studied the role of reading vis-à-vis leisure activities and daily functioning among a group of seniors (n = 26) with moderate or severe vision loss, in most cases a result of ARMD. For purposes of the study, reading was defined as involving written material, including that performed with adaptive devices such as talking books or with the assistance of others. Despite vision loss, the participants in nearly all cases continued to view reading as an "extremely important" activity, spending the same amount of time reading both before and after vision loss (about 7 hours per week) and for the same reasons (e.g., for

pleasure and education). However, the sources of popular reading materials changed, as evidenced by a notable shift away from newspapers and magazines in favor of talking books. Even adaptive devices such as magnifiers and closed-circuit television were not sufficiently effective to allow for the reading of newspapers and magazines. The authors identified three "reading-related barriers" to the instrumental activities of daily living: reading print, reading dials, and currency. To compensate for these difficulties, participants embraced a number of strategies, for example, giving up the activity, simplifying the activity, learning new skills, and/or compensating by using adaptive devices and the support of others.

Leisure activities. A qualitative study of two community-dwelling, blind elderly individuals by Stevens-Ratchford and Krause (2004) found that visual impairment contributed to increased time spent on in-home leisure activities rather than communitybased activities. Data were based on several instruments: the Brief Cognitive Rating Scale (BCRS); the Enabler, designed to assess accessibility of home to surrounding environment; a structured interview designed to identify and evaluate participants' leisure activities; and a checklist of proactive behaviors (e.g., use of adaptive devices, modifications in task performance). Though only two respondents were included (believed to be representative based on a purposive sampling strategy), the investigators collected varied and extensive data (i.e., seven face-to-face interviews during an eightweek period for each participant). Specifically, respondents who described themselves as active prior to vision loss were now forced to relinquish the leisure interests and activities they most valued, according to the authors. For one participant, it was participation in a music group; for the other, it was a hobby that involved building and flying motorized airplanes. They each gave up other activities as well, although they did participate in community-based activities. However, transportation difficulties increased the time they spent at home. To allow for participation in home-based activities, participants used various proactive behaviors. For example, one participant modified the home environment; the other adapted the leisure activities to mesh with his limitations. Respondents perceived involvement in leisure activities as key to their well-being.

Psychosocial problems. The availability of psychosocial services for visually impaired elderly patients including those with ARMD "has been identified as an unmet need in the field of ophthalmological treatment, rehabilitation, and education" (Wahl, Kammerer, Holz et al., 2006, p. 533) despite the fact that ARMD has been associated with functional and emotional problems.

Lee and Brennan (2006) conducted a study of stress and coping among the visually impaired elderly based on data from two previous studies (Horowitz & Reinhardt, 1998). Both samples consisted of patients seen at the Lighthouse International in New York City (n = 507, with a mean age of 78.8 years). Data were based on structured interviews that included questions on: socio-demographics; health and vision status; subjective experience of vision loss; functional ability; support from family/friends; participation in activities; use of rehabilitative services; and coping behavior. Respondents were characterized as follows based on their response to stress associated with vision loss: "stoics" (n = 83); "complainers" (n = 42); "taciturns" (n = 304); "sentimentalists" (N = 67); and "articulates" (n = 11) (p. 4). The taciturns,

accounting for three-fifths of respondents, were more apt to receive emotional and instrumental support and less apt to reveal their negative thoughts and feelings associated with their ability to engage in daily activities (e.g., reading, housework, and mobility). Respondents were also categorized based on coping styles: "mavericks" (n = 12); "autonomous" (n = 76); "pragmatists" (n = 44); "hermits" (n = 41); and "nonchalants" (n = 334). The nonchalant, accounting for two-thirds of respondents, in fact failed to reveal any coping mechanisms other than to say they relied "on their own internal resources" or "help from significant others" (p. 6).

Locus of Control

"Locus of Control Reinforcement," a construct developed by Julian Rotter in the 1950s, "refers to an individual's perception about the underlying main causes of events in his/her life," that is, "internal control" (i.e., "what we do") or "external control" (i.e., what outside forces such as "god or powerful others" do), conceptualized along a continuum (Neill, 2006, p. 1). That is, individuals with internal locus of control believe that their reinforcements (rewards) are a function of their own "behavior, capacities, or attributes" (Pilisuk et al., 1993, p. 1). Generally, an internal locus of control is considered more desirable than an external locus of control (as cited by Neill, 2006). [For Rotter's Locus of Control Scale, see <www.ballarat.edu.au/ard/ bssh/psych/rot.htm>]

Heckhausen and Schultz (1999) proposed "a life-span theory of development centered around the construct of control" and that "applied to all cultures and throughout historical time" (p. 2). [See Gould, 1999, for a critique of the claim for universality of Heckhausen and Schultz's theory.] Heckhausen and Schultz categorized control as "primary" (i.e., external control over the environment) or "secondary" control (i.e., internal control over oneself) (Gould, p. 2), noting that the two types of control complemented rather than competed with each other. This control system allows an individual to "optimize" development during latter stages of life when faced with declining ability to function (Heckhausen & Schultz, p. 14).

Locus of Control and the Elderly

Neill (2006) cited evidence that as people age, they tend to be characterized more by an internal locus of control, which may be beneficial particularly with regard to "maintain[ing] an optimistic outlook despite the presence of symptoms or the beginning of diminished capacities" (Pilisuk et al., 1993, p. 3). According to Pilisuk et al., such individuals have "a sense of mastery" over their lives (p. 3). These authors found, for example, that among a sample of elderly, an internal locus of control was associated with better self-reported health status.

Research studies have documented the importance of control for "successful aging and emotional well-being" (Kunzmann et al., 2002, p. 484). In their own research, Kunzmann et al., found that among elderly with a mean age of 85 years, perceived internal control over desirable outcomes was associated with "high emotional well-being," whereas perceived external control was "an emotional risk factor" (p. 484). *Locus of Control and ARMD*

ARMD, a progressive deterioration of the central portion of the retina, can be viewed as a chronic, degenerative illness requiring multiple adjustments to progressive vision loss over time. The literature suggests that successful adjustment is characterized by a combination of positive attitude (Kleinschmidt, 1999; Moore & Miller, 2003; Schinazi, 2007), use of alternate coping strategies and technologies (Moore & Miller, 2003; Rovner et al., 2007; Schmier, Halpern, Covert, Delgado & Sharma, 2006), and psychosocial support (Kleinschmidt, 1999; Schinazi, 2007). People who manifest successful adjustment to vision loss caused by ARMD report feeling more independent and more in control of their lives than those who are less successful (Brody et al., 2002; Brody et al., 2006; Van Tol, 2002; Wong et al., 2004). These findings suggest the presence of an underlying construct that explains successful adjustment. Such a construct is discussed in the subsequent section.

With regard to ARMD in particular, Wahl et al. (2004) offered "a test case" of Heckhausen and Schultz's (1999) theory of control (see above) based on the premise that in the absence of treatment to stop the disease progression, patients must "adapt" (p. 6) to increasing vision loss. The study sample included 90 community-dwelling elderly (average age 79.5 years) with ARMD whose control strategies were measured by the Optimization in Primary and Secondary Control scale (OPS) (German version). The OPS assesses the use of four strategies: selective primary control ("Once I decide on a goal, I do whatever I can to achieve it"); compensatory primary control ("When I cannot solve a problem by myself I ask others for help"; selective secondary control ("When I have decided on a goal, I always keep in mind its benefits"); and compensatory secondary control ("When something becomes too difficult, I can put it out of my thoughts") (pp. 10-11). Functional ability (activities of daily living and instrumental activities of daily living) was measured by a modified/expanded version of the Multilevel Assessment Instrument. Adaptation to vision loss was measured by a shortened version of the Adaptation to Vision Loss Scale (AVL) (German version). Finally, positive affect was measured by the Positive and Negative Affect Schedules (PANAS) (German version). The study found that younger participants (under age 80) functioned better in terms of activities of daily living and instrumental activities of daily living. However, no significant differences were found with regard to measures of control, affect, or adaptation to vision loss. When overall scores were considered, compensatory primary control was highest among the younger participants and compensatory secondary control was lowest.

Vision Loss and Depression

Depression is frequently associated with chronic disease, particularly, as with ARMD, when functioning is impaired. Moreover, because depression itself can be disabling, the effect of the chronic disease is compounded (Casten et al., 2002). Studies have shown that among the visually impaired, the rates of depression are at least twice that among the general population. Moreover, evidence suggests that the risk of suicide may also be higher among vision-impaired elderly (Nicholls, 2005).

According to Casten et al. (2002), ARMD offers a "pure" context for understanding the association between vision impairment, disability, and depression because ARMD is common among the elderly; contributes to extreme disability; has symptoms that are exclusive of depression; and affects the eye only. The authors studied a sample of ARMD patients over age 64 (n = 114) recruited from two clinics (low vision and retina) using interviews to assess symptoms of depression, health, vision-specific and general functioning, and medical charts to establish "ophthalmologic diagnoses and distance acuities" (p. 401). Depression was measured by the Center for Epidemiological Studies-Depression (CES-D) scale.

Just over two-fifths of participants (43%) in this study were identified as having evidence of syndromal depression, about 10 times higher than the rate for elderly in the general population (4.4%). Specifically, when compared with individuals who were not depressed, the depressed people showed worse vision-specific and general functioning as well as higher levels of depressive symptoms. However, they did not differ in terms of demographic characteristics, visual impairment severity, physical health, or specific health conditions. The authors noted the importance of identifying depression in this population by eye care professionals (e.g., ophthalmologists, optometrists, and rehabilitation specialists).

Depression has been recognized as a frequently ignored effect of ARMD in terms of both its detection and treatment. Depression can increase considerably when a patient's second eye becomes affected by ARMD (Tasman & Rovner, 2004). For example, patients with unilateral blindness due to ARMD suffered greater emotional distress than those with bilateral ARMD "despite comparable levels of disability" because, according to the investigators, patients were fearful their vision would worsen in the future (Casten, & Rovner, 2006, p. 2).

Tolman, Kleinschmidt, and Gregg (2005) studied the relationship between psychosocial adaptation to vision loss and depressive symptoms in a legally blind but otherwise healthy noninsitutionalized sample of adults (n = 144) over age 65 (with a mean age of 81.58 years) with confirmed ARMD who were patients of a large, nationally and internationally recognized ophthalmology clinic in a western university medical school. Findings showed that those with poorer adaptation to vision loss had more depressive symptoms than did those with more favorable adaptation, a finding that according to the authors was consistent with previous studies. In addition, Tolman et al. (2005) found that those with symptoms of depression used fewer rehabilitative services than other respondents. The authors concluded that health care providers must inform patients of approaches to coping with ARMD and associated vision loss.

According to a study by Rovner and Casten (2002) among older patients with bilateral ARMD (*n* = 51, mean age of 81 years), the loss of valued activities (e.g., driving, reading) attributed to vision loss was associated with depression, (Index of Affective Suffering, [IAS Level]). Activity loss was found to be the mediating factor in that the effect of visual acuity on affective distress was not significant when activity loss was not considered. Moreover, the authors suggested that IAS level is more appropriate than "depression symptom rating" and "syndromal diagnosis" as a measure of the "affective experience" of ARMD patients (p. 6). Using a broad-based approach to understanding depression, the investigators relied on three indicators of symptomatology: categorical clinical diagnosis (Center for Epidemiologic Studies-Depression [CES-D]), measure of severity (rating scale score [CES-D]), and level of distress (Index of Affective Suffering, [IAS]). The study sample included patients with preexisting ARMD in one eye (visual acuity worse than 20/70) and recent (within the past 6 weeks) onset of vision loss in the second eye (visual acuity worse than 20/70).

In another study, Rovner et al. (2007) looked more specifically at "dissatisfaction with the performance of a valued activity" as a risk factor for depression. The authors used data from the clinical trial "Preventing Depression in ARMD" (p. 790). Participants, recruited from the Wills Eye Hospital in Philadelphia, were over age 64 and were at risk for depression based on bilateral visual impairment (i.e., neovascular ARMD in one eye diagnosed within the past six months and preexisting ARMD in the other eye). Patients with pre-existing depression were excluded. Vision function was measured by the National Eye Institute-Vision Function Questionnaire (NEI VFQ-17). Evidence of depression (at two months) was based on the Modified Schedule for Affective Disorders and Schizophrenia and the Structured Interview Guide for the Hamilton Rating Scale (17item HDRA). Findings showed that for patients with ARMD, dissatisfaction with performance of valued activities was a predictor of depression over a two month period and therefore can be considered, according to the authors, "an important clinical variable and risk factor for depression (p. 792). Though these data did not explain the link between dissatisfaction and depression, the authors suggested that important "confounders" may include "social support, personality (especially neuroticism), and coping style" (p. 792). Essentially, depression was found to be a function of the disabilities associated with ARMD. Because the disability, not the ARMD, is the of cause depression, it may be that depressed patients are those who may be unable to continue valued activities despite compensatory strategies.

In a small-scale but noteworthy mixed methods study, Kleinschmidt (1999) explored the successful adjustment to ARMD based on the qualitative accounts of a sample of 12 community-dwelling, older adults significantly visually impaired by ARMD. In addition to in-depth interviews, the investigator also administered two scales: the Geriatric Depression Scale (GDS) and the State Trait Anxiety Inventory (STAI). All respondents reported having made "a good adjustment to vision loss" (p. 3) based on a positive view of both their "ability to function" and their "outlook" on life despite, in most cases, recollections of "difficulties" and "emotional struggles" when first faced with the "reality of vision loss" (p. 4) and continued "ups and downs" (p. 7). Their ability to adjust to vision loss was attributed to three factors: "prior life experiences" (i.e., strength gained from adversity, support/love from others, and past accomplishments); "internal resources" (i.e., positive attitudes, sense of humor, problem-solving ability, determination to remain active/productive, and religion); and "external resources" (i.e., personal/ professional support, role models who were successful, and self-comparison with others less fortunate) (p. 4).

Adjustment to Vision Loss

A number of demographic factors are associated with adjustment to vision loss. These include household characteristics, family structure, participation in rehabilitation training, and use of assistive devices.

Household characteristics. Not surprisingly, the likelihood of living alone increases with age (He et al., 2005), an important consideration given that living arrangements are closely related to the availability of caregivers (Federal Interagency Forum, 2008). According to Guralnik et al. (1999), "the greatest longevity revolution in history," challenges the ability of older Americans to live in place, a problem that will continue throughout the 21st century (p. 4). Older people living alone represent a sizable and increasing segment of those aged 65 and older (Administration on Aging, 2004). Among the noninstitutionalized elderly population, about 30% (10.7 million) live alone, and most of them (63%) are women (Administration on Aging, 2008). "Very vulnerable groups" among the elderly living alone include "the oldest old" and/or those with no spouse, living children, and/or siblings (Administration on Aging, 2004, p. 1). The number and proportion of "oldest-old" women (85 and older) (Guralnik et al., 1999, p. 6) living alone has increased in number since 1980, more than doubling from 508,000 to 1.3 million and increasing in proportion from 45.2% to 57.0% (He et al., 2005). Those aged 85 and older represent the "fastest growing" segment of the elderly (Federal Interagency Forum, 2000, p. 2). The implications for the aging baby boomer population are also worth noting. As they reach the age of 65, they will have fewer options for caregivers in view of the fact they have fewer children than previous generations and are less likely to be married (MSNBC, 2007).

Family structure. Traditionally, families have served as the main and preferred source of support to the (disabled) elderly, with spouses the first source of informal care, followed by children (especially daughters) (Tennstedt, 1999). However, the changes in the American family, especially in the past half-century, will affect "the future of aging," according to a report by the National Institute on Aging (2006). Because of increased divorce rates and decreased family size, the availability of family support for the elderly may be compromised (He et al., 2005). Moreover, the number of working caregivers (primarily women), expected to increase in the next decade or so, has and will continue to

affect the caregiver role in terms of the availability and quality of time as they face the "competing demand of work, family, and social obligations" (Yagoda, 2004, p. 2). *Factors in Successful Adjustment to Vision Impairment*

Despite the inherent difficulties of adapting to a chronic illness such as ARMD, research shows that successful adjustment is possible. Schinazi (2007) has suggested that adjustment to low-vision and blindness depends upon both psychological and social adjustment. In particular, "myths and misconceptions" about vision impairment on the part of the patient and society may influence the adjustment. This indicates the need for education at both the individual and societal levels about this disability. Self-identity and self-esteem are influenced by the perceptions of others, according to the author (p. 1).

Moore and Miller (2003) suggested that understanding the adjustment to visual impairment best comes from a phenomenological approach to research allowing the "meaning of the experiences . . . to come from the participants and not from the researchers' preconceived notions" (p. 12). Based on this methodology, the authors studied the experiences of 12 men with ARMD, based on in-depth interviews with each. Six themes defined their experiences: (a) the impact of ARMD on their ability or inability to accomplish daily activities, with an emphasis on their unwillingness to "be defined by their limitations;" (b) the importance of maintaining their independence despite their increasing dependence on others; (c) the need to create alternate ways of doing things including: personal coping strategies (e.g., use of touch rather than sight); the use of adaptive devices; reliance on the support of others; and keeping connected with others

(e.g., classes); (d) the acceptance that ARMD was a progressive disease; (e) the ability to face their fears about the future; and (f) maintaining a sense of hope (p. 13).

Rehabilitation/training. In the absence of effective treatment for ARMD, its management has been largely "compensatory," including the use of alternative approaches or techniques (e.g. assistive devices) to accomplish tasks (Rovner et al., 2007, p. 789) or "rehabilitative," including low vision rehabilitation, occupational therapy, social support programs, and orientation/mobility training (Rovner et al., p. 720). A number of assistive devices are available as well. They are designed to promote independence and improve day-to-day functioning, and include magnifiers, large-print books and other materials (e.g., clocks, and calculators), audio books/magazines, electronic reading devices, and speech-output systems (Casten et al., 2005). Other devices include high-powered reading lenses, glasses with prisms, bifocals, and monocular or binocular telescopes. One device in particular that can help patients read is the closed-circuit television (CCTV), which can enlarge text and sharpen contrast (for example, by creating white print on a black ground) (Silbersweig and Garvey, 2007). Communication devices, including cell phones and computers (for word processing, emailing, and Web surfing), also can be adapted for low vision users. Though some rehabilitation services address psychosocial aspects (see above) of vision loss in general, none of them address ARMD in particular (Wong et al., 2004).

Utilization of rehabilitation, optical devices, and assistive technology. Of particular note is the fact that available rehabilitative services and assistive devices/technology have been underutilized by ARMD patients mainly because patients

are unaware they exist (Casten et al., 2005). To better understand this gap in utilization, Casten et al. conducted a study to examine the relationship between knowledge and use of services, and severity of ARMD. Based on a sample of 80 elderly patients (average age of 82.5 years) with ARMD evaluated at a retinovitreous clinic at Wills Eye Hospital in Philadelphia, the investigators found that despite a high rate of reported interest in low vision services and devices, the rates of awareness and use were relatively low. Specifically, for example, just over four-fifths of patients shared a desire to receive low vision interventions, but only one-fourth were aware of such programs. For instance, although most patients used a magnifier or telescope, in most cases (four-fifths), the devices were not prescribed by a professional but rather had been purchased or obtained directly by the patient. Those with more severe vision problems used more resources. According to the authors, the findings suggested that health professionals, namely ophthalmologists and optometrists, may not be sufficiently informed of low vision interventions, or may not be discussing these options with patients.

Schmier, Halpern et al. (2006) also studied the extent to which patients used services and devices as a function of the level of visual impairment. The study sample included 803 patients with ARMD (mean age 73 years) who were registered members of the Macular Degeneration Partnership in the United States. Two self-report instruments were used: the ARMD Health and Impact questionnaire, which includes questions on patient background and ocular conditions along with a checklist of possible services and devices; and the Daily Living Tasks Dependent on Vision (DLTV) questionnaire, which evaluates the impact of vision loss or blindness on ability to function; level of visual acuity; and use of caregiver services. Overall, respondents reported using rehabilitation training, support groups, and transportation services along with visual devices, with increased use associated with declining visual acuity.

Wong et al. (2004) found that functional limitations were related to the degree of visual impairment such that patients with unilateral ARMD (as compared with bilateral ARMD) were limited little or not at all in their activities of daily living. Despite their ability to function, they were concerned about potential vision loss and the associated loss of independence. A contributing factor was that optical aids and adaptive devices become decreasingly effective as the disease progresses. For those with bilateral ARMD, simple daily tasks such as reading, shopping, or crossing a street "required concentration, planning, recall capabilities, and the coordination of sensory modalities like hearing and touching" (p. 633). Because of loss of independence and self-autonomy, some participants were confined to their homes, having given up participation in social activities. Despite such limitations, those who were issued "white canes" often relegated them to "the bottom of a drawer or in the corner of a room," associating them with "weakness" (p. 634). Those who were socially isolated became victims of ARMD, according to the authors. Those who participated in a rehabilitation program within six months of diagnosis found that the assistive devices (e.g., magnifier and close circuit television) were not that helpful. However, techniques such as tactile markings, audiotapes, and color-coding were found to be helpful in performing daily activities.

Effectiveness of Interventions

Low vision rehabilitation. Using a randomized controlled study design, Reeves et al. (2004) studied the effectiveness of three approaches to low vision rehabilitation for ARMD among a sample (n = 194) of patients referred to the low vision clinic of a hospital in the United Kingdom. The three interventions were categorized as hospital-based, conventional, low vision rehabilitation (CLVR) as provided by the hospital eye services; hospital-based, enhanced conventional, low vision rehabilitation (CELVR) with supplementary home visits by a community care worker that did not include rehabilitation; and hospital-based, conventional, low vision rehabilitation (CELVR) enhanced by home visits by a rehabilitation officer for the visually impaired. The findings showed that enhanced low vision rehabilitation was no more effective than conventional low vision rehabilitation.

In a Canadian study, Scanlon and Cuddeford (2004) examined the effectiveness of a low vision rehabilitation intervention for ARMD that included an extended educational period (five one-hour sessions), comparing it with the traditional format (a single onehour session). The investigators proposed that the time-extended rehabilitation would increase the utilization of low vision devices (see discussion on underutilization above), thereby enhancing participants' ability to read (i.e., read 1M print) and thereby improve their participation in activities and overall quality of living. Data were based on two instruments: the 25-item National Eye Institute Visual Function Questionnaire (NEI-VSQ) to measure the effect of visual impairment on health-related quality-of-life, and the Pepper VSTT to measure the ability to read based on speed and accuracy. The sample included 64 individuals (with an average age of 81 years), assigned in equal numbers to the experimental and the control group. Findings showed that the extended teaching significantly contributed to reading ability and self-perceived quality of life. In part, the positive outcome was attributed to the enhanced interaction between client and teacher, namely, the provision of "encouragement and positive reinforcement" (p. 608).

Lamoureaux et al. (2007) examined the effectiveness of a multidisciplinary lowvision rehabilitation program on quality of life among 192 patients (average age 80.3 years) with moderate to severe vision impairment. Most participants had ARMD. The Impact of Vision Impairment (IVI) instrument was used to measure quality of life. The findings showed that overall IVI scores improved, as did scores on the reading/accessing information and emotional well-being subscales. No significant improvement was noted for the mobility/ independence subscale, however. The authors indicated that despite these gains, the strength and clinical significance of the intervention were modest.

Instructional classes. Minnesota Services for the Blind, which provides classes in Adjustment to Blindness for those over age 55, surveyed 140 trainees, most of whom were aged 75 or older, who completed training during 1998 and 1999. The Adaptation to Vision Loss (AVL) scale and other survey items developed by the investigator were used to determine satisfaction with instruction, changes in attitudes toward blindness, adjustment to blindness, and frequently used alternative techniques for daily activities (Van Tol, 2002, p. 3). Training primarily included techniques and devices used to accomplish instrumental daily activities. Findings indicated that respondents were generally satisfied with training (94% were "very" or "somewhat" satisfied). Most respondents showed a positive change in attitude regarding blindness (85% said their attitude was "much better" or "somewhat better") and "good adjustment" (mean score of 18.3, range of 7.0 to 23.6 on the AVL scale). In addition, respondents reported frequently use of the alternative techniques (especially "markings on appliances," "asking for assistance in the store," "dialing the phone by touch," and "tactile or folding methods to handle money") and adaptive devices (especially "time telling pieces," "better lighting," "darker writing devices," and "talking books" to facilitate instrumental daily life activities) (p. 4).

Self-management program. Based on the results of a pilot study that showed the positive effect of a self-management program (believed to be the first of its kind used on an elderly, visually impaired population) on reducing emotional distress for participants with ARMD, Brody et al., (2002) conducted further research to see if the intervention would have an even greater impact on a subgroup of depressed patients. To do so, they included an assessment for clinical depression based on the standardized methods of the Structured Clinical Interview for the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*. Using a randomized controlled study design, the authors assigned 231 community-dwelling patients with advanced ARMD to either a 6-week, 12-hour self-management program (n = 86), a 12-hour tape-recorded health lecture series (n = 74), or to a waiting list (n = 72). The self-management intervention, based on models successfully used for other chronic diseases, included the formal and informal presentation of didactic information (e.g., information about ARMD services) and the development of problem-solving skills, both cognitive and behavioral (e.g.,

communicating about ARMD, adaptive behaviors). The Profile of Mood States (POM), a 65-item self-report inventory, was used as a measure of emotional distress, a useful tool according to the investigators because it did include somatic symptoms that might be confused with physical illness. The study also looked at the impact of the intervention on everyday functioning, based on the results of the National Eye Institute Visual Function Questionnaire (NEI-VFQ), "a functional measure of health-related quality of life in relation to vision" (p. 5). Other measures were also used to identify mediating variables (e.g., social support and interaction, outlook on life, self-efficacy). Findings showed that the self-management program contributed to both improved mood and increased functioning (especially for depressed participants). When the mediator variables were considered, participants with "less distress" and "better functioning" were more likely to report "greater self-efficacy" (p. 6). The findings of the pilot study were confirmed.

Brody et al., (2006) studied the effectiveness of the self-management intervention reported above on a sub-sample of depressed patients, again based on a randomized, controlled study design. Outcome measures included the Geriatric Depression Scale (GDS-15), National Eye Institute Visual Function Questionnaire (NEI-VFQ), and the ARMD Self-Efficacy Questionnaire. Twelve participants were randomly assigned to an ARMD self-management, and 20 participants were assigned to one of two control groups. At six-month follow-up, the patients in the self-management group (originally identified as clinically depressed at baseline) showed significant reduction in depressive symptoms compared with each of the control groups. The reduction in symptoms of depression was attributed to greater self-efficacy in the experimental group. *Low vision services/aids.* Scilley et al. (2004) evaluated the effectiveness of low vision rehabilitation for age-related maculopathy (ARM) patients with attention to its effect on "vision-specific health-related quality of life (HRQoL)" (p. 131). They used the 25-item National Eye Institute Visual Function Questionnaire (NEI VFQ-25), administered by phone interview, to assess vision-specific HRQoL. Medical records provided additional data on ocular health and visual function. The participants included 127 patients of a university-affiliated low vision clinic. The findings showed that patients who utilized low vision services reported significant improvement to their vision-specific HRQoL.

Peer support. Milner (2002) studied the effectiveness of peer training on the provision of assistance and support to those with recent vision impairment and its impact on peer workers, the training organization, and the community. The study site was the Vision Australia Foundation, a "best-practice" model designed for peer training using a "client-centered," "self-directed' mode of learning" that allowed vision-impaired trainers to share their "knowledge, experience, and skills" to help others (p. 107). The intervention was based on teleconferencing as a medium for interaction between peer training manual to ensure quality and consistency of teaching. Both educational and group-facilitation techniques were used. Positive outcomes included increased confidence and self-esteem among peers, group support for clients, increased community and professional awareness of vision loss and requisite support needs of clients, and ability to

service clients in remote and rural areas. The author also discussed the advantages and disadvantages of teleconferencing for peer training.

Support group for partners. As noted above, as ARMD progresses, patients often become increasingly dependent upon family and friends for support and assistance with daily activities. To address the role of such caregivers (typically spouses or partners), Cimarolli et al. (2004) studied the effectiveness of support groups for people who were living with a person with ARMD. The participants included 32 support group members who had been living with a visually impaired person for an average of 40 years. Four group models were studied: in-person group for visually impaired individuals and their partners (2 sessions with a discussion guide curriculum); in-person group for sighted partners only (9 sessions with a discussion guide curriculum); remote group (telephone conference call every two to three weeks with a discussion guide curriculum) for sighted partners only; and sighted partners only (in-person self-directed group for the first three monthly meetings then remote for last six sessions). Based on a pretest-posttest design, the investigators found the programs to have a positive impact on the participating partners, though any differences among the program models were not noted. Specifically, participants reportedly became more knowledgeable about the impact of vision loss on their partners, improved their ability to communicate with their partners, and felt less "trapped" by their caregiver role (p. 5).

Measuring Adjustment to Vision Loss

Wahl, Kammerer, Holz et al. (2006) evaluated emotion-focused and problemfocused interventions for ARMD patients using a pretest-posttest study design. The participants were outpatients at the Department of Ophthalmology at the University of Heidelberg, Germany. The three week/three-session intervention used for this study was based on a five-week/five-session program model previously used by other researchers, based on the assumption that three weeks were sufficiently long to have a positive effect on an older population with ARMD. The emotion-focused intervention was designed to help patients address negative and burdensome emotions related to the day-to-day experience of vision loss by talking about them in a group setting. Emotional adaptation was measured by the 15-item short version of the Geriatric Depression Scale (GDS). The problem-focused intervention was designed to help patients cope with day-to-day problems caused by ARMD in a strongly "I can make it' manner" (p. 537). Problem orientation was measured by the subscale Active Problem Orientation from the Freidberg Inventory on Coping with Illness. A third measure, to examine overall adjustment, was the Adaptation to Vision Loss Scale (AVL) (German version) which assessed a patient's realistic acceptance of vision loss. The findings only partially confirmed the authors' expectations. The participants in the emotion-focused group showed only a limited decrease in depression; however those in the problem-focused group showed an increase in active problem orientation and in adjustment to vision loss.

Davis and Lovie-Kitchin (1995) compared ARMD patients (*n* = 30; average age of 81.4 years) with matched controls (based on age and sex) to understand psychosocial adjustment to ARMD. Four scales were used: Life Satisfaction Index-Well-Being (LSI-W); Social Support Scale (SSS); Revised Feelings of Inadequacy Scale (RFIS); and Hassles Scale (HS). Data also included demographic and vision loss factors, and a

measure of functional capacity (Self-Care Assessment Schedule, SCAS). When compared with the control participants, those with ARMD reported significantly poorer mobility, life satisfaction, and social support, and significantly more daily hassles; group differences were not noted for self-esteem, functional capacity, or health status.

Based on a study of 30 (with a mean age of 83 years) individuals with age-related vision loss (in 40% of cases due to ARMD), Wong (2006) found that psychosocial adjustment to vision loss (well-being) was related to adaptation to vision loss (as measured by the Adaptation to Age-related Vision Loss Scale [AVL], emotions (as measured by a project-specific instrument), and time (as measured by years since vision loss). Findings showed that adaptation to vision loss and associated emotions became more positive as patients progressed through developmental stages of grief proposed by Kubler-Ross.

As suggested by clinical evidence (Horowitz & Reinhardt, 1998), psychosocial adjustment to age-related vision loss exists along a continuum "ranging from elements of acceptance and functional compensation to denial, dependence, or despondence" (p. 1). To address the gap in empirical research on adaptation to vision loss among the elderly (noted above), the authors developed a conceptual framework and measurement scale to assess adaptation to age-related vision loss. They identified three general components of adjustment: "(1) acceptance of the vision loss: the extent to which the older person accepts vision loss in a realistic manner, neither rejecting it as inconsequential nor succumbing to it as being totally incapacitating"; "(2) attitudes toward rehabilitative training: the extent to which the older person has a positive and optimistic attitude toward

the importance of, and potential for, learning new skills that compensate for vision loss"; and "(3) attitudes toward relationships with family members and friends: the extent to which the older person possesses a positive outlook towards continuing relationships with sighted family members and friends, neither rejecting assistance when needed nor becoming excessively dependent on others" (p. 3).

Based on this framework, Horowitz and Reinhardt (1998) developed the 33-item AVL scale with each component of adjustment (above) represented by 11 items. The scale was tested on two samples of noninstitutionalized patients age 65 or older with age-related vision loss (n = 498 combined); other data were collected as well, for example, health status, ability to function, objective and subjective aspects of vision loss, support system, and demographic characteristics. The scale was found to be both reliable and valid and a useful tool for: clinically assessing the psychosocial status of the visually impaired elderly; evaluating vision rehabilitation interventions; and conducting longitudinal and cross sectional surveys of visually impaired elderly. The data showed that AVL scores were positively related to satisfaction with life scores; negatively related to depressive symptomatology scores; and positively related to the "single-item rating of adaptation to vision" (p. 6).

Research on adjustment to vision loss is relatively sparse and mainly has been comparative (Davis & Lovie-Kitchin, 1995; Wahl, Kammerer, Holz et al., 2006), correlational (Wong, 2006), or theoretical (Horowitz & Rinehardt, 1998). To date, no studies were found which attempted to relate adjustment to other factors, such as depression or locus of control. Because the present study attempted to assess the presence of relationships among these factors as well as the contribution each variable makes to an overall model of adjustment, the most appropriate research design is multiple regression.

Conclusion

Age-related vision loss represents "one of the most disabling conditions of later life," limiting a person's ability "to function independently at home and in the community (Lee & Brennan, 2006, p. 1). In fact, according to a recent survey by the American Foundation for the Blind (2007), Americans strongly believe that severe vision loss or blindness would seriously impact their quality of life. For three-fourths of respondents, the greatest concern would be losing the ability to live independently.

Visual impairment disproportionately affects those aged 50 and over; age-related eye diseases are the leading cause of low vision and blindness. Advanced age-related macular degeneration, in particular, affects about 1.8 million Americans and an estimated 8 million are at high risk for the disease. The sheer size of the baby boom population (78 million) and the fact that in 2011 they will begin to turn age 65 means that America is on the cusp of vision loss epidemic (NIH, n.d.). Though age as a risk factor for the disease is significant given the changing population demographics, namely the growth of people age 65 and over, other risk factors have been identified, including race, sex, family history, height, eye color, cardiovascular disease, and cigarette smoking (Gurwood & Meyers, 2007; NEI, 2008).

Age-related macular degeneration, which causes the loss of "central vision" (Mitchell & Bradley, 2006, p. 5), has serious physical, social, psychological, and functional consequences for patients. ARMD has been associated with morbidity (Crews et al., 2006) and mortality (Cugati et al., 2007); crime victimization (Bozeman, 2004); unemployment (La Grow, 2004); cognitive impairment (Pham et al., 2006); inability to perform activities of daily living (Ryan et al., 2003); lack of participation in leisure and social activities (Stevens-Ratchford & Krause, 2004); psychosocial problems (Davis & Lovie-Kitchin, 1995; Horowitz & Reinhardt, 1998; Wahl et al., 2006; Wong, 2006); stress (Lee & Brennan, 2006); and depression (Casten et al., 2002; Tasman & Rovner, 2004; Tolman et al., 2005; Rovner & Casten, 2002; Rovner et al., 2007).

The ability to adjust and adapt to vision impairment for the elderly should also be considered within the context of their living arrangements. The desire of many patients to remain in place has become more difficult than in the past because an increasing number and proportion of the elderly are living alone. In part this is because, when compared with previous generations, baby boomers are more likely to be single, separated, or divorced, and to have had fewer children, thereby resulting in the lack of a caregiver support system (Administration on Aging, 2008; 2004; Federal Agency Forum, 2000; Guralnik et al., 1999; He et al., 2005; MSNBC, 2007; Tennstedt, 1999; Yagoda, 2004). In addition, more elderly are living in the suburbs than ever before, faced with the challenge of accessing services (Fein, 1994).

Because the disease is not well understood in terms of its etiology and progression, and "proven" treatment modalities have not been identified, patients must rely on "compensatory" (Rovner et al., 2007, p. 789) and "rehabilitative" (Casten et al., 2005, p. 720) strategies for adjusting to the disease. Research has identified factors that may contribute to successful adjustment to the disease, such as "a positive outlook" (Kleinschmidt, 1999), self-esteem (Schinazi, 2007), and use of coping strategies (Moore & Miller, 2003). The use of adaptive devices has been shown to have variable and/or limited success in improved functional ability in part because patients may not be aware they exist (Casten et al., 2005) or they are not effective (Wong et al., 2004). The degree to which patients use rehabilitative services and devices may be a function of the level of visual acuity, with greater use associated with greater impairment (Schmier, Halpern et al., 2006; Wong et al., 2004). More generally, the theory of "locus of control" has been offered as a conceptual framework for understanding adaptation to vision loss and blindness such that internal control may contribute to more successful aging (see, Heckhausen & Schultz, 1999; Neill, 2006; Pilisuk et al., 1993).

The literature suggests that in the absence of treatment for ARMD, health care providers must become more vigilant in conveying information to patients about the prevention of ARMD and the resources available for patients with ARMD. Mazoyer, Knoblauch, Fontanay, Koenig, and Vital-Durand (1999) noted that ARMD patients should be encouraged to make the most of the functional vision that remains, suggesting the importance of rehabilitative programs and activities and the use of adaptive devices and technology.

In conclusion, the research literature supports the hypothesis that, controlling for a number of demographic factors, locus of control may predict adaptation to vision loss caused by ARMD. Specifically, the present study tests the hypothesis that internal locus of control is associated with better adaptation to ARMD-related vision loss in a sample of

individuals aged 60 and older. The next chapter of the study explains the research design and methods used to test this hypothesis.

CHAPTER: 3

RESEARCH METHOD

Introduction

The primary research question of this study is, "Does locus of control predict adjustment to vision loss when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression?" Previous portions of the study introduced the problem of adjustment to vision loss in older adults with ARMD and reviewed the literature pertinent to the major variables of the investigation. The purpose of this chapter is to present and discuss the methodology employed during the research to achieve its objectives and answer the research questions posed in the first chapter. Following subsections are devoted to this purpose. Subsections below explain the study's research design, instruments, the method used for gathering data, and data analysis procedures.

Research Design

This quantitative study evaluates participant scores on three instruments, Adaptation to Age-Related Vision Loss Scale (AVL) (Horowitz & Rinehardt, 1998), the Multidimensional Health Locus of Control (MHLC) Scale (Wallston, Wallston, Kaplan, & Maides, 1976), the Geriatric Depression Scale (GDS) (Yesavage et al., 1983), and a demographic scale developed by the researcher. This study employs a correlational (observational), cross-sectional research design. The design is correlational because no experimental manipulation or random assignment of participants to groups is employed. Correlational research designs focus on the relationships or associations between naturally occurring variables. In the current study the associations between health locus of control (assessed via the MHLC scale) and adaptation to vision loss (assessed via the AVL scale) are examined while controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, the use of medical treatments, the use of visual assistance devices, engagement in rehabilitation training, and depression. The design is cross-sectional because the variables of interest in this study are assessed at a single point in time. In this type of design, all variables collected are treated as dependent variables, and no causality among the variables can be inferred (Campbell & Stanley, 1963).

Participants

An a priori power analysis was conducted to determine the required sample size for this study using the G*Power (Faul, 2008) computer program. As discussed below, the primary inferential technique employed in this study is multiple regression analysis. In the regression analysis, there are 10 control variables and one independent variable. The key effect for addressing the research question in this study is the ability of MHLC scores to explain variance in AVL scores over and above the variance explained by the control variables. Using an α level of .05, two-tailed tests, and assuming that MHLC scores explain 10% of the variance in AVL scores over and above the variance explained by the control variables, power of 80% would be achieved with 73 respondents (Cohen, 1988). Therefore, the target sample size for this study was 73 respondents.

Participants were recruited from support group participants associated with centers for people with visual impairment in Ohio. Random selection was used and all necessary signed releases were obtained. The sample consisted of 75 adults (24 male, 51 female) between the ages of 60 and 96 (M = 70.92) who had been diagnosed with ARMD for at least 6 months. Participants' education levels were elementary (n = 9, 12%); high school (n = 20, 26.7%); some college (n = 19, 25.3%), and college graduate (n = 27, 36%). Nearly all (n = 74, 98.7%) reported having right eye macular degeneration, while approximately two-thirds (n = 68, 90.7%) reported having left eye macular degeneration. The majority (n = 67, 89.3%) of participants had macular degeneration in both eyes. Thirty-nine (52%) of the participants reported having wet macular degeneration, and 44 (58.7%) reported having dry macular degeneration. Forty-three (57.3%) participants were currently receiving medical treatment; 60 (80.0%) were currently using a visual assistive device; and 21 (28.0%) were currently undergoing rehabilitation training. The time frame measured was the adjustment that had taken place from 6 months after diagnosis to the time the study was conducted. In the sample, the years since diagnosis ranged from 1 - 32 years, with a mean of 9.63 years (SD = 7.71).

Instruments

Adaptation to Age-Related Vision Loss (AVL)

The AVL (Horowitz & Rinehardt, 1998) (Appendix A) is a 24-item self-report instrument that asks respondents to indicate their agreement or disagreement with statements regarding the impact of vision loss on their lives. AVL24 scoring is as follows: 1 = agree and 0 = disagree. Items 3, 8, 15, 21, and 24 are reverse coded (positively worded). An example of a question from the AVL is: "Because of my vision loss, I feel like I can never really do things for myself." The scale yields a single, combined score ranging 0 - 24, with higher scores indicating more successful adaptation to visual impairment.

Reliability. In the first of Horowitz and Rinehardt's (1998) validation studies, scores ranged from 4 - 24 (M = 17.4, SD = 4.8); in the second study, scores ranged from 3 - 24, (M = 17.8, SD = 5.0). Horowitz and Rinehardt assessed the internal reliability of the scale using Cronbach's alpha and obtained α coefficients of .84 (study 1) and .86 (study 2). These results gave evidence of good internal consistency of the 24-item scale.

Validity. Horowitz and Rinehardt (1998) evaluated validity of the AVL by correlating scores with scores on general measures of subjective well-being. Specifically, the authors examined zero-order correlations between AVL scores and the LSI-A (Neugarten et al., 1961), a measure of life satisfaction, and the CES-D (Radloff, 1977), a measure of depressive symptoms. The correlation between AVL scale score and a single, four-point, self-rated item of adaptation to vision loss ("In general, how well do you feel you have adapted to your vision loss?: very well, moderately well, poorly, not at all.") was used as a criterion for convergent validity.

Results of the validity analysis showed that AVL scores were positively associated with life satisfaction scores (r = .63 and .49), negatively associated with depressive symptom scores (r = .74 and -.55), and positively associated with the singleitem rating of adaptation to vision loss (r = .37 and .45, respectively) (Horowitz & Rinehardt, 1998). Results suggest that adaptation to a visual impairment is part of, but is not the same as, global well-being.

Multidimensional Health Locus of Control (MHLC) Scale

The MHLC scales (Wallston et al., 1976) (Appendix B) are a group of three equivalent, 18-item, self-report instruments that assess a person's beliefs about whether their health status is caused by that individual's actions (versus fate, luck, or chance) and, if so, whether the individual's locus of control is internal (dependent on the person's own actions) or external (dependent on the actions of other people). Respondents are asked to rate their agreement with a number of statements using a 6-point Likert-type scale ranging from 1 (strongly disagree) to 6 (strongly agree). The score for each subscale is the sum of the values for each item on the subscale (where 1 = "strongly disagree" and 6= "strongly agree"). No items need to be reversed before summing, and all of the subscales are independent of one another. That is, there is no "total" MHLC score. The Internal subscale has a possible score range of 6 -36 and consists of questions 1, 6, 8, 12, 13, and 17. The chance subscale has a possible score range of 6 - 36 and consists of questions 2, 4, 9, 11, 15, and 16. The doctors subscale has a possible score range of $3 - 10^{-10}$ 18 and consists of questions 3, 5, and 14. The other people subscale has a possible score range of 3 - 18 and consists of questions 7, 10, and 18.

Forms A and B of the MHLC consist of three subscales: internal, chance, and powerful others. Examples of internal include self thoughts and decisions. Examples of chance include the disease itself, timing, or risks taken.

Form C, the version used in this study, is designed to be used with persons who have an existing health condition. For this reason, in addition to the internal and chance subscales used in Forms A and B, Form C contains two subscales: doctors and other people, instead of powerful others, for a total of four subscales. Examples of doctors include personal physician, retinal specialists, or other medical persons. Examples of other people include friends and family. An example of an item from Form C is, "If I see my doctor regularly, I am less likely to have problems with my condition." According to the authors of the scale, the researcher is free to substitute the name of a particular illness for "condition" in order to enable the researcher to assess the respondent's beliefs about the impact of the particular condition. The score on each subscale is computed by summing the values for each item on the subscale (i.e., where 1 = "strongly disagree" and 6 = "strongly agree"). There are only subscale scores for the MHLC ("Scoring Instructions," 2008).

According to Wallston (1993), the MHLC scales have been used in hundreds of studies, with results indicating moderate reliability (Cronbach α ranges from .60 - .75) and test-retest stability coefficients range from .60 - .70). Wallston et al.'s (1976) original validation study indicated that concurrent validity with Rotter's I-E scale was .33, indicating that the scale was not strongly correlated with a scale with which it is supposed to differ.

Geriatric Depression Scale (GDS)

The Geriatric Depression Scale (GDS) (Yesavage et al., 1983) (Appendix C) is considered one of the best assessments of depression in older people (Kurlowicz & Greenberg, 2007). Two forms of the GDS exist. The Long Form consists of 30 items, which ask participants to respond with yes or no regarding how they have felt over the previous week. The Short Form (Sheik & Yesavage, 1986) consists of 15 items and takes about 5-7 minutes to complete using items from the Long Form GDS with the strongest correlation with depressive symptoms. Ten of the 15 items, when answered "yes," indicate the presence of depression, and five (items 1, 5, 7, 11, & 13) indicate depression when answered "no." Summing the "yes" answers to items 2, 3, 4, 6, 8, 9, 10, and 12 and summing the "no" answers to items 1, 5, 7, 11, and 13, derive scores. Possible scores range from 0-15, with 0-4 considered normal; 5-8 considered indicative of mild depression; 9-11 considered indicative of moderate depression; and 12-15 considered indicative of severe depression. The researcher chose to use the Short Form GDS because its shortness makes it more easily used by the target population, which has difficulty seeing. According to Kurlewicz and Greenberg (2007), the GDS has been used in community, acute, and long-term care settings with older adults, and has been found to have 92% sensitivity and 89% specificity for depression. The instrument has also been found to have good validity and reliability; both forms of the test differentiated between depressed adults (r = .84, p < .001) (Sheikh & Yesavage, 1986).

Pilot Study

The adequacy of previous trials of the MHLC, GDS, and AVL makes a pilot study of the instruments unnecessary. However, to determine and standardize how much time it may take for completion of the survey, a pilot survey was conducted using a participant with a determined low visual acuity. It was assumed that this participant would require an average time to complete the survey. The amount of time required by this participant was used only as a guide in determining the amount of time participants in the main study could take on average to complete the study.

Data Collection Procedures

Following Institution Review Board approval (IRB approval #

02-26-09-0292948), the researcher contacted the organizations described previously. Once potential participants had been identified the researcher discussed the study with the prospective participants using a predetermined script (Appendix C) to reduce bias. A Research Assistant was trained to administer the surveys. Willing participants received a packet consisting of a consent form (Appendix B), demographic form (Appendix D), and the MHLC (Appendix F), AVL (Appendix E), and GDS (Appendix G). The research assistant was trained according to the training manual shown in Appendix H and signed a confidentiality agreement as shown in Appendix I.

Participants were asked to sign the consent form. The consent form was then immediately removed and placed in a separate envelope, thereby removing any possible identification back to the participant. The participants were then given oral instructions and were asked to complete the demographic sheet, MHLC, AVL, and GDS with minimal assistance, defined as the research assistant reading the questions aloud to participants reporting visual difficulties, or filling in the survey for participants who could recite their answers, but who reported difficulty with filling out forms. The research assistant ensured that each participant fully understood each item on the assessments. Data were collected until, at least, the desired sample size was obtained. When the participants completed the materials in the packet, the researcher collected the packets. The anonymity and confidentiality of participants were maintained by identifying all participants by a code number only. Each survey packet was numbered sequentially. Each form within the packet was numbered according to the number of the packet. In this way, no personally identifying information was collected and confidentiality was ensured.

Data Analysis

Data collected in this study were analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows. The description of the sample was obtained by calculating the descriptive statistics for all the demographic variables. Descriptive statistics were calculated for all dependent variables (scale scores). The dependent variable distributions were examined to ensure that the variables that were correlated had similar distributions. Bivariate scatterplots among all variable pairs were constructed to assess for adherence to linearity.

Both descriptive and inferential statistical analyses were performed. Initially, descriptive statistics were performed for all study variables including frequencies and percentages for the categorical variables and ranges, means, and standard deviations for the continuous scales. In addition, internal consistency reliability coefficients (Cronbach's α) were computed for the composite measures for the AVL, MHLC, and GDS. Inferential analyses in the form of multiple regression analysis were then performed using two-tailed tests and an α level of .05.

Preliminary inferential analyses consisted of examining the bivariate relationships between the control and independent variables on the one hand, and the dependent variables on the other hand. As previously noted, multiple regression was used.

Regression, as explained by Zikmund (1991), is a statistical tool used "for measuring the linear association between a dependent and independent variable...[It] attempts to predict the values of a continuous dependent variables from the specific values of the independent variable" (p. 541). Multiple regression, on the other hand, looks at the effects of more than one independent variable (Babbie, 1998). Because the MHLC consists of separate subscales rather than a single scale score, and because age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistive devices, rehabilitation training, depression, and locus of control served as independent variables, there are multiple independent variables in this study, making multiple regression the statistical technique of choice. In this study, a hierarchical entry procedure was followed in the multiple regression analysis. Specifically, all of the control variables were entered simultaneously in the first block of the model to address the first research question. Then, locus of control was entered into the regression model in the second block to address the second research question. This allows for the determination of whether or not locus of control explains variance in the dependent variable over and above the variance explained by the control variables.

First, Pearson correlation coefficients (Pearson's r) were computed between the dependent variable AVL scores and age and MHLC scores. Then, independent samples t tests with AVL scores as the dependent variable were conducted for sex (male or female), education (less than a bachelor's degree or a bachelor's degree and higher), ARMD in one or both eyes (Right or Left), wet or dry (ARMD and if so in which eye), when

diagnosed, the use of medical treatments (yes or no), the use of visual assistance devices (yes or no), engagement in rehabilitation training (yes or no), and presence of depression (yes or no).

As noted previously, the first research question of this study is "Do age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression predict adjustment to vision loss?" To answer this question, a multiple regression analysis was performed. The control variables (age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression) were entered in the multiple regression model as predictors of adjustment to vision loss. The overall ability of the regression model to explain variance in adjustment to vision loss was judged by the value of R^2 , and the contribution of each individual control variable to the prediction of adjustment of vision loss scores was judged by the β coefficients.

The second research question of this study is, "Does locus of control predict adjustment to vision loss in older adults when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression?" To answer this research question, the MHLC scores were entered into the regression model from the first research question as a second block, and the increase in prediction was examined. Specifically, the change in R^2 , and the statistical significance of that change, was examined. If the change in R^2 for the second block was statistically significant, it indicates that locus of control predicts adjustment to vision loss when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression.

Summary

The present chapter has provided a description of the research design, sampling technique, instruments, and procedures of this study. This correlational, cross-sectional study evaluates participant scores on the Multidimensional Health Locus of Control (MHLC) Scale, the Adjustment to Vision Loss Scale (AVL), Geriatric Depression Scale, and a demographic scale. Study participants were 75 adults over the age of 60 who had been diagnosed with ARMD for at least 6 months.

CHAPTER: 4:

RESULTS

This study examined locus of control and adjustment to ARMD in a sample of 75 adults aged 60 and older diagnosed with ARMD for at least 6 months, using the Multidimensional Health Locus of Control Scale-Form C (MHLC), the Adaptation to Age-Related Vision Loss Scale (AVL), and the Geriatric Depression Scale-Short Form (GDS). Data collected in this study was analyzed using SPSS for Windows. The present chapter presents the analysis of data and results of the study. The chapter begins with a description of the sample using descriptive statistics for all the demographic variables and dependent variables (scale scores). The next section presents preliminary inferential analyses examining the bivariate relationships between the control and independent variables and the dependent variables. The subsequent section presents hierarchical regression analyses designed to answer the research questions. A summary concludes the chapter.

Sample Descriptive Statistics

Demographics of the Sample

The following categorical variables were investigated for the 75 participants: sex, education level, right/left/both eye macular degeneration, wet/dry macular degeneration, currently receiving medical treatment, currently using visual assistive device, currently undergoing rehabilitation training (Table 1). Slightly more than two-thirds (n = 51, 68%) of participants were female, and about one-third (n = 24, 32%) were male.

| | Frequency | Percentage |
|-----------------------------------|-----------|---------------|
| Sex | | |
| Male | 24 | 32.0 |
| Female | 51 | 68.0 |
| Education | | |
| Elementary | 9 | 12.0 |
| High school | 20 | 26.7 |
| Some college | 19 | 25.3 |
| College graduate | 27 | 36.0 |
| Right eye macular degeneration | | |
| No | 1 | 1.3 |
| Yes | 74 | 98.7 |
| Left eye macular degeneration | | |
| No | 7 | 9.3 |
| Yes | 68 | 90.7 |
| Macular degeneration in both eyes | | |
| No | 8 | 10.7 |
| Yes | 67 | 89.3 |
| Wet macular degeneration | | |
| No | 36 | 48.0 |
| Yes | 39 | 52.0 |
| Dry macular degeneration | | |
| No | 31 | 41.3 |
| Yes | 44 | 58.7 |
| | | (table contin |

| Table 1 |
|---|
| Descriptive Statistics for Categorical Demographic and Background Variables |

| | Frequency | Percentage |
|--|-----------|------------|
| Currently receiving medical treatment | | |
| No | 32 | 42.7 |
| Yes | 43 | 57.3 |
| Currently using visual assistance device | | |
| No | 15 | 20.0 |
| Yes | 60 | 80.0 |
| Currently undergoing rehabilitation training | | |
| No | 54 | 72.0 |
| Yes | 21 | 28.0 |
| | | |

Participants' education levels were elementary (n = 9, 12%); high school (n = 20, 26.7%); some college (n = 19, 25.3%), and college graduate (n = 27, 36%). Nearly all (n = 74, 98.7%) reported having right eye macular degeneration, while approximately twothirds (n = 68, 90.7%) reported having left eye macular degeneration. The majority (n = 67, 89.3%) of participants had macular degeneration in both eyes. Thirty-nine (52%) of the participants reported having wet macular degeneration, and 44 (58.7%) reported having dry macular degeneration. Forty-three (57.3%) participants were currently receiving medical treatment; 60 (80.0%) were currently using a visual assistive device; and 21 (28.0%) were currently undergoing rehabilitation training.

The following continuous variables were investigated: age, age at diagnosis, and years since diagnosis (Table 2). All 75 of the participants were between the ages of 60

| | Min. | Max. | M | SD |
|-----------------------|------|------|-------|-------|
| Age | 60 | 96 | 80.55 | 9.82 |
| Age at diagnosis | 47 | 92 | 70.92 | 10.59 |
| Years since diagnosis | 1 | 32 | 9.63 | 7.71 |

Table 2Descriptive Statistics for Continuous Demographic and Background Variables

and 96, with a mean age of 80.55 (SD = 9.82) years. The youngest age at which a participant had been diagnosed was 47 years; the oldest age was 92, with a mean age at diagnosis of 70.92 (SD = 10.59). The years since diagnosis ranged from 1 – 32 years, with a mean of 9.63 years (SD = 7.71).

Dependent Variables

Descriptive statistics for the composite scores on adjustment, locus of control, and depression were computed next. Scores for each scale (AVL, MHLC, and GDS) are discussed below. Internal consistency reliability coefficients (Cronbach's α) were computed for the composite measures for the AVL, MHLC, and GDS. Results for all scales appear in Table 3.

Adjustment to vision loss. The AVL yields a single, combined score ranging 0 - 24, with higher scores indicating more successful adaptation to visual impairment. Present scale scores ranged from 1 -24, with a mean score of 18.13 (SD = 5.86). The present mean was comparable to those of Horowitz and Rinehardt's (1998) validation studies, where scores ranged from 4 – 24 (M = 17.4, SD = 4.8) and from 3 - 24, (M = 17.8, SD = 5.0). Internal consistency reliability for this scale was excellent ($\alpha = .92$, vs. Horowitz & Rinehardt's, .84 and .86), meaning that the scale reliably measured adjustment to vision loss.

| | Min. | Max. | М | SD | Alpha |
|------------------------------------|------|------|-------|------|-------|
| Adjustment to macular degeneration | 1 | 24 | 18.13 | 5.86 | .92 |
| Mental health locus of control | | | | | |
| Internal | 9 | 28 | 18.37 | 5.71 | .75 |
| Chance | 10 | 35 | 23.07 | 5.84 | .72 |
| Doctors or others | 3 | 18 | 9.16 | 3.00 | .52 |
| Depression | 0 | 13 | 5.28 | 4.54 | .91 |
| | | | | | |

Table 3Descriptive Statistics for Adjustment, Locus of Control, and Depression Scales

Mental health locus of control. The MHLC has three subscales: internal, chance, and doctors or others. The internal and chance subscales have a possible score range of 6 -36; the doctors and others subscales have a possible score range of 3 - 18. There is no "total" MHLC score. Rather, a higher score on a particular subscale indicates that the respondent attributes higher levels of control to self, chance, doctors, or others, as the case may be. In the present sample, internal scores ranged from a minimum of 9 to a maximum of 28. The mean internal score was 18.37 (*SD* = 5.71). Internal consistency reliability for this scale was good and comparable to those of Wallston (1993) ($\alpha = .75$), meaning that the scale reliably measured mental health locus of control (internal). Chance scores ranged from a minimum of 10 to a maximum of 35. The mean chance score was 23.07 (SD = 5.84). Internal consistency reliability for this scale was good ($\alpha = .72$), meaning that the scale reliably measured mental health locus of control (chance). Doctors or other scores ranged from a minimum of 3 to a maximum of 18. The mean chance score was 9.16 (SD = 3.00). Internal consistency reliability for this scale was $\alpha = .52$, meaning that the scale did not measure mental health locus of control (doctors or others) as reliably as did the other two subscales. However, because this subscale has only 3 items, the reliability of .52, while low, is to be expected, as reliability is partly a function of the number of scale items.

Depression. Possible scores on the GDS Short Form range from 0-15, with 0-4 considered normal; 5-8 considered indicative of mild depression; 9-11 considered indicative of moderate depression; and 12-15 considered indicative of severe depression. Present scale scores ranged from 0 - 13, with a mean score of 5.28 (*SD* = 4.54). Internal consistency reliability for this scale was excellent (α = .91), meaning that the scale reliably measured depression.

Bivariate Correlations

Inferential analyses in the form of correlations were next performed using twotailed tests and an α level of .05. Table 4 shows the results of bivariate correlations

Table 4

| | r | p |
|-----------------------------------|-----|-------|
| Age | .24 | .039 |
| Years since diagnosis | 02 | .854 |
| Internal locus of control | .35 | .002 |
| Chance locus of control | 48 | <.001 |
| Doctor or others locus of control | 41 | <.001 |
| Depression | 79 | <.001 |
| | | |

Correlations Between Adjustment to Vision Loss and Age, Years Since Diagnosis, Mental Health Locus of Control, and Depression Scores (N = 75)

between adjustment to vision loss and the following variables: age, years since diagnosis, mental health locus of control, and depression for the 75 participants. There was a positive association between age and adjustment to vision loss (r = .24, p = .039). The positive value for r means that older age was associated with better adjustment than younger age. Number of years since diagnosis was not correlated with adjustment to vision loss.

All three of the locus of control subscale scores were correlated with adjustment to vision loss. Mental health locus of control-internal (r = .35, p = .002) was positively correlated; (r = .35, p = .002); mental health locus of control-chance (r = -.48, p < .001) and mental health locus of control-doctor or others (r = -.41, p < .001) were negatively correlated. These results suggest that having a more internal locus of control, a lower chance locus of control, and a lower doctor or others locus of control were associated

with better adjustment to vision loss. In other words, participants who felt that they were in control of their vision loss rather than chance or their doctors experienced a better adjustment.

There was a strong, negative correlation between depression and adjustment to vision loss (r = -.79, p < .001). In other words, more depressed individuals had poorer adjustment to vision loss.

Next, independent samples *t* tests with AVL scores as the dependent variable were conducted for sex (male or female), education (less than a bachelor's degree or a bachelor's degree and higher), ARMD in one or both eyes (Right or Left), wet or dry (ARMD and if so in which eye), when diagnosed, the use of medical treatments (yes or no), the use of visual assistance devices (yes or no), engagement in rehabilitation training (yes or no), and presence of depression (yes or no). Table 5 shows the results. No differences in adjustment to vision loss were found based on education, whether one or both eyes was affected by macular degeneration, whether participants had wet or dry MD, or whether participants were currently receiving medical treatment or not.

Three statistically significant comparisons were found: sex, use of visual assistive device, and current engagement in rehabilitation training. Group means for males were 16.08; those for females were 19.09 (t(73)= -2.12, p = .037). This means that females had better adjustment to vision loss than males. Those currently using visual

Table 5

Adjustment to Vision Loss Scores as a Function of Sex, Education, Number of Eyes with Macular Degeneration, Wet Macular Degeneration, Dry Macular Degeneration, The Use of Medical Treatments, the Use of Visual Assistance Devices, and Engagement in Rehabilitation Training (N = 75)

| 8() | | | | | |
|--|----------------|--------------|-------|----|------|
| | М | SD | t | df | р |
| Sex | | | | | |
| Male Female | 16.08 19.09 | 7.05 5.01 | -2.12 | 73 | .037 |
| Education | | | 54 | 73 | .589 |
| Less than a bachelor's degree Bachelor's degree or higher | 17.85 18.62 | 5.73 6.18 | | | |
| Macular degeneration in both eyes | | | .37 | 73 | .710 |
| No Yes | 18.86 18.04 | 4.67 6.01 | | | |
| Wet macular degeneration | | | 19 | 73 | .852 |
| No Yes | 18.00 18.25 | 6.61 5.16 | | | |
| Dry macular degeneration | | | 64 | 73 | .524 |
| No Yes | 17.61 18.49 | 6.11 5.73 | | | |

Table continues

| | М | SD | t | df | р |
|--|----------------|--------------|-------|----|------|
| Currently receiving medical treatment | | | 73 | 73 | .471 |
| No Yes | 17.56 18.55 | 5.62 6.07 | | | |
| Currently using visual assistance device | | | -3.13 | | .003 |
| No Yes | 14.13 19.13 | 6.72 5.23 | | | |
| Currently undergoing rehabilitation training | | | -2.26 | | .027 |
| No Yes | 17.20 20.52 | 6.43 3.07 | | | |

assistance devices (m = 19.13) had better adjustment to vision loss than those who were not (m = 19.13; t(73) = -3.13, p = .003). Those who were currently in rehabilitative training (m = 20.52) had better adjustment to vision loss than those who were not (m =17.20; t(73) = -2.26, p = .027).

Multiple Regression Analysis

Data Analysis

A hierarchical entry procedure was followed in the multiple regression analysis. That is, to answer the first research question, all of the control variables were entered simultaneously in the first block of the model. Then, to answer the second research question, the three locus of control variables were entered into the regression model in the second block. This enabled a determination of whether or not locus of control explained variance in the dependent variable over and above the variance explained by the control variables.

Research Question 1

The first research question of this study was, "Do age, gender, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression predict adjustment to vision loss?" To answer this question, a multiple regression analysis was performed. The control variables (age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression) were entered in the multiple regression model as predictors of adjustment to vision loss. The overall ability of the regression model to explain variance in adjustment to vision loss was judged by the value of R^2 , and the contribution of each individual control variable to the prediction of adjustment of vision loss scores was judged by the β coefficients.

Results of the first regression analysis appear in Table 6. Results of the ANOVA [F(10, 64) = 2.14, p = .034] indicated that the regression model was statistically significant: as a group, the control variables predicted adjustment to vision loss to a statistically significant degree. $R^2 = .25$, which means that 25% of the variance in adjustment to vision loss scores was explained by the control variables. However, the adjusted R^2 indicates that a better (more conservative) estimate of the true population R^2

Table 6

*Results of Regression Analysis with Control Variables as Predictors of Adjustment to Vision Loss (*N = 75*)*

| | В | SE_B | β | t | р |
|--|-------|--------|-----|-------|------|
| Constant | 8.37 | 6.17 | | 1.36 | .180 |
| Age | .08 | .08 | .13 | .99 | .326 |
| Sex | 1.22 | 1.52 | .10 | .80 | .427 |
| Education | .74 | 1.41 | .06 | .52 | .602 |
| Eyes with macular degeneration | -3.20 | 2.22 | 17 | -1.44 | .154 |
| Wet macular degeneration | .75 | 1.46 | .06 | .52 | .608 |
| Dry macular degeneration | 2.16 | 1.47 | .18 | 1.46 | .148 |
| Years since diagnosis | 05 | .09 | 07 | 56 | .575 |
| Currently receiving medical treatment | -1.28 | 1.49 | 11 | 86 | .394 |
| Currently using visual assistance device | 5.23 | 1.88 | .36 | 2.78 | .007 |
| Currently undergoing rehabilitation training | 2.75 | 1.58 | .21 | 1.75 | .086 |

(the R^2 to be expected if the whole population were examined rather than just a sample) was .13, which means that 13% of the variance would be explained by the control variables. Regarding individual variables, only current use of a visual assistance device was statistically significant (t = 2.78, p = .007, $\beta = .36$). The positive β coefficient indicates that those who were currently using a visual assistance device had better adjustment to vision loss than those who were not.

Thus, the answer to the first research question is, yes: age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression predict adjustment to vision loss collectively explain approximately 13% of adjustment to vision loss, with current use of a visual assistive device being the only statistically significant factor associated with better adjustment.

Research Question 2

The second research question of this study was, "Does locus of control predict adjustment to vision loss in older adults when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression?" To answer this research question, the MHLC scores were entered into the regression model from the first research question as a second block, and the increase in prediction was examined. In other words, the change in R^2 , and the statistical significance of that change, was examined. If the change in R^2 for the second block were statistically significant, it would indicate that locus of control predicts adjustment to vision loss when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression.

Results of the second regression analysis appear in Table 7. Results of the ANOVA [F(3, 61) = 13.77, p < .001] indicated that the addition of the locus of control variables was statistically significant. The overall R^2 was .55, which means that 55% of the variance in adjustment to vision loss scores was explained. The adjusted R^2 indicates that a better (more conservative) estimate of the true population R^2 (the R^2 to be expected the whole population were examined rather than just a sample) was .46, which means that 46% of the variance would be explained by the model including the control variables and the locus of control measures. The change R^2 for the addition of the locus of control variables explained 30% of the variance in adjustment to vision loss over and above the variance that was explained by the controls.

Two control variables were statistically significant: current use of a visual assistance device (t = 2.57, p = .013, $\beta = .27$) and undergoing rehabilitative training (t = 2.83, p = .006, $\beta = .27$). The positive β coefficients for these variables indicate that those who were currently using a visual assistance device and undergoing rehabilitative training had better adjustment to vision loss than those who were not.

Table 7

Results of Regression Analysis with Control Variables and Locus of Control Scores as Predictors of Adjustment to Vision Loss (N = 75)

| | В | SE_B | β | t | р |
|--|-------|--------|-----|-------|------|
| Constant | 13.38 | 6.51 | | 2.06 | .044 |
| Age | .06 | .06 | .10 | .96 | .343 |
| Sex | .46 | 1.24 | .04 | .37 | .712 |
| Education | 1.11 | 1.12 | .09 | .99 | .326 |
| Eyes with macular degeneration | -3.07 | 1.77 | 16 | -1.73 | .088 |
| Wet macular degeneration | 18 | 1.18 | 02 | 15 | .882 |
| Dry macular degeneration | .94 | 1.18 | .08 | .80 | .430 |
| Years since diagnosis | 05 | .07 | 07 | 70 | .489 |
| Currently receiving medical treatment | 77 | 1.22 | 07 | 63 | .530 |
| Currently using visual assistance device | 3.88 | 1.51 | .27 | 2.57 | .013 |
| Currently undergoing rehabilitation training | 3.57 | 1.26 | .27 | 2.83 | .006 |
| Internal locus of control | .41 | .09 | .40 | 4.40 | .000 |
| Chance locus of control | 19 | .12 | 19 | -1.56 | .124 |
| Doctors or others locus of control | 54 | .23 | 28 | -2.39 | .020 |

Note. Overall R2 = .55, Overall Adjusted $R^2 = .46$, Change $R^2 = .30$, Change F(3, 61) = 13.77, p < .001.

Two of the mental health locus of control variables were statistically significant: internal (t = 4.40, p = .000, $\beta = .40$) and doctor/other (t = -2.39, p = .020, $\beta = -.28$). The positive β coefficient for mental health locus of control-internal indicates that those who had a higher internal locus of control had better adjustment to vision loss than those who had a lower internal locus of control. The negative β coefficient for mental health locus of control-doctor/others indicates that those who had a higher doctor/other locus of control had a worse adjustment to vision loss than those who had a lower doctor/other locus of control.

Thus, the answer to the second research question is yes: locus of control does predict adjustment to vision loss in older adults when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression. The mental health locus of control variables were strongly predictive of adjustment to vision loss over and above the prediction from the controls, explaining an additional 30% of the variance. Further, having a more internal locus of control (feeling personally efficacious in one's vision loss) and a lower doctor/other locus of control (not believing that doctors/others are the efficacious ones) is the best pathway to good adjustment to vision loss.

Summary

This chapter has presented the analysis of data gathered from responses by 75 participants aged 60 and older who have been diagnosed with ARMD for at least 6 months. Tests used were the Multidimensional Health Locus of Control Scale-Form C (MHLC), the Adaptation to Age-Related Vision Loss Scale (AVL) and the Geriatric

Depression Scale-Short Form (GDS). Possible relationships were examined between locus of control and adjustment to ARMD while controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression. Results showed that locus of control accounted for 30% of the variance in adjustment over and above what was explained by the control variables. The next and final chapter of the study presents results, conclusions, and recommendations based on the findings of the research.

CHAPTER: 5:

SUMMARY, CONCLUSION, AND RECOMMENDATIONS

Vision loss is the third most common chronic condition (after arthritis and heart disease) that forces the elderly to require assistance with activities of daily living (Lupsakko et al., 2003), thereby contributing to a loss of independence and a poorer quality of life (Casten & Rovner, 2006). For example, those with severe visual impairment have been found to be more than five times as likely (39% compared with 7%) as those with 20/40 vision to be limited in their activities of daily living, and more than twice as likely (70% compared with 29%) to have mobility limitations (Guralnik et al., 1999). People aged 65 and older accounted for 12.8% of the population and about 30% of all visually impaired individuals in 2001 (Desai et al., 2001), and this number is expected to grow as the population born in the decades immediately after World War II reaches older age (AAR, 2008; NAEVR & NEI, 2006). The implications for society are significant, as the burden of disease will be borne not only by older adults with ARMD but also by family members who may lose productive work time caring for them and by society as a whole, which will face increasing costs for medical and disability payments and services. The present study, by identifying factors associated with better adjustment, may contribute to social change by enabling the development of interventions designed to improve adjustment and thereby facilitate the continued independence of individuals with ARMD. Such an outcome would be of benefit not only to those with ARMD but also to their families and society by reducing the burden of disease.

Despite the growing prevalence of ARMD, the emotional and functional consequences of sensory impairment in the elderly have not been adequately studied (Casten & Rovner, 2006). Horowitz and Reinhardt (1998) also noted the lack of empirical data on functional and bio-psychosocial adjustment to visual impairment among the elderly and emphasized the profound effects of vision loss on those who have been fully sighted for most of their lives. The present research addressed this gap by using multiple regression analyses to examine the role that locus of control, the independent variable, plays in older people's adaptation to age-related vision loss, the dependent variable. Control variables included age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual devices, rehabilitation training, and depression.

AVL (Horowitz & Rinehardt, 1998) scores in the present sample were similar to but somewhat higher than those of the samples used by Horowitz and Reinhardt (1998) in developing the scale. The mean for the present sample was slightly higher but within one standard deviation of the Horowitz and Reinhardt validation samples.

Normal locus of control scores for patients with chronic illnesses are different than for healthy adults. MHLC (Wallston et al., 1976) scores in the present sample were notably different from mean scores for chronic patients presented by Wallston and Wallston (1981). Participants in the present sample exhibited internal and chance locus of control scores at the lower range of normal, while the sample average for doctors or others was much lower than that of Wallston and Wallston's sample. However, the Wallston and Wallston means do not include data for Form C, which, because it was designed for use with medically ill patients, would presumably have lower means for the internal subscale and higher means for chance and doctors or others. Sample mean scores for the GDS (Yesavage et al., 1983) were indicative of mild depression.

Results of hypothesis testing showed a positive association between older age and adjustment to vision loss. An association was found between all three of the locus of control subscale scores and adjustment to vision loss, with higher scores for internal locus of control associated with better adjustment to vision loss, and lower scores on locus of control-chance and locus of control-doctor or -others were associated with better adjustment to vision loss, as expected. Also as expected, higher scores on depression were associated with lower scores on adjustment to vision loss. Statistically significant relationships were found for female sex, use of visual devices, and use of rehabilitative training relative to adjustment.

Summary and Interpretation of Findings

The theoretical framework used in this study was locus of control. According to Pilisuk et al. (1993), individuals with an internal locus of control have "a sense of mastery" over their lives and tend to report better health status (p. 3).For elderly people around age 85, higher external locus of control is considered "an emotional risk factor" (Kunzmannn et al., 2002, p. 484). Locus of control has been identified as a theoretical framework for examining how patients with ARMD respond to the disease (Pilisuk et al., 1993; Kunzmann et al., 2002), including a test case of the theory (Wahl et al., 2004).

The first research question of this study addressed variables that, independent of locus of control, could affect adjustment to vision loss. To identify the effects of these

variables, the following question was answered first: "Do age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression predict adjustment to vision loss?" The answer to this question was, yes, these variables collectively explained approximately 13% of adjustment to vision loss.

Current use of a visual assistive device was associated with better adjustment. Also, women and those who were currently in rehabilitative training showed better adjustment to vision loss than men and those who were not in rehabilitative training. Results of this study also showed that older age was associated with better adjustment than younger age. The use of assistive devices and rehabilitative training would be expected to exert a positive effect on adjustment. The positive results for older age and female sex were not expected, as neither sex nor age is known to be associated with better adjustment (Fisher & Lerner, 2005, p. 1124; Fletcher, Dreer, & Elliott, 2005; Schultz & Schultz, 2005). The present results represent a new finding for both age and sex.

Locus of control refers to an individual's belief system regarding the causes of his or her experiences and the factors to which the person attributes success or failure in controlling his or her life (Neill, 2006). Therefore, the second research question of this study asked whether locus of control predicted adjustment to vision loss in older adults when controlling for the demographic factors discussed above. The answer to this research question is also yes. Locus of control was found to predict adjustment to vision loss in older adults when controlling for age, sex, education, ARMD in one or both eyes, wet or dry, when diagnosed, medical treatments, visual assistance devices, rehabilitation training, and depression.

Mental health locus of control was strongly predictive of adjustment to vision loss over and above the prediction from the control variables, explaining an additional 30% of the variance. Specifically, having a more internal locus of control (feeling personally efficacious in dealing with vision loss) and a lower doctor/other locus of control (not looking at doctors/others as more efficacious than individuals themselves) is characteristic of older adults with good adjustment to vision loss.

Number of years since diagnosis was not correlated with adjustment to vision loss, meaning that adjustment does not increase (or decrease) with the passage of time since diagnosis. This finding may be explained by the chronic, progressive nature of ARMD. That is, incurable diseases which grow progressively worse pose the need for continual adjustments on the part of those who experience them (Charmaz, 1995; Gordon, Feldman, & Crose, 1998; Schiaffino, Shawaryn, & Blum, 1998; Sidell, 1997). Consequently, the progressive vision loss of ARMD requires that individuals with the disease continually adjust to flares as well as to new, more severe symptomology, effectively resetting the clock with every new worsening of symptoms.

Another possible explanation for the lack of correlation between years since diagnosis and adjustment scores may have to do with the limitations of the AVL. As noted by Horowitz and Reinhardt (1998), the dichotomous nature of the instrument (yes/no questions) makes possible a ceiling effect in the scores. This, they noted, limits the AVL's usefulness in detecting change over time for individuals who had been diagnosed for many years.

Education also was not found to be associated with adjustment to vision loss. This finding can be explained by the fact that vision is considered by most to be the most treasured of all the senses (Zullo, n.d.). That is, regardless of an individual's education level, sight makes a range of activities possible, easier, or more meaningful: people with a high school education are as likely to feel as sad at the inability to see their newborn grandchildren as those with doctorates.

The finding that older age is associated with better adjustment may be explained by reference to locus of control theory, because, as people age, they tend to be characterized more by an internal locus of control (Neill, 2006), a characteristic that may enable them to "maintain an optimistic outlook despite the presence of symptoms or the beginning of diminished capacities" (Pilisuk et al., 1993, p. 3). The finding that female sex is associated with better adjustment also may be explained by locus of control theory. Researchers have argued that particular sex-based differences for particular item categories for assessing locus of control may exist (Schultz & Schultz, 2005). For example, some research has suggested men may have a greater internal locus of control when asked questions about academic achievement (Strickland & Haley, 1980). The present finding suggests that women may have a greater internal locus of control than men regarding questions about health.

Implications for Social Change

The results of this study provide some important additions to the existing literature and enhance social change initiatives. The association of higher internal locus of control with better adjustment indicates that psychosocial interventions should include teaching internal locus of control thinking and skills. Given that rehabilitation training was found to increase adjustment to vision loss, the inclusion of attitudinal components in such training is likely to do much to improve outcomes for people with ARMD. Increased independence will help to mitigate the difficulties experienced by people with ARMD, reduce their dependency on others by becoming more self-sufficient, and improve their ability to maintain their quality of life. When considering that the number of people with visual impairment is expected to increase significantly by 2020 (AAR, 2008; NAEVR & NEI, 2006) it is vitally important that every effort is made to better understand those with ARMD and how they make the adjustment to their vision loss. Understanding a person's locus of control allows for those working with them to provide assistance that is more likely to be helpful as they strive to maintain a good quality of life and remain more self-sufficient. This study will be disseminated to individuals and organizations directly responsible for the rehabilitative training, support, medical treatments, providing assistive devices as well as the participants themselves. The results of this research will ultimately open new doors of understanding ARMD and those who struggle with it everyday. With this new understanding will also come greater knowledge of ARMD and the greater awareness of the large population who have this disease.

Limitations

There are some limitations to the present results. The participants all had ARMD, and to assure that the participants understood each question, a research assistant was available to verbally ask each question and record each answer. This format may have influenced the answers in some cases, as some participants may have tried to answer in a way they believed they should answer rather than being truthful. Another limitation pertains to the fact that the participants all came from the Cincinnati metropolitan area, and so most had resources at their disposal to assist them in their living with their ARMD. It is possible that a non-urban sample may have produced different results owing to differences in the availability of resources. A third limitation has to do with the design of the study. Although results show statistically significant associations between locus of control and adjustment to vision loss, they do not indicate direction of the relationship. That is, it is not clear whether having a higher internal locus of control leads to better adjustment, or if achieving better adjustment leads to higher internal locus of control. The fact that some control variables (depression, age, sex, use of assistive devices, current enrollment in rehabilitative training) contributed to better adjustment suggests that the relationship is multifactorial as well.

Recommendations for Action

Results of the study suggest that future interventions could be directed at helping individuals with ARMD who are at greater risk of poorer adjustment to vision loss. For example, both men and individuals diagnosed earlier in life are at greater risk of poorer outcomes than are women and older people. Specifically, interventions should focus on altering factors that are susceptible to change, such as depression, use of assistive devices, and rehabilitative training. Given that ARMD is a chronic disease with a degenerative course, it is likely that intervention administered shortly after diagnosis will need to be followed up and increased in order to facilitate continuing adjustment to changes in disease status.

These study results will be shared with many different groups and individuals who have been a part of this study and who have showed interest in utilizing the results to better understand and work with this population. The research sites have asked that the results be disseminated among their support groups as well as their staffs. These organizations work directly with this population on a day to day basis assisting with their needs for assistive devices, rehabilitative training and support. It is recommended that the risk factors for poorer adjustment, as indicated by the results of this study, be used in assessing persons with ARMD when they are initially screened at the research sites. This would allow for a more strategically appropriate course of adaptation training for each person with ARMD. It is also recommended that patients receive updated training and support over the course of their illness. Results will also be shared with Cincinnati Eye Institute where several of the retinal specialists who provide medical care for this population practice. It is important that these organizations and medical professionals understand more about the "whole person" with ARMD in order to more effectively provide for their needs. It is critically important that the physicians working with the ARMD patient be aware of the benefits that referral for adaptation and rehabilitation training brings to this population. The physicians treating this population need also to be aware of the role that LOC plays in patients' willingness to receive adaptive treatment. Also, given that mild depression appears to be characteristic of this population, it is recommended that physicians specifically assess for and treat this condition in their patients with ARMD.

Results will also be shared with many of the long-term nursing facilities in the Cincinnati area. There are many residents in these facilities who have ARMD and therefore the staffs need to have a better understanding of the population, their needs and their adjustment to ARMD. It is possible that many undiagnosed people reside in these facilities. If long term care facilities have a better understanding of what ARMD is and the help that is available people residing in these facilities could be reached and treated more effectively.

The Counseling Source in Cincinnati has also requested that this information be shared with their therapist. The Counseling Source provides psychological services to many of the long term nursing facilities in the Cincinnati area and believes it important that their therapist have a better understanding of ARMD in order to better assist their clients.

Results of this research show that psychological services tailored to the specific needs of the ARMD population are needed. To facilitate transmission of these finding, this study will be presented at the 2009 Ohio Psychological Association Meeting in Columbus, Ohio on October 23, 2009. The intended outcome is that the results be disseminated to psychologists from across the state of Ohio and carried back into their home communities, further advancing knowledge about ARMD.

The complete results will also be shared with Dr. Ken Wallston at Vanderbilt University as well as Dr. Amy Horowitz at Lighthouse International at their request.

Recommendations for Further Study

Present results regarding the associations between age, sex, and adjustment to vision loss should be replicated and extended. Specifically, research is needed to assess whether male sex or younger age do predispose toward poorer adjustment. If this were the case, interventions tailored to these groups could be fashioned so as to increase adjustment and, it is hope, increase the quality of life of these individuals.

Many interesting factors were revealed in the results of this study that would generate new studies and new questions. The prevalence of macular degeneration in the right eye would be a topic to explore with medical professionals. There is a need to further examine the age at which a person was diagnosed and their willingness to receive medical treatment, assistive devices and rehabilitative training. There is also a need to conduct this research in areas where living situations, ability to meet with others with ARMD, and to have ways of getting out to attend to daily needs present greater challenges, such as in rural areas, where the population may not have the resources that are available in urban communities. In addition, further studies that examine the pathways to better adjustment (e. g., use of structural equation models or mediator/moderator models) are called for in order to understand the multifactorial nature of adjustment to vision loss.

One area of great emotional distress and consequent depressive affect that came up with almost every participant was when they were told or realized they could no longer drive. The emotional impact of loss of independence was profound in almost every case. It would be very pertinent to explore the events that produced the greatest emotional trauma for people with ARMD. What have they given up that was the hardest to accept? Have they found a replacement for what they have given up, and is it emotionally satisfying?

Conclusion

This research identified significant positive correlations between internal locus of control and adjustment to vision loss associated with ARMD. Age was shown to be a factor in that those who were older experienced adjustment in a more positive way than the younger participants. Sex also provided significant positive correlation as it was revealed that females adjusted better than males to ARMD. Rehabilitative training and the use of assistive devices were also shown to be positive factors in adjustment to ARMD.

It became apparent to the researcher during this study that there are a large number of people with this disease and that number is growing every day. When considering the grave negative affects of ARMD, it is apparent that any new knowledge, when used in a responsible way, will advance and promote the quality of life of people living with this disease. It is an area in great need for more investigation, particularly in view of the adjustments that each person with ARMD must make and the increasing prevalence of the disease as life spans increase and a large age cohort approaches its later years. It is hoped that the results of this study will enable people with ARMD not only to live long, but to live well.

REFERENCES

- Administration on Aging (2004). Aging into the 21st century. Retrieved from <u>http://www.aoa.gov/AoARoot/Aging_Statistics/future_growth/aging21/aging_21.</u> <u>aspx</u>
- Administration on Aging (2008). A statistical profile of older Americans Aged 65+. Retrieved from http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2008/docs/2008profile.pdf
- American Foundation for the Blind (2007). Key findings: National poll on severe vision loss/blindness. Retrieved from <u>http://www.afb.org/seniorsite</u>
- Babbie, E. (1998). The practice of social research (8th ed.). New York: Wadsworth.
- Bourla, D. H. & Young, T. A. (2006). Age-related macular degeneration: A practical approach to a challenging disease. *Journal of the American Geriatrics Society, 54* (7), 1130-1135. Retrieved from <u>http://www.aafp.org/afp/20061101/tips/12.html</u>
- Bozeman, L.A. (2004). Environmental and personal safety: No vision required [Electronic version]. *Journal of Visual Impairment & Blindness, 98,* 434, 4p.
- Brody, B.L., Roch–Levecq, A., Gamst, A.C., Maclean, K., Kaplan, R.M., & Brown, S.I. (2002). Self-management of age-related macular degeneration and quality of life [Electronic version]. Archives of Ophthalmology, 120, 1477-1483.
- Brody, B.L., Roch–Levecq, A., Kaplan, R.M., Moutier, C.Y., & Brown, S.I. (2006). Agerelated macular degeneration: Self-management and reduction of depressive symptoms in a randomized controlled study [Electronic version]. *JAGS*, 54, 1558-1562. doi:10.1111/j.1532-5415.2006.0081.x
- Bylsma, F.W. & Doninger, N. (2004). Neuropsychological assessment in individuals with severe visual impairment [Electronic version]. *Topics in Geriatric Rehabilitation*, 20, 196-203.
- Campbell. D. T. & Stanley, J. C. (1963). *Experimental and quasi-experimental designs* for research. Chicago, IL: Rand McNally.
- Casten, R.J., Maloney, E.K., & Rovner, B.W. (2005). Knowledge and use of low vision services among persons with age-related macular degeneration [Electronic version]. *The Journal of Visual Impairment & Blindness*, 720-724.
- Casten, R.J., & Rovner, B.W. (2006). Vision loss and depression in the elderly [Electronic version]. *Psychiatric Times*, 1-6.

- Casten, R.J., Rovner, B.W., & Edmonds, S.E. (2002). The impact of depression in older adults with age-related macular degeneration [Electronic version]. *Journal of Visual Impairment & Blindness*, 399-406.
- Charmaz, K. (1995). The body, identity, and self: Adapting to impairment [Electronic version]. *Sociological Quarterly*, 36, 657-680. doi:10.1111/j.1533-8525.1995.tb00459.x
- Cimarolli, V.R., Sussman-Slalka, C.J., & Goodman, C.R. (2004). "Program for Partners": Support group for partners of adults with visual impairments" [Electronic version]. *Journal of Visual Impairment & Blindness*, 98, 1-10.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.) New York: Academic Press.
- Crews, J.E., & Campbell, V. A. (2004). Vision impairment and hearing loss among community-dwelling older Americans: Implications for health and functioning [Electronic version]. *American Journal of Public Health, 94,* 823-828.
- Crews, J.E., Jones, G.C., & Kim, J.H. (2006). Double Jeopardy: The effects of comorbid conditions among older people with vision loss [Electronic version]. *Journal of Vision Impairment & Blindness, Special Supplement,* 824-846.
- Cugati, S. et al. (2007). Visual impairment, age-related macular degeneration, cataract, and long-term mortality [Electronic version]. *Archives of Ophthalmology, 125,* 917-924. doi:10.1001/archopht.125.7.917
- Davis, C., & Lovie-Kitchin, J. (1995). Psychosocial adjustment to age-related macular degeneration [Electronic version]. *Journal of Visual Impairment & Blindness*, 89, 16, 1-13.
- de Rekeneire et al. (2003). Is a fall just a fall: Correlates of falling in healthy older persons. The health, aging and body composition study [Electronic version]. *JAGS*. *51*, 841-8. doi:10.1046/j.1365-2389.2003.51267.x
- Desai, M., Pratt, L.A., Lentzner, H., & Robinson, K.N. (2001). Trends in vision and hearing among older Americans [Electronic Version]. Aging Trends, No. 2. Hyattsville, ND: National Center for Health Statistics.
- Faul, F. (2008). *G*Power* (Version 3.01) [computer program]. Kiel, Germany: Author.
- Federal Interagency Forum on Age-Related Statistics (2000, March). Older Americans 2000: Key indicators of well-being. Washington, DC: U.S. Government Printing Office.

- Federal Interagency Forum on Age-Related Statistics (2008, March). Older Americans 2008: Key indicators of well-being. Washington, DC: U.S. Government Printing Office.
- Fein, F., B. (1994, July 19). Empty lawns: Aging in the suburbs: A special report [Electronic version]. *The New York Times*. Retrieved March 23, 2008, from <u>http://nytimes.com</u>
- Ferris, F.L., & Tielsch, J.M. (2004). Blindness and visual impairment. A public health issue for the future as well as today [Electronic version]. Archives of Ophthalmology, 122, 451-452. doi:10.1001/archopht.122.4.451
- Fisher, C. B. & Lerner, R. M. (Eds.) (2005). "Vision impairment, late life adjustment and rehabilitation." *Encyclopedia of applied developmental science. Volume 2.* Thousand Oaks, CA: Sage.
- Fletcher, D. C., Dreer, L. E., & Elliott, T. R. (2005). Tactile analogue scale instrument for investigation of low vision patient psychological characteristics. *Vision 2005 -Proceedings of the International Congress*. 4 - 7 April 2005, London, UK. Vol. 1282. pp. 125-128. doi: http://dx.doi.org/10.1016/j.ics.2005.05.173
- Frey, W.H. (1999, June). Beyond Social Security: The local aspects of an aging America. Retrieved March 23, 2008, from http:// www.brookings.edu/reports/1999/06demographics_frey.aspx?p=1
- Friedman, D.S., O'Colmain, B.J., Munoz, B., Tomany, S.C., McCarty, C., de Jong, P.T.V.M. et al. (2004). Prevalence of age-related macular degeneration in the United States [Electronic version]. Archives of Ophthalmology, 122, 564-572. doi:10.1001/archopht.122.4.564
- Gordon, P.A., Feldman, D., & Crose, R. (1998). The meaning of disability: How women with chronic illness view their experiences [Electronic version]. *The Journal of Rehabilitation, 64*, 1-12.
- Gould, S. (1999). A critique of Heckhausen and Schultz's life-span theory of control from a cross cultural perspective [Electronic version]. *Psychological Review*, 106, 1-31. doi:10.1037/0033-295X.106.3.597
- Grunwald, H. (2003). Excerpt from Twilight: Losing sight, gaining insight [Electronic version]. *Generations, 27, 102-104*.
- Guralnik, J., Alecxih, L., Branch, L.G., & Wiener, J.M. (1999).
- Gurwood, A.S., & Meyers, M. (2007). A compendium of clinical studies [Electronic version]. *Review of Optometry*, 4+

- Harvard Health Publications (Ed.) (2007). The aging eye: Preventing and treating eye disease. Harvard Medical School, 28-34.
- He, W., Sengupta, M., Velkoff, V.A., & DeBarros, K.A. (2005, December). 65+ in the United States: 2005. Retrieved March 25, 2008, from <u>http://www.census.gov/prod/2006pubs/p23-209.pdf</u>
- Heckhausen, J., & Schultz, R. (1999). The primacy of primary control is a human universal: A reply to Gould's (1999) critique of the life-span theory of control [Electronic version]. *Psychological Review*, 106, 605-609. doi:10.1037/0033-295X.106.3.605
- Heine, C., & Browning, C.J. (2002). Communication and psychosocial consequences of sensory loss in older adults: overview and rehabilitation directions [Electronic version]. *Disability and Rehabilitation, 24, 763-773.* doi:10.1080/09638280210129162
- Horowitz, A., & Reinhardt, J. (1998). Development of the adaptation to age-related vision loss scale. *Journal of Visual Impairment & Blindness*, 92(1), 30-42.
- Ivers, R.Q., Cumming, R., &, Mitchell, P. (2002). Poor vision and risk of falls and fractures in older Australians: The Blue Mountain Eye Study [Electronic version]. *NSW Public Health Bulletin*, 13, 8-10. doi:10.1071/NB020005
- Ivers, R.Q., Norton, R., Cumming, R.G., Butler, M., &, Campbell, A.J. (2000). Visual impairment and hip fracture [Electronic version]. American Journal of Epidemiology, 152, 1-14. doi:10.1093/aje/152.7.633
- Kleinschmidt, J.J. (1999). Older adult's perspectives on their successful adjustment to vision loss [Electronic version]. *Journal of Visual Impairment & Blindness, 93,* 1-14.
- Kunzmann, U., Little, T., & Smith, J. (2002). Perceiving control: A double-edged sword in old age [Electronic version]. *Journal of Gerontology: Psychological Sciences*, 57B, Special Section, P484-P491.
- Kurlowicz, L.H., & Greenberg, S. (2007). The Geriatric Depression Scale. The Hartford Institute for Geriatric Nursing. Retrieved from http://www.hartfordign.org
- La Grow, S.J. (2004). Factors that affect employment status of working-age adults with visual impairments in New Zealand [Electronic version]. *Journal of Visual Impairment & Blindness, 98,* 1-14.
- Lamoureaux, E.L., Pallant, J.F., Pesudovs, K., Rees, G., Hassell, J.B., & Keeffe, J.E. (2007). The effectiveness of low-vision rehabilitation on participation in daily

living and quality of life [Electronic version]. *Investigative Ophthalmology, 48,* 1476-1482. doi:10.1167/iovs.06-0610

- Lee, E.O., & Brennan, M. (2006). Stress constellations and coping styles of older adults with age-related visual impairment [Electronic version] *Health & Social Work*, 31, 289-298.
- Lord, S.R. (2003). Vision, balance and falls in the elderly [Electronic version]. *Geriatric Times, IV*, 1-4.
- Lupsakko, T.A., Mantyjarvi, M.I., Kautianinen, H.J., & Sulkava, R.O. (2003). Decrease in functional or cognitive capacity explains the lack of eye examination in visually impaired older persons [Electronic version]. JAGS, 51, 573-574. doi:10.1046/j.1532-5415.2003.51173.x
- Mazoyer, V., Knoblauch, K., Fontanay, S., Koenig, F., & Vital-Durand, F. (1999). Identification of low-pass filtered images by low-vision patients [Electronic version]. *Visual Impairment Research*, 1, 187-192.
- Milner, K. (2002). People with low vision learning to assist and support others new to their sight loss through teleconferencing [Electronic version]. *Visual Impairment Research*, *4*, 107-112.
- Mitchell, J., & Bradley, C. (2006, October). Quality of life in age- related macular degeneration: A review of the literature. Report to AMD Alliance International.
- Moore, L.W., & Miller, M. (2003). Older men's experiences of living with severe visual impairment [Electronic version]. *Journal of Advanced Nursing*, *43*, 10-18. DOI:10.1046/j.1365-2648.2003.02668.x
- MSNBC (2007, October 30). Boomers to put off retiring, since they have to. Retrieved from http://www.msnbc.msn.com/id/19173780/
- National Alliance for Eye and Vision Research [NAEVR] (n.d.).
- National Alliance for Eye and Vision Research and Alliance for Aging Research (2008). The Silver Book®: Vision loss: Chronic disease and medical innovation in an aging nation. Retrieved from <u>http://www.silverbook.org</u>
- National Center for Health Statistics (2007). Life expectancy. Retrieved from http://www.cdc.gov/nchs/fastats/lifexpec.htm
- National Eye Institute (2002). Vision problems in the U.S.: Prevalence of adult vision impairment and age-related eye diseases in America. Retrieved from

http://www.preventblindness.net/site/DocServer/CDD_Vision_Report.pdf?docID =1324

- National Eye Institute (2006). Vision loss from eye diseases will increase as Americans age. Retrieved from <u>http://www.nei.nih.gov/news/pressreleases/041204.asp</u>
- National Eye Institute (2008). Age-related macular degeneration. Retrieved from <u>http://www.nei.nih.gov/health/maculardegen/armd_facts.asp</u>
- National Institute on Aging. (2006). Dramatic changes in U.S. aging highlighted in new census, NIH report. Retrieved from <u>http://www.nia.nih.gov/NewsAndEvents/PressReleases/PR2006030965PlusReport.htm</u>
- National Institutes of Health (n.d). Fact sheet: Age-related macular degeneration (AMD). Retrieved April 2, 2008, from http:// www.nih.gov/about/researchresultsforthepublic/MacularDegeneration.pdf
- Neill, J. (2006). What is locus of control? Retrieved from http://www.wilderdom.com/psychology/loc/LocusOfControlWhatIs.html
- Nicholls, T. (2005). Out of sight, out of mind? *Healthcare Counseling & Psychotherapy Journal, 5,* 24-27.
- Pham, T.Q., Kifley, A., Mitchell, P., & Wang, J.J. (2006). Relation of age-related macular degeneration and cognitive impairment in an older population [Electronic version]. *Gerontology*, 52, 353-358. doi:10.1159-00094984
- Pilisuk, M., Montgomery, M..B., Parks, S.H., Acredolo, C. (1993). Locus of control, life stress, and social networks: Gender differences in the health status of the elderly [Electronic version]. Sex Roles: A Journal of Research, 28, 1-13. doi:10.1007/BF00299278
- Reeves, B.C., Harper, R.A., & Russell, W.B. (2004). Enhanced low-vision rehabilitation for people with age related degeneration: A randomized controlled trial [Electronic version]. *British Journal of Ophthalmology, 88, 1-12.* doi:10.1136/bjo.2003.037457
- Rovner, B.W., & Casten, R.J. (2002). Activity loss and depression in age-related macular degeneration [Electronic version]. *American Journal of Geriatric Psychiatry*, 10, 305-310. doi:10.1176/appi.ajgp.10.3.305
- Rovner, B.W., Casten, R.J., Hegel, M.T., Hauck, W.W., & Tasman, W.S. (2007). Dissatisfaction with performance of valued activities predicts depression in age-

related macular degeneration [Electronic version]. *International Journal of Geriatric Psychiatry*, 22, 789-793. doi:10.1002/gps.1742

- Ryan, E.B., Anas, A.P., Beamer, M., & Bajorek, S. (2003). Coping with age-related vision loss in everyday reading activities [Electronic version]. *Educational Gerontology, 29*, 37-54. doi:10.1080/713844234
- Scanlon, J.M., & Cuddeford (2004). Low vision rehabilitation: A comparison of traditional and extended teaching programs [Electronic version]. *Journal of Visual Impairment & Blindness*, 601-611.
- Schiaffino, K., Shawaryn, M., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses [Electronic version]. *Health Psychology*, 17, 262-268. doi:10.1037/0278-6133.17.3.262
- Schinazi, V.R. (2007, February). Psychosocial implications of blindness and low vision. Working paper series, Center for Advanced Spatial Analysis, University College of London, UK.
- Schmier, J.K., & Covert, D. W. (2006). Validation of the Daily Living Tasks Dependent on Vision (DLTV) Questionnaire in a U.S. population with age-related macular degeneration [Electronic version]. *Ophthalmic Epidemiology*, *13*, 137-143. doi:10.1080-09286580600573049
- Schmier, J.K., Halpern, M.T., Covert, D.W., Delgado, J., & Sharma, S.(2006). Impact of visual impairment on service and device use by individuals with age-related macular degeneration (AMD [Electronic version]. *Disability and Rehabilitation*, 28, 1331-1338. doi:10.1080/09638280600621436
- Scilley, K., DeCarlo, D.K., Wells, J., & Owsley, C. (2004). Vision-specific healthrelated quality of life in age-related maculopathy patients presenting for low vision services [Electronic version]. *Ophthalmic Epidemiology*, 11, 1131-146. doi:10.1076/opep.11.2.131.28159
- Scoring instructions for the MHLC. (2008). Retrieved from http://www.vanderbilt.edu/nursing/kwallston/scoringmhlc.htm
- Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In T.L. Brink (Ed.), *Clinical Gerontology: A Guide to Assessment and Intervention* (pp. 165-173). NY: The Haworth Press, Inc.
- Schultz, D.P. & Schultz, S.E. (2005). *Theories of personality* (8th ed.). Belmont, CA: Wadsworth.

- Sidell, N. (1997). Adult adjustment to chronic illness: A review of the literature [Electronic version]. *Health & Social Work, 22,* 1-20.
- Silbersweig, L.A, & Garvey, N. (2007). Improving quality of life for low vision patients [Electronic version]. *Ophthalmology Times*, 43, 45.
- Stevens-Ratchford, & R., Krause, A. (2004). Visually Impaired older adults and homebased leisure activities: The effects of person-environment congruence [Electronic version]. *Journal of Visual Impairment & Blindness*, 98, 14, 1-14.
- Strickland, B. R., & Haley, W. E. (1980). Sex differences on the Rotter IE Scale. *Journal* of Personality and Social Psychology, 39, 930-939.
- Tasman, W., & Rovener, B. (2004). Age-related macular degeneration: Treating the whole patient [Electronic version]. Archives of Ophthalmology, 122, 648-649. doi:10.1001/archopth.122.4.648
- Tennstedt, S. (1999, March). Family caregiving in an aging society. Paper presented at the U.S. Administration on Aging Symposium, Baltimore, MD.
- Tolman, J., Kleinschmidt, J.J., & Gregg, C.H. (2005). Psychosocial adaptation to visual impairment and its relationship to depressive affect in older adults with agerelated macular degeneration [Electronic version]. *The Gerontologist*, 45, 747-753.
- U.S. Bureau of the Census (2000). Census bureau projects doubling of nation's population by 2100. Retrieved April 2, 2008, from <u>http://www.census.gov/Press-Release/www/2000/cb00-05.html</u>
- Van Tol, R.R. (2002). Self-reported independent living outcome measures of blind elders attending adjustment training. Unpublished Masters of Science Degree, University of Wisconsin-Stout, Wisconsin.
- Wahl, H., Becker, S., Burmedi, D., & Schilling, O. (2004). The role of primary and secondary control in adaptation to age-related vision loss: A study of older adults with macular degeneration [Electronic version]. *Psychology and Aging*, 19, 1-20. doi:10.1037/0882-7974.19.1.235
- Wahl, H., Kammerer, A., Holz, F., Miller, D., Becker, S., Kasper, R. et al. (2006). Psychosocial intervention for age-related macular degeneration: A pilot project [Electronic version]. *Journal of Visual Impairment & Blindness*, 533-544.
- Wallston, K. A. (1993). Frequently asked questions. Retrieved from http://www.vanderbilt.edu/nursing/kwallston/FAQMHLC.htm

- Wallston, K.A. & Wallston, B.S. (1981). Health locus of control scales. In H. Lefcourt (Ed.) Research with the locus of control construct, Volume 1. New York: Academic Press. <u>http://www.vanderbilt.edu/nursing/kwallston/Health%20Locus%20of%20Control</u> <u>%20Scales.pdf</u>
- Wallston, B. S., Wallston, K. A., Kaplan, G. D., & Maides, S. A. (1976). The development and validation of the health related locus of control (HLC) scale. *Journal of Consulting and Clinical Psychology*, 44, 580-585. Retrieved from http://www.vanderbilt.edu/nursing/kwallston/A10.pdf
- Wong, K.B. (2006). Age-related vision loss: A comparison of adaptation, emotions, and time. Unpublished master' thesis, California State University, Fullerton, California.
- Wong, E., Guymer, R.H., Hassell, J.B., & Keeffe, J.E. (2004). The experience of agerelated macular degeneration {Electronic version]. *Journal of Visual Impairment* & *Blindness*, 98, 629-640.
- Yagoda, L. (2004). Working caregivers: issues and opportunities for social work practice. Retrieved from <u>http://www.socialworkers.org/practice/aging/aging0804.pdf</u>
- Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M.B., & Leirer, V.O. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37-49. doi:10.1016/0022-3956(82)90033-4
- Zikmund, W. G. (1991). *Business research methods*. (2nd ed.). Chicago, IL: Dryden Press.
- Zullo, N. (n.d.) Depression in elderly care recipients. Retrieved from <u>http://www.longtermcarelink.net/eldercare/depression_elderly_care_recipients.ht</u> <u>m</u>

APPENDIX A

LETTERS OF COOPERATION FROM COMMUNITY RESEARCH PARTNERS

Clovernook Center for the Blind and Visually Impaired 7000 Hamilton Ave. Cincinnati, Ohio 45231 513-522-3860 http://clovernook.org/services.php

January 29, 2009

Dear Ms. Stinnette,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Locus of Control & Adjustment to Vision Loss among People with Age Related Macular Degeneration within <u>Clovernook Center</u>. As part of this study, I authorize you to <u>contact individuals within our support groups that I have spoken with</u>, <u>described the study to</u>, and who have agreed to participate. Individuals' participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely, Ms. Maureen Fink Licensed Social Worker Cincinnati Association for the Blind and Visually Impaired 2045 Gilbert Ave. Cincinnati, Ohio 45202 513-221-8558 http://www.cincyblind.org/#Top%20of%20Page

January 29, 2009

Dear Ms. Stinnette,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Locus of Control & Adjustment to Vision Loss among People with Age Related Macular Degeneration within the Cincinnati Association for the Blind and Visually Impaired. As part of this study, I authorize you to contact individuals within our support groups that I have spoken with, described the study to, and who have agreed to participate. Individuals' participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely, Ms. Kathy Roberts, LSW Manager of Social Services

APPENDIX B

CONSENT FORM

You are invited to take part in a research study of a person's adjustment to vision loss due to Age Related Macular Degeneration. You were chosen for because you fit the criteria needed for this study. You are 60 years of age or older, you have Age-Related Macular Degeneration and it has been longer than 6 months since you were diagnosed. Please read this form or have the Research Assistant read it to you and ask any questions you have before agreeing to be part of the study.

This study is being conducted by a researcher named Delinda Stinnette, who is a doctoral student at Walden University. Delinda also has Macular Degeneration and is very interested in the fact that this study may help to make adjustment to vision loss due to Age Related Macular Degeneration easier for others.

Background Information:

The purpose of this study is to better understand how individuals over the age of 60 with Age Related Macular Degeneration adjust to their vision loss. By better understanding this adjustment process we can hopefully help others with Age Related Macular Degeneration to develop the skills necessary to adapt to their loss and maintain their overall quality of life. The results of the proposed study will be an important addition to the existing literature and will provide guidance for the development of interventions to reduce the difficulties experienced by people with Age Related Macular Degeneration, reduce their dependency on others by becoming more self-sufficient, and improve their ability to maintain their quality of life.

Procedures:

If you agree to be in this study, you will be asked to:

- Read and sign a consent form and you will be given a copy
- Give some very general information regarding yourself. No personal information such as name or address will be included.
- You will then be asked to either answer questions on three very short survey forms or if desired a Research Assistant can ask the questions verbally and record your answers. All answers are in the form of True or False, Yes, No or a scale, which ranges from strongly disagree (1) to strongly agree (6)

Voluntary Nature of the Study:

Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one at Cincinnati Association for the Blind and Visually Impaired or Clovernook Center for the Blind and Visually Impaired will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. If you feel stressed during the

study you may stop at any time. You may skip any questions that you feel are too personal.

Risks and Benefits of Being in the Study:

While there are no risks to you by participating in the study the advantages for the future adjustment of others to Age Related Macular Degeneration and the positive social change that may come from the results are very advantageous.

Compensation:

There is no compensation to you for participating in this study.

Confidentiality:

Any information you provide will be kept confidential. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via 513-470-9351 or dedeann@fuse.net. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration** date.

The researcher will give you a copy of this form to keep.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Written or Electronic* Signature

Researcher's Written or Electronic* Signature

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

APPENDIX C

BRIEFING SCRIPT

It's great to meet you (name of participant). I am (name). I am acting as a research assistant for Delinda Stinnette, who is doing research on how people with Age-related Macular Degeneration deal with their illness.

If you say that you want to do this, I will give you some questionnaires that will take you about 60 minutes to answer. These questions will ask you about your age, sex, illness, moods, and other feelings. You may skip any questions that you do not want to answer.

It is your choice to do this or not to do this. Even if you say that you want to do this now, you may change your mind at any time, even after you've answered the questions. You are not required to do this in order to receive treatment for ARMD, so if you say yes or no your treatment will not change. All of your answers to the questions will be kept in a locked cabinet and only I will have the key.

If you want, when we are done with this study, you can ask to get a copy of what I learned.

Do you have any questions?

You will be given a consent form to sign. Please read it and feel free to ask any questions before you sign it.

Thank you.

APPENDIX D

DEMOGRAPHIC DATA FORM

PLEASE ANSWER THE FOLLOWING QUESTIONS:

1.) Age -_____

2.) Sex - Female _____ Male _____

3.) Highest Level of Education:

| a. Elementary School b. High School/GED c. Some College/ Technical T d. College, B.A., B.S., M.A., | Fraining | | | | | |
|---|--|--|--|--|--|--|
| 4.) When were you first diagnosed w | ith Macular Degeneration? | | | | | |
| 5.) Tell me about your Macular Degeneration: Circle the answer | | | | | | |
| a. Right Eye Macular Degenera | ntion Yes No | | | | | |
| Wet | Yes No Unknown | | | | | |
| Dry | Yes No Unknown | | | | | |
| b. Left Eye Macular Degenerat Wet Dry | ion Yes No Yes No Unknown Yes No Unknown | | | | | |

6.) Are You Receiving Medical Treatments From a Medical Doctor/retinal specialist for your Macular Degeneration?

Yes-____ No-____

DEMOGRAPHIC DATA FORM CONTINUED

7.) Do You Use <u>ANY</u> Visual Assistance Devices Such as, Special Lighting, Magnifying Glasses, Cane, Computer Programs, Etc.? Yes-_____No-_____ 8.) Are You Receiving Any Rehabilitation Training To

Help You Adjust To Your Vision Loss? (For instance at Clovernook Center or Cincinnati Association for the Blind and Visually Impaired.)

Yes-_____No-_____

THANK YOU

APPENDIX E

ADAPTATION TO AGE-RELATED VISION LOSS SCALE

PLEASE CIRCLE EITHER TRUE OR FALSE

- 1. Because of my vision loss, I feel like I can never really do things for myself. **True** False
- 2. Most services available to visually impaired persons are useless in really helping them with their problems. **True False**
- 3. I can still do many of the things I love; it just takes me longer because of my visual impairment. **True False**
- 4. Visual impairment is the cause of all my problems. **True False**
- 5. Some people in the family act as though the visually impaired person is a burden to them. **True** False
- 6. A visually impaired person can never really be happy. **True False**
- 7. Because of my trouble seeing, I am afraid that people will take advantage of me.True False
- 8. By learning new ways of doing things (that compensate for vision loss), a visually impaired person has a chance to be more independent.
 True False
- 9. Visually impaired persons cannot afford to talk back or argue with family and friends. **True** False
- 10. People should not expect too much from visually impaired persons. **True** False

ADAPTATION TO AGE-RELATED VISION LOSS SCALE CONTINUED

11. People who experience vision loss late in life will never be able to learn how to get around without bumping into things. **True False**

- 12. It is too hard for older people to learn new ways of doing things (that compensate for vision loss) if they become visually impaired.True False
- 13. Visually impaired people may as well accept the fact that visual impairment makes people pretty helpless. **True False**
- 14. It is degrading for visually impaired persons to depend so much on family and friends. **True False**
- 15. Although the circumstances of my life have been changed, I am still the same person I was before my visual impairment. True False
- 16. Sighted people generally dislike being with visually impaired people (because of their vision problems). True False
- 17. Sighted people expect visually impaired persons to do things that are impossible.True False
- Visually impaired people have to depend on sighted people to do most of the things they did for themselves. True False
- 19. Losing one's sight means losing one's self. **True False**
- 20. People with vision problems are uncomfortable making new friends because they cannot always see people's faces clearly. **True False**
- 21. I feel comfortable asking my family and friends for help with things I can no longer do because of my vision loss. True False

ADAPTATION TO AGE-RELATED VISION LOSS SCALE CONTINUED

- 22. When a person becomes visually impaired, sighted friends don't understand him or her as they did before. **True** False
- 23. It is better for persons with vision problems to let other people do things for them.True False

24. There are worse things that can happen to a person than losing vision. **True False**

APPENDIX F

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE FORM C

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale, which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)

4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)

| | | SD | MD | D | A | MA | SA |
|----|---|----|----|---|---|----|----|
| 1 | If my ARMD worsens, it is my own behavior which determines how soon I will feel better again. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2 | As to my ARMD, what will be will be. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3 | If I see my doctor regularly, I am less likely to have problems with my ARMD. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4 | Most things that affect my condition happen to me by chance. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5 | Whenever my ARMD worsens, I should consult a medically trained professional. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6 | I am directly responsible for my ARMD getting better or worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7 | Other people play a big role in whether my ARMD improves, stays the same, or gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8 | Whatever goes wrong with my ARMD is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9 | Luck plays a big part in determining how my ARMD improves. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10 | In order for my ARMD to improve, it is up to other people to see that the right things happen. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11 | Whatever improvement occurs with my ARMD is largely a matter of good fortune. | 1 | 2 | 3 | 4 | 5 | 6 |

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| 12 | The main thing which affects my ARMD is what I myself do. | 1 | 2 | 3 | 4 | 5 | 6 |
|----|--|---|---|---|---|---|---|
| 13 | I deserve the credit when my ARMD improves and the blame when it gets worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 14 | Following doctor's orders to the letter is the best way to keep my ARMD from getting any worse. | 1 | 2 | 3 | 4 | 5 | 6 |
| 15 | If my ARMD worsens, it's a matter of fate. | 1 | 2 | 3 | 4 | 5 | 6 |
| 16 | If I am lucky, my ARMD will get better. | 1 | 2 | 3 | 4 | 5 | 6 |
| 17 | If my ARMD takes a turn for the worse, it is because I have not been taking proper care of myself. | 1 | 2 | 3 | 4 | 5 | 6 |
| 18 | The type of help I receive from other people determines how soon my ARMD improves. | 1 | 2 | 3 | 4 | 5 | 6 |

APPENDIX G

GERIATRIC DEPRESSION SCALE: SHORT FORM

Choose the best answer for how you have felt over the past week: Circle your answer.

- 1. Are you basically satisfied with your life? YES / NO
- 2. Have you dropped many of your activities and interests? YES / NO
- 3. Do you feel that your life is empty? YES / NO
- 4. Do you often get bored? YES / NO
- 5. Are you in good spirits most of the time? YES / NO
- 6. Are you afraid that something bad is going to happen to you? YES / NO
- 7. Do you feel happy most of the time? YES / NO
- 8. Do you often feel helpless? YES / NO
- 9. Do you prefer to stay at home, rather than going out and doing new things? YES / NO
- 10. Do you feel you have more problems with memory than most? YES / NO
- 11. Do you think it is wonderful to be alive now? YES / NO
- 12. Do you feel pretty worthless the way you are now? YES / NO
- 13. Do you feel full of energy? YES / NO
- 14. Do you feel that your situation is hopeless? YES / NO
- 15. Do you think that most people are better off than you are? YES / NO

Answers in bold indicate depression. Score 1 point for each bolded answer.

A score > 5 points is suggestive of depression.

A score > 10 points is almost always indicative of depression.

A score > 5 points should warrant a follow-up comprehensive assessment.

APPENDIX H

TRAINING MANUAL FOR RESEARCH ASSISTANT

Training Manual for Chase Strieker Conducting data collection for Delinda Stinnette "Locus of Control & Adjustment to Vision Loss among People with Age Related Macular Degeneration"

During training with the Research Assistant (RA) the following information was passed to and discussed with Mr. Strieker. Ms. Stinnette was comfortable that he grasped the information and was prepared to administer the instruments in a competent and confidential manner.

- 1. Provided RA with the proposal and instruments to be administered.
- 2. Proposal and each instrument were reviewed and any questions the RA had were answered. Demographics, Adaptation to Age-Related Vision Loss Scale, Multidimensional Health Locus of Control Scale and Geriatric Depression Scale (Short Form) were each thoroughly discussed.
- 3. Went over confidentially agreement and RA signed.
- 4. Reviewed the Consent form to be signed by participants and explained that after signature, the participant received a copy and a copy is to be placed in a separate envelope apart from the instruments.
- 5. Reviewed how RA should introduce himself at each interview. RA is prepared to again introduce the purpose of the interview along with the positive nature of the study.
- 6. Requested RA present at each interview neatly dressed preferably no jeans or T-shirts taking into account the professionalism and the age of the participants.
- 7. Reviewed what RA might expect when working with participants with Age Related Macular Degeneration.
- 8. Reviewed also any other potential situation he might encounter such as hearing loss, mobility problems, etc., and making certain that the participant understands each question.
- 9. After completing the four instruments place back in original envelope.
- 10. Before leaving be certain to thank participant and remind them that they have Ms. Stinnette's number and e-mail if they have any questions. They also have the Walden contact should they have any questions or comments later.

APPENDIX I

CONFIDENTIALITY AGREEMENT

CONFIDENTIALITY AGREEMENT

Name of Signer:

During the course of my activity in collecting data for this research: "Locus of Control & Adjustment to Vision Loss among People with Age Related Macular Degeneration", I will have access to information, which is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

- 1. I will not disclose or discuss any confidential information with others, including friends or family.
- 2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
- 3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant's name is not used.
- 4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
- 5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
- 6. I understand that violation of this agreement will have legal implications.
- 7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature:

Date:

CURRICULUM VITAE

| Delinda A. Stinnette, M.A. 7449 Quiet Time Place West Chester, OH 45069 (513) 755-1984 Home (513) 470-9351 Cell <u>dedeann@fuse.net</u> | |
|--|------|
| Education | |
| Doctor of Philosophy – Counseling Psychology | 2009 |
| Walden University, Minneapolis, Minnesota | |
| Master of Arts – Family Pastoral Counseling/Religious Studies College of Mount St. Joseph, Cincinnati, OH | 1999 |
| Bachelor of Arts - Liberal Arts College of Mount St. Joseph, Cincinnati, OH | 1993 |

Relevant Professional Experience:

Psychology Assistant 2007 - Present

The Counseling Source, Cincinnati, OH

This field training (practicum and internship) was designed to develop clinical skills in assessment and ongoing counseling while working with adults affiliated with area nursing facilities. Counseling interventions as well as familiarity with the role of the Mental Health Agency in serving adults residing in nursing facilities was the main focus. Treatment plans, comprehensive assessments, accurate and detailed progress notes were all part of the preparation and served to increase the ability to provide accurate DSM-IV diagnosis and ongoing psychological treatment and interventions. After completion of practicum and internship I continue on staff as a Psychology Assistant.

Case Manager Specialist – Intensive Youth Services 2006 – 2007 Community Mental Health Center, Inc. Brookville, IN Provided diagnostic, therapeutic, consultative/education and case management services to children, adolescents and families involved in the child and adolescent Intensive Youth Services Program.

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| | 999 – Present |
| Winning Guidance, West Chester, OH Provide stress management, life coaching, smoking cessation, Weight mar esteem building, balance and positive outlook, marriage counseling, finance interviewing skills, resumes and career counseling. Utilize Solution Focus most clients. | cial counseling, |
| Director | 1980 - 1983 |
| Valley Workshop, Waynesboro, VA Contract acquisition and program coordinator in a sheltered workshop for adults. | special needs |
| Other Experience: | |
| Senior Customer Care Manager Wireless Division Senior Marketing Manager Retail Operator and Directory Services Cincinnati Bell Telephone, Cincinnati, OH | 1997 – 2004 |
| General Manager, National Sales and Marketing Manager Engineered Cordset Division General Cable Corporation, Highland Heights, KY | 1988 - 1997 |
| National Sales Manager Virginia Plastics Company, Roanoke, VA | 1983 – 1988 |
| Community Service: | |
| Little Sisters of the Poor, Cincinnati, OH Care and comfort to the elderly | 1991 – 1992 |
| Talbert House, Cincinnati, OH Worked with women in drug rehabilitation program | 1992 |
| Radio Readers – Cincinnati Association for the Blind Read the newspaper for the visually handicapped | 1992 - 1993 |
| First Step Home, Cincinnati, OH Worked with women and their children in a recovery program. Taught money management, job-seeking skills, resumes, job applications | 1993 – 1994 |
| St. Michael's Center, Cincinnati, OH | 1996 – 1999 |

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|---|------------------------|--|--|--|
| Worked with a population involved in drug rehabilitation and also low in families to prepare for financial survival and to utilize all sources of aid. | come | | | |
| Mission Honduras Worked with children in an orphanage in Honduras | 1998 | | | |
| St. John the Evangelist Church, West Chester, OH Peace and Justice Commission | 1998 – 2000 | | | |
| Licenses and Certifications: | | | | |
| International Medical and Dental Hypnotherapy Association Life Coach, Coach University | Certified Certified | | | |
| Professional Presentations and Papers: | | | | |
| The Onset of Old Age for Baby Boomers: The Journey and the Destination Poster Presentation, Walden Summer Research Symposium, Indiana University Bloomington, IN (2007) | | | | |
| Locus of Control and Adjustment to Vision Loss in People with ARMD Poster Presentation, Ohio Psychological Assn., Columbus, OH (2009) | | | | |
| Honors and Awards: | | | | |
| Dream Team for Leadership Cincinnati Bell Telephone | 1999 - 2001 | | | |
| Cincinnati Building Bridges Award, Cincinnati, OH | 2000 | | | |
| Award for Exceptional Service, The Counseling Source, Cincinnati, OH | 2008 | | | |
| Professional Affiliations: | | | | |
| American Psychological Association | | | | |

American Psychological Association Psi Chi National Honor Society in Psychology International Medical and Dental Hypnotherapy Association Ohio Psychological Association