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## Difference in Health Literacy Level Between Older Adults With and Without Low Vision

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DIFFERENCE IN HEALTH LITERACY LEVEL BETWEEN OLDER ADULTS WITH  
AND WITHOUT LOW VISION

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,  
in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2012

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# DIFFERENCE IN HEALTH LITERACY LEVEL BETWEEN OLDER ADULTS WITH AND WITHOUT LOW VISION

MARY L. WARREN

## HEALTH EDUCATION AND HEALTH PROMOTION

### ABSTRACT

Functional health literacy is the ability to understand and apply health information from printed documents and is dependent on reading. Few studies have examined functional health literacy levels in visual impaired older adults despite the fact low vision is common among older adults and impairs reading performance. This study investigated whether community dwelling older adults with moderate visual impairment from age-related macular degeneration had lower health literacy levels compared to older adults without low vision. The Test of Functional Health Literacy for Adults (TOFHLA) was administered to 50 adults aged 65- 94 years with AMD and 50 normally sighted adults matched on age, gender and education. Inclusion criteria included a minimum of high school education and annual income of \$20,000; English speaking, and minimal risk for depression or dementia. The participant also had to report reading at least 20 minutes daily. TOFHLA scores were recorded for two timing conditions: the standard test time limit and unlimited time that permitted participants to take as much time as needed to complete the test.

Low vision participants scored significantly lower than controls on both time conditions but significantly improved scores on unlimited time. Given extra time to complete the test, 98% of the low vision participants were classified as having adequate health literacy levels compared to 60% on the standard time condition. Significant associations were found among TOFHLA scores and acuity, reading speed and critical print size in the low vision group on the standard time condition. A partial correlation showed that reading speed and acuity contributed to TOFHLA scores on the standard time condition. Only acuity significantly correlated with TOFHLA scores in the unlimited time condition. Significant associations were also found among TOFHLA scores and reading frequency and activity level in the entire sample. The study findings suggest that slower reading speed associated with AMD significantly influenced test performance on the standard time condition, but did not account for all of the difference in scores between the groups. Reduced acuity also may have contributed to lower TOFHLA scores by affecting reading accuracy.

Keywords: Health literacy, functional health literacy, low vision, macular degeneration,

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## CHAPTER 1

### INTRODUCTION

#### Chronic Disease in the United States

By 2030 the population of older adults in the United States is projected to double with almost one out of every five Americans over the age of 65 years (Administration on Aging, 2010). Because of medical advances and public health efforts that have reduced death from diseases and accidents, Americans who reach age 65 today can expect to live average of 18.6 additional years (Administration on Aging, 2010). Whereas infectious diseases had the great effect for most of the 20<sup>th</sup> century, chronic diseases are now the leading cause of illness and disability among older adults (Centers for Disease Control & Prevention, [CDC] 2007). Chronic diseases are defined as conditions that last at least one year, limit the person's ability to engage in daily activities, and/or require ongoing medical care (Robert Wood Johnson Foundation [RWJF], 2010 p.13). They often have no cure, are medically complex, and require a significant amount of coordinated care to avoid progression of the disease and disability (CDC, 2009). An estimated 90% of older Americans live with one or more chronic medical condition (RWJF, 2010). Currently, 84% of U.S. health care dollars are spent on persons with chronic diseases, mostly among those over 65 years of age (RWJF, 2010). Older adults with multiple chronic conditions consume the most health care resources accounting for 98% of all Medicare expenditures (RWJF, 2010). Additionally, they have been found to use health services more regularly

and receive a greater array of services, and consume more medications, averaging 57 prescriptions per year for persons with five or more chronic conditions (RWJF, 2010; Vogeli et al., 2007)

The rising prevalence and cost of chronic diseases has forced a paradigm shift in the delivery of health care to Americans. Because chronic diseases are ongoing, the person must learn to live with the disease. Lifestyle and behavior change become critical components of successfully managing the disease and maintaining quality of life (Clark, 2003). Persons with chronic disease are required to relinquish the traditionally passive role of patient and assume a new dynamic role as a partner with health care providers (Clark, 2003). Their shift from “patient” to “partner” means they must become knowledgeable managers of their medical conditions (Clark, p. 290). The term, *self-management*, was coined to describe this partnership. In self-management, the patient assumes primary responsibility for handling the health condition with assistance from health care providers who encourage and provide *self-management support* to the patient’s efforts. Health care providers deliver this support by educating the patient in how to manage the disease and coordinating care among health services (Adams & Corrigan, 2003; Clark, 2003).

Successful self-management requires an educated and knowledgeable consumer who is capable of identifying and managing risk factors to minimize morbidity and mortality, adhering to medical regimens, and navigating the complexities of the health care system to obtain needed services (Adams & Corrigan, 2003; Clark, 2003). Health care providers heavily utilize print media to provide educational and medical support

through pamphlets, articles, books and the internet. Thus, competent self-management of chronic disease requires persons to possess adequate levels of functional health literacy.

### Functional Health Literacy

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. 6). Investigators have identified various forms of health literacy (McCray, 2005), but most research has focused on *functional* health literacy, which is dependent on reading and numeracy skills (Nielsen-Bohlman, Panzer, & Kindig, 2004). Functional health literacy requires that the person be able to read prose (e.g. read instructions), locate and use information in documents (e.g., read graphs and forms), and decipher numbers embedded in print materials (e.g. calculate correct dosages). The concept is closely aligned with general literacy and encompasses a wide range of reading and numeracy skills applied in five health areas: health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (Rudd, 2007). Over 190 health-related functional literacy tasks have been identified ranging from purchasing wholesome food to selecting and applying for insurance coverage (Rudd, 2007).

Adult literacy levels in the United States (U.S.) are determined through administration of the National Assessment of Adult Literacy (NAAL) conducted by the National Center for Education Statistics of the U.S. Department of Education. The assessment was last administered to a representative sample of 19,000 adults in 2003.

Embedded for the first time within the 2003 NAAL survey were 28 items representing three domains of functional health literacy: clinical (knowledge of medical information), prevention (knowledge of health information), and navigation of the health system (knowledge of procedures and policies for obtaining services). The survey used real world examples to measure the ability of American adults to obtain information from three types of printed health materials: prose, documents and numbers. The results of the NAAL separated respondents into four levels of health literacy skill based on scores: (1) below basic, (2) basic, (3) intermediate and (4) proficient. Although 53% of the sample demonstrated intermediate levels of health literacy and 12% were classified as proficient; 38% of the respondents scored at basic or below basic levels, a figure that represented 93 million American adults (Kutner, Greenberg, Jin, & Paulsen, 2006). Adults at this skill level were only able to locate and understand simple and easily identifiable health information and complete simple one-step, concrete math calculations.

Multiple studies have shown that older adults have lower functional health literacy levels than younger adults (Baker, Gazmararian, Sudano, & Patterson, 2000; Benson & Forman, 2002; Billek-Sawbney & Reichert, 2005; Cordasco, Asch, Franco, & Mangione, 2009; Cutilli, 2007; Downey & Zun, 2008; Gazmararian, Baker, & Williams, 1999; Kutner, Greenberg, Jin, & Paulsen, 2006; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). The association of older age with low health literacy levels may reflect lower educational attainment among this current generation of older adults (Cutilli, 2007; Jackson, Davis, Murphy, Bairnsfather, & George, 1994; Weiss, Reed & Kligman, 1995) but it could also be related to age-related declines in cognition and reading performance (Baker, Gazmararian, Sudano, &

Patterson, 2000; Brown & Park, 2002; Finucane, et al., 2002; Levinthal, Morrow, Tu, Wu, & Murray, 2008; Morrow et al., 2006). Associations also have been found between functional health literacy and variables that influence general literacy levels including education, socioeconomic status, race and culture, and primary language. Numerous studies have shown that persons who are minorities, have less education, live in poverty, and whose primary language is not English demonstrate lower health literacy levels (Bennett et al., 1998; Berkman et al., 2004; Brice et al., 2008; Britigan, Murnan, & Rojas-Guyler, 2009; Cordasco, Asch, Franco, & Mangione, 2009; Downey & Zun, 2008; Fang, Panguluri, Machtiger, & Schillinger, 2009; Gazmararian, Baker, & Williams, 1999; Jeppesen, Coyle, & Miser, 2009; Kalichman et al., 2000; Liventhal, Morrow, Tu, Wu, & Murray, 2008; Martin et al., 2009; Morrow et al., 2006; Munoz et al., 2008; Nielsen-Bohlman, Panzer, & Kindig, 2004; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Schillinger et al., 2002; Shea et al., 2004; Williams et al., 1995; Zun, Sadoun, & Downey, 2006). However, the research has also shown that even well educated persons can demonstrate low health literacy when confronted with the need to understand specific health information or navigate a complex, unfamiliar health system (Andrus & Roth, 2002; Benson & Forman, 2002).

### Low Health Literacy and Health Outcomes

Concern among health care providers about low health literacy levels derives from its association with health outcomes. Berkman, Sheridan, Donahue, Halpern and Crotty (2011) conducted a systematic review of the evidence relating low health literacy

and health outcomes. The investigators reviewed 96 good and fair quality studies. They found consistent moderate associations between low health literacy levels and increased hospitalization and use of emergency care, lower use of preventative medical screenings and poorer self-management skills especially in taking medications appropriately. Low health literacy levels were consistently associated with poorer health status and increased mortality among older adults.

Low health literacy has been shown to be associated with adverse health outcomes in persons with various chronic diseases including diabetes (Fang, Machtinger, Wang, & Schillinger, 2006; Gazmararian et al., 2006; Kripalani et al., 2006; Roth & Ivey, 2005), hypertension (Morris, MacLean, & Littenberg, 2006; Williams, Baker, Parker, & Nurss, 1998), cardiovascular disease (Safeer, Cooke, & Keenan, 2006); cancer (Amalraj, Starkweather, Nguyen, & Naeim, 2009; Dolan et al., 2004), AIDS (Kalichman et al., 2000), glaucoma (Muir et al., 2006), kidney disease (Grubbs, Gregorich, Perez-Stable, & Hsu, 2009), and rheumatoid arthritis (Buchbinder, Hall, & Youd, 2006). Adverse health outcomes associated with low literacy have also been reported following medical/surgical procedures such as total hip surgery (Wilson & McLemore, 1997). Multiple studies have shown associations between low health literacy and increased risk of improper medication use and lower adherence to medication regimens among older adults (Fang, Machtinger, Wang, & Schillinger, 2006; Gazmararian et al., 2006; Kripalani et al., 2006; Juzych et al., 2008; Muir et al., 2006; Roth & Ivey, 2005; Schillinger et al., 2002).

Low health literacy may adversely affect health outcomes by influencing the timing and use of health care services, determining when persons first access health services, and how many services they receive. Studies have found low health literacy to



be independently associated with poor understanding of disease, which may limit health-seeking behaviors (Ellish, Royak-Schaler, Passmore, & Higginbotham, 2007; Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Schillinger et al., 2002; Sparks & Nussbaum, 2008; von Wagner, Semmler, Good, & Wardle, 2009; Williams, Baker, Parker, & Nurss, 1998). Persons with low health literacy are less likely to obtain medical screening for high-risk conditions leading to later diagnosis (Dolan et al., 2004). They also might not recognize the early signs of diseases such as cancer or diabetes and wait to seek medical care until they are much sicker (Bennett et al., 1998; Dolan et al., 2004; Munoz et al., 2008; Nielsen-Bohlman, Panzer, & Kindig, 2004). Persons with low health literacy also may not fully use available health services because they do not understand how to successfully navigate the health care system to obtain needed services (Scott, Gazmararian, Williams, & Baker, 2002; Sudore et al., 2006). Greater health disparities among persons with low health literacy might subsequently contribute to increased risk of hospitalization and higher mortality rates (Baker, Parker, Williams, & Scott, 1998; Baker et al., 2007; Gazmararian, Baker, & Williams, 1999 b). However, the literature has not been consistent and some studies have not shown associations between low health literacy and preventable hospital admissions (Arozullah et al., 2006). These inconclusive findings underscore the complexity of chronic disease management and the fact that many factors influence health care usage. Although the relationship between low health literacy and health outcomes has been well established, it is clear that health literacy alone cannot account for all of the challenges that persons with chronic diseases face in managing their diseases, nor can adequate health literacy levels among Americans guarantee optimal health outcomes. Multiple factors have been shown to influence the

access to and utilization of health services and health outcomes including socioeconomic level, educational attainment, language, race, and culture (Lee, Arozullah, & Cho, 2004).

In response to the large and growing body of research on the influence of health literacy on health outcomes, prominent national organizations and leaders representing federal, private, and consumer stakeholders have publically recognized health literacy as a critical component in ensuring the health of the American public (American Association of Retired People, n.d.; Department of Health and Human Services (DHHS); Carmona, 2003; The Joint Commission, 2007). These stakeholders have identified health literacy as an essential tool for navigating the health care system to obtain needed services, manage chronic conditions and reduce health disparities among Americans. The first objective in the health communication and health information technology topic area in Healthy People 2020 targets improving the health literacy of Americans and identifies three target measures to increase the proportion of Americans who are able to communicate effectively with health care providers (DHHS, n.d.). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), which provides quality assurance oversight for U.S. hospitals, identified adequate health literacy as being crucial to ensure patient safety. JCAHO established specific accreditation and certification benchmarks for health communications to ensure that patients were able to understand the health information they received (Ross, 2007; The Joint Commission, 2007).

Low health literacy has also been identified as a public health issue. In an editorial in the *American Journal of Preventive Medicine*, Gazmararian, Curran, Parker, Bernhardt, and DeBuono (2005) called for public health officials to shift the emphasis in health communications away from delivery of the message to whether the message is

understood. In 1999, the American Medical Association (AMA) convened an ad hoc committee to study health literacy (Council on Scientific Affairs for the American Medical Association, 1999). The committee's report, reflecting the common stance taken by national health care stakeholders, stated five principal reasons why health policy makers should care about health literacy: (a) to empower consumers to manage their health issues, (b) to ensure that persons receive quality medical care, (c) to reduce adverse health outcomes (d) to avoid health care costs brought on by consumers who did not understand the importance of health information, and (e) to reduce health care disparities for vulnerable populations. The AMA subsequently adopted policies to increase awareness among physicians of the incidence and challenges related to low health literacy and developed educational programs for undergraduate, graduate, and practicing physicians to promote the best methods for identifying and communicating with persons with low literacy (Council on Scientific Affairs for the American Medical Association, 1999),

### Low Vision

Among the 72 million older Americans living in the year 2030, 7.7 million will wake up every day with a chronic medical condition known as low vision (Congdon et al., 2004; Leonard, 2002). Low vision results from eye conditions that cannot be corrected by medical or surgical intervention or eyeglasses. Persons with low vision have some usable vision but their vision loss is severe enough to interfere with completing daily activities. Low vision does not include blindness, which is the inability to see light

or form or use vision for activities. Persons with low vision exist in a state between good vision and blindness in that they are able to see but they do not see well. Low vision is divided into four impairment levels for diagnostic purposes, medical treatment, and rehabilitation (Centers for Medicare and Medicaid Services [CMS], 2002). The levels are based on the person's distance visual acuity and include the categories of moderate, severe or profound impairment, and near blindness. Persons begin to experience difficulty reading at moderate levels of visual impairment experience but are generally able to continue to read using magnifying devices until visual acuity reaches the level of profound impairment (Colenbrander & Fletcher, 1995). In addition to reduced acuity, persons with low vision experience difficulty distinguishing color and low contrast features (Legge, 2007; Travis et al., 2004). Colors often appear faded, and persons have difficulty distinguishing between gradations of colors. Contrast sensitivity is the ability to distinguish objects that contrast little from the background. Persons with impaired contrast ability have difficulty in seeing objects with low contrast features such as water spilled on a floor, facial features, and the depth in stairs and curbs or poor quality printed text. Impairment of these visual functions cause persons with low vision to experience limitations completing basic activities of daily living (ADL) like eating, grooming and dressing, and more complex instrumental ADLs such as meal preparation, medication management, shopping, and driving (Crews, 2000; Lamoureux, Hassell, & Keeffe, 2004; Lindo & Nordholm, 1999; Travis, Boerner, Reinhardt, & Horowitz, 2004).

Aging is considered one of the best predictors for developing low vision; two-thirds of all persons with low vision are over 65 years of age (Congdon et al, 2004.). Three chronic progressing eye diseases account for the majority of low vision in older

Americans: age-related macular degeneration (AMD), open-angle glaucoma and diabetic retinopathy (Javitt, Zhou, & Willke, 2007). The three diseases are age-related because their prevalence increases significantly with age and are chronic because they last more than a year and cannot be cured, and cause irreversible vision loss. They are also progressive because vision continues to decline without consistent medical care and self-management (Desai, Pratt, Lentzner, & Robinson, 2001). Although prevalence varies among races, the three diseases affect all racial groups (Congdon et al. 2004; Klein et al., 2006). Minorities and women comprise the majority of persons with low vision (Javitt, Zhou, & Willke, 2007; West et al., 1997). Elderly Hispanic American, African American, and Native Americans experience higher rates of visual impairment than Caucasian Americans (Congdon et al., 2004) possibly because of health disparities (Owsley et al., 2006). More women have low vision because they live longer than men and experience higher rates of visual impairment with each successive decade of life (Javitt, Zhou, Maguire, Fine, & Willke, 2003).

Older adults with low vision experience increasing levels of disability as their eye disease progresses (Crews, 2000; Jones, Rovner, Crews, & Danielson, 2009; Lamoureux, Hassell, & Keeffe, 2004; Lindo & Nordholm, 1999; Travis, Boerner, Reinhardt, & Horowitz, 2004). In addition, consistent with the literature on aging and chronic disease, most visually impaired older adults have at least one other chronic medical condition (Brody et al., 2001; Crews, Jones, & Kim, 2006). Vision loss often interacts synergistically with other co-morbidities to increase the risk of disability (Crews, Jones, & Kim, 2006; Fried et al., 1999; Jones, Rovner, Crews, & Danielson, 2009; Vogeli et al., 2007). Vision loss has been associated with falls and fractures among elderly persons (de

Boer et al., 2004; Sloan et al., 2005), and persons with low vision are over represented among older adults with hip fracture (Cox et al., 2005). In addition, activity limitations from vision loss have been associated with the development of depression, which is estimated to affect nearly two-thirds of older adults with low vision (Crews et al., 2006; Jones, Rovner, Crews, & Danielson, 2009). Co-existence of these two conditions can significantly impair health and participation in daily activities (Jones, Rovner, Crews, & Danielson, 2009). Hearing loss is another significant co-morbidity in older visually impaired adults with a prevalence rate of 21% (Berry, Mascia, & Steinman, 2004). The combination of vision and hearing impairment, referred to as dual sensory impairment, has been associated with increased disability in older adults (Crews & Campbell, 2004; Saunders & Echi, 2007).

The economic burden associated with age-related eye diseases is significant (Fiscella, Lee, Davis, & Walt, 2009; Frick et al., 2007; Gupta, Brown, & Brown, 2007; Javitt, Zhou, & Willke, 2007; Lee et al., 2006). The annual economic cost of the four major causes of vision impairment in older adults (macular degeneration, glaucoma, diabetic retinopathy, and cataracts) was estimated at 35.4 billion dollars in 2004 (Rein et al., 2006). Much of this cost was attributed to non-eye related medical care incurred as vision impairment increased including admission to a skilled nursing or long-term care unit and treatment for depression or injury related to vision loss such as a fall (Javitt, Zhou, & Willke, 2007).

## Self-Management of Age-Related Eye Disease

While older adults living with macular degeneration, glaucoma, or diabetic retinopathy face the prospect of progressing vision loss or even blindness as the disease progresses, research has suggested that adept self-management may help to reduce and possibly prevent additional vision loss (Bressler et al., 2003; Chui & Taylor, 2007; Chui, Klein, Gensler, & Taylor, 2009; Knudtson, Klein, & Klein, 2006; Muir et al., 2006; Nath, 2007; Seddon, Cote, Davis, & Rosner, 2003; Rothman et al., 2004; The Diabetes Control and Complications Trial Research Group, 1993; SanGiovanni et al., 2007; United Kingdom Prospective Diabetes Study Group, 1998). Each disease requires a specific set of self-management skills and health knowledge to successfully manage the condition.

### *Age-Related Macular Degeneration*

Research completed within the last decade has confirmed that AMD is a disease of circulation with the same modifiable risk factors as those for heart disease. Self-management of the disease to prevent further vision loss focuses on engaging in the life style changes recommended for heart disease: regulation of diet, blood pressure and exercise levels, and smoking cessation (Anand, Bressler, Davis, Ferris, & Klein, 2000; Bressler et al., 2003; Chakravarthy et al., 2007; Chiu, Milton, Gensler, & Taylor, 2007; Clemons, Milton, Klein, Seddon, & Ferris, 2005; Hogg et al., 2008; Klein et al., 2007a; Klein et al., 2007b; Knudtson, Klein, & Klein, 2006; Thornton et al., 2005; SanGiovanni et al., 2007a; Seddon, Cote, Davis, & Rosner, 2003; Seddon, Gensler, & Milton, 2006; Wong & Mitchell, 2007). Research has also focused on using vitamin supplementation to

prevent or reduce progression of AMD (Bressler et al., 2003; Chiu & Taylor, 2007; Taylor, Tiskellis, Robman, McCarty, & McNeil, 2002). Much of this research has produced conflicting results, making it difficult for older consumers with AMD to know whether they should take a vitamin supplement and the correct formulation and amount. Subsequently, studies have shown that older adults either do not take a correctly formulated vitamin or take the wrong dosage reducing the effectiveness of the supplement and increasing their risk of experiencing serious side effects (Charkoudian et al., 2008; Johnson, Munoz, Gottlieb, & Jarrard, 2007). In addition they frequently consume non-prescribed herbal supplements, some of which have been shown to increase the risk of vision loss (Fraunfelder, 2004; West, Oren, & Moroi, 2006).

Despite the substantial research on modifiable risk factors, no studies have specifically addressed the need for older adults with AMD to possess good health literacy levels or health knowledge in order to better manage their disease. The lack of research may stem from the fact that English-speaking Caucasians are at most risk for developing advanced AMD and it may be assumed that they have adequate levels of health literacy. It may also be that, because research findings on diet, supplementation, and exercise are relatively new, ophthalmologists and optometrists are just becoming aware of the need to educate patients about lifestyle changes and self-management.

### *Glaucoma*

Early stages of the open angle glaucoma disease are asymptomatic. The absence of symptoms increases the need for educational efforts to ensure that persons at-risk are



aware of the importance of obtaining annual eye examinations and that persons with the disease comply with medication regimens. Early detection of the disease through community and physician administered glaucoma screening is considered essential in reducing vision loss (Nduaguba & Lee, 2006). African Americans and Hispanic Americans experience higher rates of visual impairment and blindness from glaucoma because of higher genetic risk but also because they are more likely to be diagnosed at an advanced stage of the disease (Congdon et al., 2004; Oliver et al., 2002). While genetic predisposition is non-modifiable, late stage diagnosis can be reversed among at risk persons by increasing knowledge of disease risk and the importance of early screening (Friedman, Cramer, & Quigley, 2005). Low health literacy levels have been shown to be associated with lower knowledge regarding glaucoma and with later stage diagnosis (Friedman, Cramer, & Quigley, 2005; Juzych et al., 2008; Nduaguba & Lee, 2006).

Once diagnosed, self-management to prevent further vision loss requires adherence to a complex daily medication regimen involving administration of multiple different eye drops (Muir et al., 2006). Medication adherence is critical to controlling disease progression (Olthoff, Schouten, van de Borne, & Webers, 2005; Sleath et al., 2006). Numerous studies have shown associations between inadequate knowledge and poor adherence to medications in persons with glaucoma (Ellish, Royak-Schaler, Passmore, & Higginbotham, 2007; Friedman et al., 2008; Lacey, Cate, & Broadway, 2009; Muir et al., 2006; Sleath et al., 2006).

### *Diabetic Retinopathy*

Unlike AMD, the importance of health education and health literacy for persons with diabetes has been consistently addressed in the literature because of the complexity of this disease (Nath, 2007). Persons with diabetes are at elevated risk for several serious health conditions including cardiovascular and kidney disease, amputation, and stroke. They are also at risk for other vision threatening eye diseases including glaucoma and cataracts (Klein, & Klein, 1995). Patient knowledge of risk factors and how to reduce them is considered critical to avoiding disability and death. The patient must be adept at self-management particularly monitoring and maintaining stable blood glucose and blood pressure levels to reduce onset and severity of diabetic retinopathy (Rowe, MacLean, & Shekelle, 2004; The Diabetes Control & Complications Trial Research Group, 1993; United Kingdom Prospective Diabetes Study Group, 1998; Wong & Mitchell, 2007).

### Importance of Self-Management of Eye Disease

The studies on risk factors for the three prevalent low vision eye diseases have demonstrated the importance of self-management in preventing further vision impairment and disability. Older adults with low vision who actively engage in self-management by taking appropriate vitamin supplements, adhering to medication regimens, exercising regularly, eating a healthy diet, lowering blood pressure, and monitoring blood glucose levels improve the odds that they will be able to preserve vision and functional ability as they age. Older adults with low vision also experience high rates of co-morbid chronic diseases that threaten their health and quality of life. The modifiable risk factors for two

of the primary eye diseases in older adults (AMD and diabetic retinopathy) correspond with those for cardiovascular disease, the most prevalent chronic disease of older adults. The research has also shown that it is possible to reduce vision impairment by applying self-management skills including early screening, adherence to medications, and changes in lifestyle and health behavior. But when self-management is ignored, vision declines and disability increases.

Health care providers and public health officials have acknowledged the relationship between healthy eyes and a healthy body and the importance of reducing the modifiable risk factors. In 2007, the CDC launched a coordinated public health initiative called the Vision Health Initiative (VHI) (CDC, n.d.). The initiative's purpose is to prevent and control eye diseases and improve the quality of life for Americans with and at risk for eye disease. In its first publication, *Improving the Nation's Vision Health: A Coordinated Public Health Approach* (2007), the VHI highlighted the relationship between age-related eye diseases and chronic diseases affecting circulation, stating "we must not disassociate vision health from the prevention and management of diabetes, high blood pressure, and other chronic diseases" (CDC, 2007, p.16). The report called for efforts to increase awareness of vision health among individuals, public health professionals, and health care providers. The VHI report specifically acknowledged the importance of adequate health literacy in ensuring that individuals maintain their ocular health, and it identified key areas associated with low health literacy including patient belief systems, education and language barriers, and concordance between physician and patient.

Despite research showing the importance of self-management in controlling eye diseases, little attention has been given to the health education needs of persons with low vision (Harrison, Mackert, & Watkins, 2010). Beverly, Bath, and Booth (2004) completed a systematic literature review to identify the health information needs reported by persons with visual impairment. Overall, they found that the needs of persons with visual impairment varied little from those without vision loss. People with vision impairment needed health education on how to manage co-morbid conditions as well as information about their specific eye condition. They wanted this information so that they could engage in effective self-management and participate fully in the health decision-making process. Like other health consumers, people with vision loss also wanted the information delivered to them in “plain English.”

Although the literature is sparse, four qualitative studies have employed focus groups or in-depth interviews of persons with vision impairment to identify barriers to obtaining knowledge about medical and eye conditions, self-management procedures, and access to health care services (Harrison, Mackert, & Watkins, 2010; O’Day, Killeen, & Iezzoni, 2004; Pollard, Simpson, Lamoureux, & Keefee, 2003; Williams, 2002). Four barrier themes emerged from this research, two of which are pertinent to providing health education on self-management. The two barriers were (a) poor communication with the physician, including the physician’s perception they were not able to participate in their health care, and (b) receiving health materials in inaccessible formats. Participants reported frequently being given printed materials in formats that they could not see well enough to read, which reduced their awareness of health issues and their ability to participate fully in self-management. Participants also reported frequently encountering

health care providers who did not understand their limited visual ability to read print or watch videos and demonstrations. These complaints reflect one of the unique challenges of living with low vision, that it is a hidden disability because the person often shows no outward signs of impairment such as thick glasses or a long white cane. In the absence of these outward cues, health care providers may mistakenly assume that the person has normal vision. In addition, because low vision is a disease of older adults, health care providers may interpret difficulty in comprehending information as being due to age or cognitive impairment rather than vision loss (Harrison, Mackert, & Watkins, 2010).

### Gaps in Evidence Examining Health Literacy and Low Vision

While older adults with low vision both experience and manage chronic diseases, there is a paucity of research investigating the relationship between health literacy and health outcomes in this population. DeWalt, Berkman, Sheridan, Lohr, & Pignone (2004) reviewed 44 articles on health literacy and health outcomes; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd (2005) reviewed 85 articles on the prevalence of limited health literacy. Neither review identified specific studies addressing limited health literacy and low vision. Only two research studies were found that examined the relationship between health literacy levels and vision outcomes. Schillinger et al. (2002) administered the *Short Test of Functional Health Literacy* (s-TOFHLA) to 408 patients with type 2 diabetes. The investigators found that persons with low S-TOFHLA scores that classified them as having inadequate health literacy were 2.7 times more likely to have diabetic retinopathy. Juzych et al. (2008) administered the reading comprehension

section of the TOFHLA to 204 patients with glaucoma. Half of the sample was classified as having adequate health literacy and the other as having poor health literacy based on TOFHLA scores. Participants with poor health literacy had experienced significantly greater visual field loss, missed more medical appointments and reported having missed taking eye drops more often than those with adequate health literacy. These studies suggested that low health literacy may contribute to poorer vision outcomes in persons with eye disease, but the investigators did not address whether reading impairment associated with low vision influenced the health literacy level of persons with low vision.

While research has demonstrated that older adults experience lower functional health literacy levels, it is not known whether those with age-related eye diseases are further compromised as a consequence of the effect of vision loss on reading performance. Although many older adults with low vision can read standard-sized print with magnifiers, acuity less than normal levels has been commonly used as exclusionary criteria in health literacy studies (Paasche-Orlow et al., 2005). Investigators have asserted that participants with reduced acuity might not be able to accurately complete tests of functional health literacy and have required participants to have normal to near normal levels of acuity. This inclusion criteria has been enforced even though the TOFHLA, a commonly used functional health literacy test, has a large print version that accommodates persons with acuity as low as 20/100 (Nurss, Parker & Baker, 1995). For example, the studies on functional health literacy and vision outcomes completed by Schillinger et al., (2002) and Juzych et al., (2008) used the large print version of the TOFHLA but required that their patients have 20/50 or better Snellen acuity to participate in the study.

Excluding adults with low vision from studies has restricted the ability to investigate the effect of vision impairment on lower functional health literacy levels. It may be that older adults with low vision have the same health literacy levels as their peers with good vision, but there has been no research to confirm this assumption. Paasche-Orlow et al., (2005) cited the exclusion of persons with low vision as one of four important reasons why the prevalence of health literacy limitations among American adults may be under estimated.

It is important to know the health literacy levels of older adults with low vision because despite the effect of vision impairment and other co-morbidities, the majority of older adults with low vision are able to remain in the community and live independently. Nearly two-thirds of older adults with low vision live in their own homes (Elliott et al., 1997) and one-third live alone without in-home or family support (Sloan, Ostermann, Brown, & Lee, 2005; West et al., 1997). It is likely that these persons are responsible for self-management of chronic conditions. Their ability to complete self-management to prevent further vision loss and disability depends, in part, on their level of health literacy just as it does for those with normal sight. If it is known that low vision creates an additional barrier to achieving adequate health literacy, steps can be taken to modify health education materials to make them accessible to older adults with vision impairment.

### Study Purpose

The primary purpose of the study was to determine whether community-dwelling older adults with low vision who were still reading demonstrated lower functional health literacy levels than community-dwelling older adults with normal sight as measured by a standardized test of functional health literacy. A second purpose of the study was to examine associations among vision and reading-related variables and functional health literacy scores in persons with low vision and associations among non vision-related variables related to reading performance and functional health literacy scores in older adults in general. The participants included in this investigation were people with moderate to severe vision impairment who reported reading a minimum of 20 minutes daily. Participants resided in their home, the home of family member, friend, or in an independent living apartment in a retirement center. The sample was restricted to persons with AMD, because the effect of AMD on visual function and reading performance has been well investigated, whereas little is known about the effects of diabetic retinopathy and glaucoma on reading performance.

The study investigated four research questions

1. Do older adults with low vision differ from older adults with normal sight in vision-related variables including acuity, contrast sensitivity, reading speed, critical print size and scotoma, and reading-related variables including number of items typically read, reading frequency and perceived reading difficulty and satisfaction?



2. Do community dwelling older adults with low vision score lower on the Test of Functional Health Literacy for Adults (TOFHLA) than community dwelling older adults with normal sight
3. Are vision-related variables-acuity, contrast sensitivity, reading speed, critical print size and scotoma associated with lower TOFHLA scores in community-dwelling older adults with low vision?
4. Are variables associated with reading performance in older adults including age, gender, education, occupation, reading frequency and activity associated with TOFHLA scores?

### Delimitations

The intent of the study was to determine whether older adults with low vision demonstrated lower scores on a test of functional health literacy than older adults without low vision and to examine the variables that might be associated with test scores. It was not the intent of the investigation to examine causal pathways between low vision and functional health literacy levels. It was also not the intent of the study to examine the influence of social determinants of health literacy on TOFHLA performance. Deliberate efforts were made to study a sample of high functioning community dwelling persons whose education level and socioeconomic status provided them with resources that should ensure good literacy skills. Although applying these criteria increased the ability to discern if the difference in scores between the two groups in the study could be attributed to low vision it prevented generalization of the findings to non-Caucasian, less

educated and lower income populations. In addition, the study was restricted to low vision participants who had received low vision rehabilitation and were proficient in using magnifying devices to read. This limited the generalization of study findings to the small fraction of visually impaired older adults who have received low vision rehabilitation services and who are trained to use magnifying devices. Finally although the low vision sample was limited to persons with AMD, it was not the intent of the investigation to examine specifically how AMD and the changes in visual functions associated with the disease interacted with each other to influence reading performance on the TOFHLA.

### Operational Definitions

*Activity limitation:* functional limitations and disabilities that restrict a person from performing normal activities without assistance such as walking, dressing and bathing or affect a person's ability to work or attend school" (RWJF, 2010, p.13). Also referred to as limitations in ADL.

*Age-related eye disease:* disease typically acquired in later adulthood after age 65 (e.g. macular degeneration, glaucoma) or in the case of diabetic retinopathy after the person has had diabetes for a while. For the purpose of this study, age-related eye disease will refer to three conditions only: macular degeneration, open angle glaucoma, and diabetic retinopathy.

*Adult with low vision who is still reading:* to be considered as "still reading" the participant must demonstrate a distance acuity between 20/60 and 20/400 Snellen acuity

tested at a 1 meter distance and must self-report a score of 4 on question 3 of the Reading Behavior Inventory indicating that he or she reads a minimum of 20 minutes per day.

*Central scotoma*: scotoma within the central 20 degrees of the visual field and impinging on the fovea (Schuchard, 1993).

*Chronic conditions*: medical conditions that last a year or longer, limit what one can do and/or require ongoing medical care. (RWJF, 2010).

*Cognitive reserve*: intellectual capacity (Stern, 2002).

*Community-dwelling adults*: non-institutionalized adults who reside in the community in their home, the home of family member, friend or in a retirement center. Persons who reside in nursing homes, extended care facilities, skilled nursing units are considered as institutionalized.

*Contrast sensitivity function*: a visual function: the ability to distinguish objects as they diminish in contrast from the background.

*Critical print size*: the smallest print size at which a person can still obtain maximum reading speed (Legge, 2007 p. 103).

*Education*: the number of years of completed formal education including GED.

*Extrinsic variable*: external to the person created by influences such as socioeconomic status, education, occupation, and primary language.

*Functional health literacy:* person's capability to obtain, process and understand printed information to maintain or improve health and encompasses both reading and numeracy.

*Habitual correction:* the participant's acuity measured when wearing their eyeglasses with their current refraction.

*Intrinsic variable:* innate to the person such as age, gender, race, and cognitive ability/reserve.

*Magnifying device:* an optical or electronic device that magnifies print.

*Moderate visual impairment:* best corrected Snellen acuity between 20/60 and 20/160.

*Munit:* a unit of measurement for critical print size and indicating the size of letters and numbers required for reading. Legge (2007) defined as the physical size of an optotype (e.g. letter or number) that subtends 5 minutes of arc at the distance in meters indicated by the M unit.

*Non-vision variable:* age, gender, highest level of education, occupation, years in retirement, and self-reported average annual household income level.

*Numeracy:* ability to complete simple math calculations and interpret the meaning of numbers in health materials.

*Older adult:* adult age 65 years or older.

*Primary occupation:* the occupation that the person engaged in during 50% or more his or her working years: ages 20-65.

*Reading fluency:* ability to read print quickly without significant effort (Legge, 2007).

*Reading speed:* also called reading rate-number of words per minute that a person can read; typical adult readers can read at a rate of approximately 250-300 words per minute (Legge, 2007).

*Self-management:* role assumed by the patient to engage in health behaviors that manage symptoms and prevent progression of chronic conditions and diseases (Clark, 2003).

*Self-management support:* the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support (Adams & Corrigan, 2003 p. 52).

*Severe vision impairment:* best corrected Snellen acuity between 20/160 and 20/400.

*Vision-related variable:* acuity, contrast sensitivity, critical print size, reading speed and scotoma.

## CHAPTER 2

### LITERATURE REVIEW

This chapter reviewed the scholarly literature on variables that influence functional health literacy in older adults and older adults with low vision. The following databases were searched to locate articles: MEDLINE, CINAHL, the Cochrane Library, PsycINFO, and ERIC. The search was restricted to articles printed in English between 1970-2011. Hand searches were also conducted of the reference lists of relevant articles.

The chapter is divided into five sections. The first section describes the target population for the study, persons with age-related macular degeneration-including disease progression and risk factors. The next section describes the primary independent variables associated with functional health literacy levels in all older adults. The third section described vision-related variables associated with reading performance adults with AMD and low vision. The fourth section examined the various measures that have been used in research to study functional health literacy. The final section described the theoretical perspective used to guide the study design and analysis and summarized the relationship between the independent and dependent variables to provide a rationale for the study design described in Chapter 3.

## Age-Related Macular Degeneration

AMD is the leading cause of low vision among older Americans, affecting nearly 28% of adults aged 75 years and older and accounting for 54% of all low vision cases (Congdon et al., 2004). AMD causes deterioration and death of photoreceptor cells within the macula and fovea of the retina creating a scotoma (e.g. blind spot) within the central visual field. Because the central visual field is comprised almost exclusively of cone photoreceptor cells that capture visual detail and color, AMD reduces acuity and the ability to see color and low contrast. Diminished visual function impairs the ability to read and identify objects with small or low contrast details. The specific cause of AMD is unknown. Research evidence has suggested that oxidative stress from compromised circulation is a significant factor (Chiu & Taylor, 2007). Vision loss is confined to the central portion of the visual field and the disease cannot cause blindness.

There are two forms of AMD, dry (also known as chronic) and wet (also known as advanced). Vision loss from dry AMD usually advances gradually over several years. and is characterized by changes in the macula. Dry AMD is the most common form of the disease and accounts for nearly 85% of cases in older adults (Haddad, Chen, Santangelo, & Seddon, 2006). Wet AMD is characterized by neovascularization, where abnormal blood vessels develop in sub-retinal layers of the retina and hemorrhage destroying the photoreceptor cells. Wet AMD is more virulent than the dry form and can cause significant vision impairment overnight. Whereas dry AMD affects all races equally, wet AMD is much more prevalent in Caucasians and appears to be associated with a genetic aberration in the complement factor H gene that controls the eye's response to inflammation (Haddad, Chen, Santangelo, & Seddon, 2006; Klein, Tunde,

Bird, & Vannewkirk, 2004; Postel et al., 2006). Caucasians are nearly seven times more likely to develop wet AMD than other racial groups (Clemons, Milton, Klein, Seddon, & Ferris, 2005). Although persons with the more prevalent dry AMD experience less vision impairment and disability, presence of the dry form in both eyes is often a precursor to the development of wet AMD. Twenty-five percent of persons with bilateral chronic AMD with geographic atrophy develop wet AMD within five years (Bressler et al., 2003).

A multi-center NIH funded study, the Age-Related Eye Disease Study (AREDS), completed in 2001, conducted research on the clinical course, prognosis, and risk factors associated with AMD. Members of the AREDS Research Group have reported the study findings through multiple publications. Among the significant research findings was that eight million Americans over age 55 years with early or intermediate stage AMD were at high risk for developing the wet form of the disease (Clemons, Milton, Klein, Seddon, & Ferris, 2005). One million members of this group were projected to develop wet AMD within 5 years (Bressler et al., 2003).

Smoking has been the only modifiable risk factor found to be consistently significantly associated with progressing to wet AMD (Clemons et al., 2005; Chakravarthy et al., 2007; Hogg et al., 2008; Klein et al., 2007a; Klein et al., 2007b; Thornton et al., 2005). The AREDS study found that body mass index (BMI) a measure of obesity, was also significantly associated with developing the geographic atrophy of the retina that signals progression of the disease from the chronic to advanced stage. Persons with elevated BMI in the AREDS study were found to be 1.5 times more likely to experience progression of AMD (Clemons, Milton, Klein, Seddon, & Ferris, 2005).



Higher waist circumference, a measure of intra-abdominal fat, was found to be associated with a two fold increase in relative risk and a higher waist-hip ratio was associated with a 1.84 times increase in relative risk for disease progression (Seddon, Cote, Davis, & Rosner, 2003). Subsequent studies have confirmed obesity as a risk factor for progression of AMD (Chakravarthy et al., 2007; Klein et al., 2007a; Klein et al., 2007b; Seddon, Gensler, Klein, & Milton, 2006).

Studies have also found elevated levels of the biomarkers C-reactive protein and homocysteine in persons with AMD, suggesting associations between wet AMD and cardiovascular disease (Hogg, et al., 2008; Seddon, Gensler, Klein, & Milton, 2006). Hypertension also has been found to be associated with AMD progression (Anand, Bressler, Davis, Ferris, & Klein, 2000; Wong & Mitchell, 2007). It has been suggested that AMD, hypertension and stroke may share common pathogenic mechanisms related to inflammatory and atherosclerotic processes that are aggravated by diet and obesity (Hogg et al., 2008; Seddon, Gensler, Milton, Klein, & Rifai, 2004; Vine, Stader, Branham, Musch, & Swaroop, 2005).

The AREDS study was a large randomized control trial on the use of vitamin supplementation to reduce the risk of developing advanced AMD (neovascular AMD or endstage geographic atrophy). The study found that adherence to a vitamin regimen consisting of specifically formulated high doses of antioxidants (vitamin C, E, and betacarotene) and zinc reduced the risk of progression to advanced AMD by 25% (Bressler et al., 2003). Five other randomized controlled trials conducted on vitamin supplementation confirmed at least some positive effect of supplementation in reducing the expected progression of the disease (Chiu & Taylor, 2007). However, several other

studies failed to confirm a benefit from taking certain antioxidants specifically vitamin E (Chiu & Taylor, 2007; Taylor, Tiskellis, Robman, McCarty, & McNeil, 2002).

To be effective, vitamin supplementation must be administered in the correct formulation and amount to persons in the beginning and intermediate stages of the disease. Two studies, one conducted in Australia (Ng & Goggin, 2006) and the other in the United States (Charkoudian et al., 2008), found that older adults who should have been taking the AREDS formulated supplement either did not take it or took the wrong dosage. Ng & Goggin (2006) found that only 53% of participants with early or intermediate stage AMD took an AREDS formulated multivitamin. Among the participants taking the supplement, only 1% took it at the correct dosage with most consuming half of the recommended dosage. In the group of participants who were aware of the supplement but not taking it, 31% reported a fear of side effects or interaction with other medications. In the American study, Charkoudian et al. (2008) found good compliance, with 93% of participants taking a supplement and 62% taking the correct dosage and formulation. However, they also found that one-third of the participants with advanced AMD were also taking a full strength dosage of the formulation even though they would not benefit from the supplement. These individuals were exposing themselves to potential health risk by using the supplement in the absence of evidence that it would be effective for their eye condition. High dosages of zinc in the formulation have been associated with the development of genitourinary disease in older adults (Johnson, Munoz, Gottlieb, & Jarrard, 2007). Johnson et al. (2007) studied participants in the AREDS trial and found a significant increase in hospital admissions for urinary tract infections and stones in persons taking the zinc versus non-zinc formulations. The

investigators cautioned against high dose zinc supplementation in older adults unless medically necessary. Research has suggested that betacarotene might increase the risk of lung cancer among smokers and an alternative AREDS formulation without zinc was developed for smokers (Chiu et al., 2009). However, Charkoudian et al. (2008) found that over half of the participants who smoked were taking the AREDS supplement with betacarotene. In addition to vitamin supplementation, older adults with AMD consume herbal supplements and other alternative medicines. Gingko biloba and lutein have been heavily promoted to prevent and treat AMD. However neither supplement has been shown to be effective for AMD (West, Oren, & Moroi, 2006) and ingestion of ginko has been linked to retinal hemorrhage and potential vision loss (Fraunfelder, 2004).

Limited studies have shown that exercise and dietary changes could slow the progression of AMD. Seddon, Cote, Davis, and Rosner (2003) found that engaging in vigorous physical activity was associated with a 25% decrease in relative risk for progression of the disease. Knudtson, Klein and Klein (2006), in a large 15-year population based study, found that people who exercised regularly three times a week at baseline were 70% less likely to develop wet AMD independent of age, gender, blood pressure, BMI, smoking, or education. However, only 25% of the study participants engaged in exercise at this level. AREDS investigators focusing on dietary intake have shown that diets rich in lutein and zeaxanthin, found in dark, green leafy vegetables like spinach and kale, may reduce risk of developing dry AMD and progressing from dry to wet AMD (SanGiovanni et al., 2007a). Other researchers have found that consuming a diet comprised of low glycemic index foods (e.g. vegetables & lean meats) and fish may have a protective effect against development and progression of AMD (Chiu, Klein,

Milton, Gensler, & Taylor, 2009; SanGiovanni et al., 2007b; Seddon, Cote, & Rosner, 2003). In contrast, ingesting a diet high in foods with elevated glycemic indexes (sugar, white bread, pasta, soda, etc.) was found to increase the risk of progressing to wet AMD (Chiu, Milton, Gensler, & Taylor, 2007).

### Variables Associated with Functional Health Literacy

The National Institute for Literacy defined adult literacy as "An individual's ability to read, write, and speak in English, compute, and solve problems at levels of proficiency necessary to function on the job, in the family of the individual, and in society" (NIL, n.d. para 1). Functional health literacy is a sub-component of general adult literacy that focuses on the ability to comprehend and interpret written information and mathematical calculations to understand and apply health-related information. This study focused on functional health literacy, but Nutbeam (2000) proposed that persons must possess two other forms of health literacy: interactive and critical. *Interactive* health literacy encompasses the oral ability to engage health professionals to obtain health information and is dependent on cognitive and social skills; *critical* health literacy involves the ability to analyze health-related information and use it in specific situations (McCray, 2005; Nutbeam, 2000). These forms of health literacy are not as dependent on reading ability, and one study has shown that persons with vision impairment who are unable to read may rely more on interactive health literacy to obtain needed information in encounters with health providers (Harrison, Mackert, & Watkins, 2010).

As a component of literacy, functional health literacy is influenced by the variables that affect literacy levels in adults. Because literacy is defined by reading performance and comprehension, these same variables influence reading performance. They include factors intrinsic to the individual: age, gender, race, innate intelligence, primary language, and age-related cognitive decline, as well as extrinsic factors that reflect environmental influences: educational attainment, occupation, socioeconomic status (SES), and culture. Because reading is the product of visual cognitive processing within the brain, the ability to read fluently is also influenced by visual variables that affect the ability to accurately decode letters and numbers and rapidly process words and sentences (Legge, 2007). These variables include: acuity, presence of central field impairment (e.g. scotoma), the ability to see print in low contrast formats (e.g. contrast sensitivity) and the ability to read at a normal reading speed (Legge, 2007). These visual variables specifically influence reading performance in older adults with AMD.

### *Reading Fluency*

Reading researchers divide the reading process into two components: the ability to decode and identify words (e.g. print skills) and the ability to know meaning of words (e.g. meaning skills) (Strucker & Davidson, 2005). Good readers demonstrate reading fluency, which is the ability to quickly read print without significant effort (Legge, 2007). The ability to quickly decode print requires an understanding of phonics and also knowledge of how words and sentences are constructed in English. Readers who must expend extra effort to decode words have less mental energy to apply to comprehension

(Strucker & Davidson, 2005). Meaning skills require a broad vocabulary and understanding of the different ways words are used to convey meaning in various contexts. Both skills are highly dependent on education. The process of becoming proficient and fluent in reading begins as the child enters grade school and continues through middle and high school years. Risk factors for low literacy among adults without dyslexia include: living in poverty, coming from a family with low literacy skills or limited English proficiency, and receiving a limited and/or poor quality education (Strucker & Davidson, 2005).

Reading fluency is considered an essential component of health literacy (Baker, Wolf, Feinglass, Thompson, Gazmararian, & Huang, 2007; Cutilli, 2007; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Wolf, Gazmararian, & Baker, 2005). DeWalt et al. (2004) reviewed 16 studies on reading ability and health literacy and found that 14 reported a significant relationship between reading ability and participant knowledge of health conditions, risk factors, medical treatments, and health services. Within this research two independent factors appeared to exert significant influence on reading comprehension: the individual's reading grade level and the readability level of text. *Reading grade* level is determined using norm-referenced tests that identify the person's average level of reading performance compared to the scores of a representative sample (Nielson-Bohlman, Panzer, & Kindig, 2004). Most American adults with high school diplomas read at the 8-9<sup>th</sup> grade reading level, but a quarter of American adults read at only the 5<sup>th</sup> grade level (Berkman et al., 2004). *Readability* level reflects the ease with which the person reads text and is dependent on the number and types of words in sentences (McCray, 2005). It is also reported as an educational grade equivalent. Most

health information is written at a readability level of 10<sup>th</sup> grade or higher (Berkman et al., 2004; Cutilli, 2007; Ross, 2007), which exceeds the skills of the average American high school graduate (Rudd, 2007). In addition, persons often overestimate the ability to read text and demonstrate less capability than indicated by level of grade completion (Andrus & Roth, 2002; Buchbinder, Hall, & Youd, 2006; Griffin, McKenna, & Tooth, 2006; Wilson, Racine, Tekieli, & Williams, 2003). Jackson, Davis, Murphy, Bairnsfather, and George (1994) found their participants' actual reading level on printed health information to be as much as five grades lower than their self-reported estimated reading level.

The difference between grade completion and reading level has created significant challenges in communicating health information using printed materials. More than 300 studies have found that written health materials exceeded the average reading ability of American adults (Nielsen-Bohlman, Panzer, & Kindig, 2004). Because of the stigma associated with low literacy, persons may hide their inability to understand printed health materials (Baker, 1999), and physicians often overestimate the person's understanding of medical information (Kelly & Haidet, 2007). A study conducted by Wilson et al. (2003) illustrated the challenges associated with using written materials to convey health information. The investigators studied the knowledge level of older African Americans requiring anticoagulation therapy for heart disease. They found that although the participants reported on average completing the 12<sup>th</sup> grade, their actual average reading skills were between the 7<sup>th</sup> and 8<sup>th</sup> grade level, and the average readability level of the educational materials they received was measured at the 11<sup>th</sup> grade level.

### *Education*

Multiple studies have shown associations between lower educational attainment and lower functional health literacy levels (Benson & Forman, 2002; Cordasco, Asch, Franco, & Mangione, 2009; Downey & Zun, 2008; Fang, Panguluri, Machtinger, & Schillinger, 2009; Gazmararian et al., 1999; Jeppesen, Coyle, & Miser, 2009; Kalichman et al., 2000; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Schillinger et al., 2002). The 2003 National Assessment of Adult Literacy survey (NAAL) found that for adults with a high school diploma or equivalent, each additional level of educational attainment (i.e. vocational, associate, bachelors, graduate studies) was associated with an increase in average functional health literacy scores (Kutner, Greenberg, Jin, & Paulsen, 2006). Persons with graduate degrees were more likely to be classified as having proficient health literacy than any other group. In contrast, a higher percentage of adults without a high school diploma or equivalency possessed below basic health literacy skills compared to all other groups. But high educational attainment did not guarantee or fully explain proficiency in health literacy skills. The NAAL also found that 4% of adults with an associate or two-year college degree and 3% of adults with four-year degrees or graduate education possessed below basic health literacy skills (Kutner, Greenberg, Jin, & Paulsen, 2006).

Other studies have also found poor correspondence between educational attainment and health literacy levels with the latter being lower than would be expected based on grade level completion (Benson & Forman, 2002; Cutilli, 2007; DeWalt et al.,



2004; Wilson & McLemore, 1997). A frequently cited study by Benson and Forman (2002) examined health literacy levels in a sample of predominantly college educated older adults living in an affluent retirement center. The investigators administered the TOFHLA to 93 older adults (average age, 83 years) and found that 30% of the sample scored 74% or less on the test, which classified them as having inadequate health literacy. Among the participants with inadequate health literacy, 32% did not understand the directions for taking a medication; 43% could not understand instructions for completing a health insurance form, and 78% were unable to understand a written consent form. However, although the sample as whole had a mean of 15 years of education and thus were considered highly educated, the low health literacy group within the sample had a broader range of educational attainment (6-18 years) and at least one participant had only a 6<sup>th</sup> grade education. In contrast, the high literacy group had a smaller educational range (11-20 yrs.) and included persons with more post-graduate education.

Discrepancies between educational attainment and health literacy may exist because educational attainment does not reflect education quality. It merely reflects the number of years of school completed and not what was learned during that time. Schools vary widely in instructional quality and resources so that a degree from one institution may not be comparable to that from another institution (Shea et al., 2004). Educational attainment also does not accurately reflect the person's innate intelligence and ability to take advantage of education. Studies have shown it is possible to complete high school without being able to read at a 12<sup>th</sup> grade level (Nielsen-Bohlman, Panzer, & Kindig, 2004). In addition, functional health literacy requires application of specific knowledge and the ability to learn and apply new information in unique and often unfamiliar and

stressful circumstances (Baker, 1999). Even highly educated individuals have reported difficulty navigating complex medical systems, comparing medical documents, and making informed health decisions (Benson & Forman, 2002).

### *Innate Intelligence*

No studies were found that directly investigated the association between a person's score on a psychometric test of intelligence and their functional health literacy level. However, researchers have investigated associations among childhood IQ and risk of premature death (Batty, Der, Macintyre, & Deary, 2006; Batty, Deary & Gottfredson, 2007; Gottfredson & Deary, 2004; Jokela, Elovainio, Singh-Manoux, & Kivimaki, 2009; Kuh, Richards, Hardy, Butterworth, & Wadsworth, 2004; Lager, Bremberg, & Vagero, 2009). Because persons with lower health literacy have been shown to experience a higher incidence of premature mortality (Baker et al., 2007), these studies may indirectly shed light on the relationship between health literacy and IQ. A systematic review of the literature on early-life IQ and adult mortality showed that persons with lower IQ experienced higher rates of mortality in mid to later life than persons with higher IQ regardless of the IQ test used, the population studied, or when the IQ data was collected (Batty, Deary, & Gottfredson, 2007). The review cited low birth weight, suboptimal brain development predisposing the person to psychiatric illness, and socioeconomic disadvantage in childhood as confounding variables that may act on mortality independently of IQ, but few studies controlled for these variables.

The review also found that lower SES measured by educational attainment, occupation, and income in later life was associated with higher mortality rates, a finding corroborated in other studies (Jokela, Elovainio, Singh-Manoux, & Kivimaki, 2009; Lager, Bremberg, & Vagero, 2009). The relationships were found only in adulthood; no relationship was found between childhood SES and the IQ/mortality gradient. Batty et al., (2007) proposed that SES might act as a mediating variable in IQ/mortality gradient where higher childhood IQ led to educational success and subsequently higher social and occupational status and income, which ultimately reduced mortality risk through greater access to healthcare and a safer job. However, Jokela, Elavainio, Singh-Manoux and Kivimaki (2009), using data from the US National Longitudinal Survey of Youth, found that SES predicted mortality in middle age adults independently of IQ. Although the association between higher IQ and mortality remained after controlling for gender, birth year, race/ethnicity, baseline health, and parental education, it disappeared when the investigators adjusted for education and income. In contrast, an adjustment for IQ had no effect on the association between SES and mortality. Lager, Bremberg, & Vagero (2009) failed to establish a link between childhood IQ, SES status, and mortality in a 65-year longitudinal study conducted in Sweden and found instead an interesting independent association between educational attainment after adjusting for IQ. In this study, women with higher IQs experienced higher rates of mortality, whereas men had lower rates of mortality, a finding also shown in a study completed by Kuh, Richards, Hardy, Butterworth, & Wadsworth, (2004) on British women born in 1946. Lager et al., (2009) suggested that lack of a protective effect from IQ in the women might be explained by the propensity of more intelligent women of this era to take up smoking as a sign of

independent thought. They cited the Wisconsin Longitudinal Study that had also found high IQ associated with smoking among women, but not men born between 1928 and 1946 and concluded that social and physical environments may mediate the relationship between IQ and mortality.

The results of the research on IQ and mortality suggest that a number of variables may mediate the relationship between childhood IQ and health. Batty, Deary, and Gottfredson (2007) developed a conceptual model to delineate the possible linkages between pre-morbid IQ and mortality. In this model, parental intelligence, socioeconomic environment, nutrition, and somatic/psychiatric illness influence the child's intellectual abilities by influencing brain development. Childhood IQ in turn exerts a protective effect against premature mortality by (a) providing socioeconomic advantages in adulthood through higher educational attainment, (b) preventing illness and injury through better understanding of risk factors and appreciating when medical intervention is needed, (c) managing disease and injury when they do occur through better understanding of self-management procedures, and (d) being able to interpret life situations better and apply more effective coping strategies. Factors b and c in this model reflect the components of proficient health literacy and suggest that childhood IQ may influence health literacy levels in adults. The association, however, is not direct or causal and is mediated in the model by SES factors including educational attainment, occupation and income, and possibly cultural and social factors.

### *Socioeconomic Level (SES)*

Low income has been associated with lower health literacy levels in some studies (Artinian, Lange, Templin, Stallwood, & Hermann, 2002; Gazmararian, Baker & Williams, 1999 b; Jackson, Davis, Murphy, Bairnsfather, & George, 1994; Schillinger et al., 2002), but other studies have found no association between income and health literacy level after controlling for other variables such as educational attainment (Kalichman et al., 2000; Gazmararian, Parker, & Baker, 1999a). It is difficult to separate the individual influences of SES, educational attainment, primary language, race, and culture because of the cyclical relationship between the factors among economically disadvantaged persons. Nearly one-third of older adults with chronic illnesses and low health literacy are identified as socioeconomically disadvantaged, defined as: low income, low educational attainment, and low health literacy (Clark, Stump, Miller, & Long, 2007). SES appears to act as a mediating variable because it can affect a person's level and quality of education and thus influence literacy and functional health literacy levels. It also may limit access to health care, thus affecting health outcomes (Kamble & Boyd, 2008; Martin et al., 2009; Shea et al., 2004). Because poverty cuts across geographic regions, no distinct differences in functional health literacy levels have been found between different geographic regions or urban and rural areas in the United States (Martin et al., 2009).

### *Occupation*

No studies were found that directly investigated an association between occupation and health literacy levels, although studies investigating health outcomes have

included this variable (Batty, Deary, & Gottfredson, 2007). Income and educational attainment appear to be used as proxies for occupation in studies investigating variables that predict low health literacy (Artinian, Lange Templin, Stallwood, & Hermann, 2002; Banerjee, Perry, Tran, & Arafat, 2009; Hanchate, Ash, Gazmararian, Wolf, & Paasche-Orlow, 2008; Jeppesen, Coyle, & Miser, 2009; Martin et al., 2009; Morrow et al., 2006). This may be because educational attainment and income are easier to classify than occupation. However, occupation may indirectly influence health literacy through its effect on age-related cognitive decline, which will be discussed later in this section.

### *Primary Language*

Although the 2003 NAAL survey found that the largest proportion of American adults with low health literacy were native born English-speakers (Berkman et al., 2004), several studies have shown a relationship between the person's primary language and low health literacy (Berkman et al., 2004; Brice et al., 2008; Britigan, Murnan, & Rojas-Guyler, 2009; Cordasco, Asch, Franco, & Mangione, 2009; Fang, Panguluri, Machtinger, & Schillinger, 2009; Munoz et al., 2008; Zun, Sadoun, & Downey, 2006). Cordasco et al. (2009) found that participants with lower health literacy scores were more likely to be older, have less formal education, limited English proficiency, and more likely to speak a non-English language at home.

Newly immigrated Hispanic and Latino populations in the United States have shown low levels of acculturation and a preference for maintaining a separate cultural environment and language, which has led to low proficiency in English (Britigan,

Murnan, & Rojas-Guyler, 2009). The lack of English proficiency forces patients to rely on interpreters and family members, which adds another level of complexity and a potential barrier to obtaining and understanding health information (Britigan et al., 2009; Brugge et al., 2009). In addition, even Spanish speakers who claim proficiency in English may over estimate their language abilities. Zun, Sadoun, and Downey (2006) found that 17% of Hispanic participants who had self-reported as proficient in reading English tested in the inadequate range on a written test of health literacy. Although there is strong evidence to suggest that language proficiency significantly influences health literacy levels, at least one study found recent immigration to the United States to be a stronger predictor of lower health literacy levels than the language spoken at home (Martin et al., 2009).

### *Race and Culture*

The Institute of Medicine report on health literacy defined culture as: “the shared ideas, meanings, and values acquired by individuals as members of society” (Nielsen-Bohlman, Panzer, & Kindig, 2004, p.110). Studies have shown consistent associations among minority status, especially African American race, and low functional health literacy levels (Bennett et al., 1998; Gazmararian, Baker, & Williams, 1999b; Jeppesen, Coyle, & Miser, 2009; Kalichman et al., 2000; Levinthal, Morrow, Tu, Wu, & Murray, 2008; Martin et al., 2009; Morrow et al., 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004; Shea et al., 2004; Williams, et al., 1995). It is difficult to disassociate race from SES, educational attainment, and quality of education, and the combination of these

factors may negatively influence the ability to understand written health information (Martin et al., 2009; Nielsen-Bohlman, Panzer, & Kindig, 2004). Cultural beliefs about health and illness associated with race and ethnicity add another dimension to health literacy levels by influencing whether the person seeks and accepts medical care (Nielsen-Bohlman, Panzer, & Kindig, 2004; Shaw, Heubner, Armin, Orzech, & Vivian, 2009). For example, older adults with lower educational attainment from minority and low income backgrounds are more likely to use home remedies and complementary therapies in addition to or instead of medical interventions (Arcury et al., 2009; Shaw et al., 2009; Shelley, Sussman, Williams, Segal, & Crabtree, 2009). Reliance on home remedies can influence whether older adults accept medical advice and correctly follow medical instructions (Arcury et al., 2009). According to Arcury et al. (2004), older Asian Americans had the highest use of complementary therapies and medicine followed by Hispanic Americans, Caucasians, and African Americans.

Much of the literature on the influence of culture and race on health literacy focuses on the interaction between patient and physician during the medical encounter (Nielsen-Bohlman, Panzer, & Kindig, 2004). The complex nature of patient-physician communication is shaped by multiple variables including attitudes on the part of both physician and patient towards race, gender, socioeconomic background, and educational attainment (Boulware et al., 2003; Brugge, Edgar, George, Heung, & Barton Laws, 2009; Lasser et al., 2008; Shea et al., 2004; Schillinger et al., 2003; Schillinger et al., 2004; Stepanikova, Mollborn, Cook, Thom, & Kramer, 2006). Culturally-informed experiences have been shown to shape how persons seek and accept health information from physicians and can create challenges in communicating, understanding, and using health



information that are separate from the person's educational attainment, general literacy level, primary language, or SES (Nielsen-Bohlman, Panzer, & Kindig, 2004; Shaw et al., 2009). For example, older African Americans have cited trust in physicians and the health care system as a barrier to accepting health information and have expressed lower levels of trust in physicians than other racial groups (Boulware et al., 2003; Owsley et al., 2006; Fang, Panguluri, Machtinger, & Schillinger, 2009; Moody-Ayres, Stewart, Covinsky, & Inouye, 2005). The mistrust felt among older African Americans has been attributed partly to a shared cultural legacy of racial discrimination and medical mistreatment including the infamous Tuskegee syphilis study conducted by the United States Health Service during the last century (Boulware et al., 2003). In addition, persons often seek concordance with their health care providers and may avoid or experience inadequate communication with health care providers who do not share the same culture and/or language (Brugge, Edgar, George, Heung & Laws, 2009; Sudore et al., 2009; Schillinger et al., 2004).

How the physician views the capability and willingness of persons from minority cultures to receive and use health information may influence the physician's health education efforts and indirectly influence health literacy levels (Arthur, Geiser, Arriola, & Kripalani, 2009; Seligman et al., 2005). Physicians may not consider the patient's health literacy level (Bass, Wilson, Griffith, & Barnett, 2002) or overestimate the patient's ability to understand medical information (Arthur et al., 2009; Kelly & Haidet, 2007). Patients may reinforce this misperception by adopting a passive interaction style characterized by accepting information without questions and hiding their lack of understanding (Arthur et al., 2009; Friedman et al., 2008). Ferguson and Candib (2002)

conducted a literature review on the influence of language, ethnicity, and race on the patient physician relationship and found that patients from minority backgrounds and those with low English language proficiency were less likely to be able to establish a rapport with, or experience an empathic response from physicians or feel like they received sufficient information from the physician. A study by Owsley et al., (2006) illustrated the disconnection between physician and patient perspectives of their interaction. The investigators conducted separate focus groups for older African Americans at risk for glaucoma and the ophthalmologists and optometrists who provided eye care to them. The study found that the eye care physicians reported that their African American patients as a rule did not make eye care a health priority or understand the importance of preventative eye care and treatment. In contrast, the African American participants reported that they highly valued both maintaining good vision and the importance of seeking regular eye care.

Health literacy levels have been shown to be associated with the type of communication that occurs between physician and patient independent of race and culture (Brugge, Edgar, George, Heung, & Barton Laws, 2009; Schillinger et al., 2003; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009; Sudore et al., 2009). Arthur et al. (2009) found that physicians adopted a paternalistic interaction style with African-American patients who had low health literacy levels and a shared-control style with patients with higher levels of health literacy. Brugge et al., (2009) conducted a qualitative study on perceptions of patient provider communications among English, Catonese, and Spanish speaking participants with high and low education levels. The investigators found that participants viewed literacy, numeracy, and language as elements of their

social relationship with the physician. These elements affected their sense of empowerment in communicating with the physician and their perception of the physician's attitude towards them. Highly educated participants in the study reported few instances of feeling disempowered in physician interactions compared to participants with low educational attainment.

Health literacy levels also influence how much the patient is able to take away from the physician encounter in terms of understanding his or her medical condition and treatment. Sudore et al. (2009) found that limited health literacy resulted in an almost two-fold increase risk in the likelihood of patient difficulties in three areas: (a) understanding the information provided by the physician during the patient visit, (b) getting the physician to understand their ailment, and (c) discussing treatment recommendations with the physician. In an earlier study, Schillinger et al. (2004) found larger odds ratios in similar communication domains among a low income but ethnically diverse sample of participants with type 2 diabetes. Participants with low functional health literacy scores were 6.29 times more likely to experience difficulty understanding the information provided by the physician and 2.7 times more likely to have difficulty understanding the treatment process explained by the physician independent of age, race/ethnicity, gender, education, and primary language. The investigators concluded that persons with low functional health literacy might experience difficulty understanding medical terminology because it is technical and unfamiliar, and because it is often transmitted at a rapid rate.

### *Gender*

The influence of gender on health literacy levels has not been clearly delineated in the literature. A few studies have shown an association between health literacy level and gender (Marks, Schectman, Groninger, & Plews-Ogan, 2009; Schillinger et al., 2002; Waldrop-Valverde et al., 2009). Jeppesen, Coyle, and Miser (2009), in a cross sectional study of persons with diabetes, found that males were 4.46 times more likely to experience low health literacy. Other studies have shown low health literacy to be associated with male gender (Marks, Schectman, Groninger, & Plews-Ogan, 2009; Morrow et al., 2006). But studies have also found no association between gender and health literacy level (Benson & Forman, 2002; Kalichman, et al., 2000; Shea et al., 2004). The ratio of males and females in studies is often determined by the specific health condition being investigated and the location of the study. Thus, there are more males in studies investigating health literacy levels among persons with prostate cancer (Kilbridge et al., 2009) and in studies conducted at Department of Veterans Affairs hospitals (Arozullah et al., 2006). Among older adults with low vision, women outnumber men because they outlive men in old age when the eye diseases causing low vision are most prevalent (Administration on Aging, 2010; Congdon et al. 2004). Thus, a study examining health literacy in older adults with low vision might find an association among gender and health literacy level based only on gender bias.

### *Age-Related Cognitive Decline*

The literature consistently has shown that older adults perform more poorly on tests of functional health literacy than younger adults (Baker, Gazmararian, Sudano, & Patterson, 2000; Billek-Sawbney & Reicherter, 2005; Cordasco, Asch, Franco, & Mangione, 2009; Cutilli, 2007; Downey & Zun, 2008; Gazmararian, Baker, & Williams, 1999b; Kutner, Greenberg, Jin, & Paulsen, 2006; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). Baker, Gazmararian, Sudano, and Patterson (2000) found a statistically significant decline of ten points in TOFHLA scores among older adults with each additional decade beyond 65 years. Finucane et al. (2002) found that older adults demonstrated significantly greater difficulty comprehending health care plan options than younger adults.

The association between age and lower functional health literacy levels may partly occur because the older adults in these studies completed fewer years of formal education than younger participants (Cutilli, 2007; Jackson, Davis, Murphy, Bairnsfather, & George, 1994). Many of the older adults in current studies were educated in the 1940s when the median education was 8.6 years compared to a median of 12.6 years for adults educated in the 1980s and 1990s (Weiss, Reed, & Kligman, 1995). However, a larger body of research evidence suggests that the association between health literacy and age may more accurately reflect the influence of age-related cognitive decline on reading performance and comprehension (Baker, Gazmararian, Sudano, & Patterson, 2000; Brown & Park, 2002; Finucane et al., 2002).

Declines in cognitive ability are associated with aging and can occur without dementia. A decline of 15-30 IQ points in fluid intelligence can occur between age 20 and 70 as a result of normal aging (Anstey & Low, 2004). Plassman et al. (2008) reported that five million American adults age 70 and older exhibited cognitive impairment without dementia. Age-related cognitive decline has been shown to affect information processing speed, working memory, and verbal recall (Gazzaley & D'Esposito, 2007). Changes in these cognitive functions in turn may affect the ability to read and understand written health information and thus functional health literacy. Because of the higher rate of cognitive decline among older adults, cognitive ability may exert greater influence on health literacy than years of education in this population (Morrow et al., 2006). Levinthal, Morrow, Tu, Wu, & Murray (2008) suggested that the relationship between education and health literacy observed in older adults may actually be a proxy for the influence of cognitive ability and that the association between advancing age and lower health literacy may be mediated by age-related cognitive decline.

Research has suggested that education, innate intelligence, an intellectually stimulating occupation, and active and continued participation in activities during old age may protect against cognitive decline by enabling the person to develop and maintain *cognitive reserve* (Agahi, Ahacic, & Parker, 2006; Ardila, Ostrosky-Solis, Rosselli, & Gomez, 2000; Finkel, Andel, Gatz, & Pedersen, 2009; Newson & Kemps, 2005; Potter, Helms, & Plassman, 2008; Scarmeas, Levy, Tang, Manly, & Stern, 2001; Schumacher & Martin, 2009; Stern, 2002; Wilson et al., 2005; Wilson et al., 2009). Cognitive reserve is simply defined as intellectual capacity (Stern, 2002). Older adults with good cognitive reserve appear to be better able to weather the ravages of age-related neurological

diseases and conditions such as dementia and stroke and retain adequate cognitive functioning into very old age (Stern, 2002). Adults with less cognitive reserve are more likely to show age-related changes in cognitive ability and experience these changes earlier because they have fewer intellectual resources to sustain them in the face of age-related diseases and conditions (Fritsch et al., 2007). Researchers have begun to view cognitive reserve as a dynamic resource influenced by a variety of factors during various stages of life. Innate intelligence defined by childhood IQ and early adult IQ may help the person establish reserve through education and maintain it through the ability to obtain intellectually stimulating employment. The increase in cognitive activity afforded by education combined with daily and extended intellectual stimulation through work has been associated with better cognitive function in older age in multiple studies (Bosma, van Boxtel, Ponds, & Houx, 2003; Finkel, Andel, Gatz, & Pedersen, 2009; Potter, Helms & Plassman, 2008; Schumacher & Martin, 2009; Wilson et al., 2005; Wilson et al., 2009; Yaffe et al., 2009) and may reduce dementia risk (Karp et al., 2009). Continued participation in activities during old age has been shown to help maintain cognitive reserve (Newson & Kemps, 2005; Scarmeas & Stern, 2003; Stern, 2006; Yaffe et al., 2009). Participation in intellectually stimulating activities such as reading books and newspapers has been consistently associated with better cognitive performance in older adults (Agahi, Ahacic, & Parker, 2006; Dellenbach & Zimprich, 2008; Gatz, Prescott, & Pedersen, 2006; Newson & Kemps, 2005; Schumacher & Martin, 2009; Wilson et. al., 2002; Wilson, Barnes, & Bennett, 2003), but higher levels of participation in everyday leisure activities such as socializing with family and friends, exercising, and completing craft activities (e.g. knitting) have also been associated with less cognitive decline

(Agahi, Ahacic, & Parker, 2006; Newson & Kemps, 2005; Scarmeas, Levy, Tang, Manly, & Stern, 2001). Despite its apparent ability to postpone cognitive decline, cognitive reserve does not prevent age-related declines in cognitive capacity as a person progresses through old age. Cognitive decline has been shown in longitudinal studies to occur in well-educated, active and engaged older adults retired from highly intellectually challenging occupations, but the amount of decline often is less than that observed in persons with less stimulating occupations and retirement (Dellenbach & Zimprich, 2008; Mackinnon, Christensen, Hofer, Korten, & Jorm, 2003; Muniz-Terrera, Matthews, Denning, Huppert & Brayne, 2009; Schumacher & Martin, 2009).

The research showing an association between activity level and cognitive reserve in older adults is disconcerting when considering the effect of low vision on activity levels in older adults. Decreases in vision have been shown to correlate with a decrease in activity levels in persons with low vision (Crews, Jones, & Kim, 2006; Slakter & Stur, 2002). O'Connor, Lamoureux and Keefee (2008) found that persons with moderate visual impairment were approximately four times more likely to experience severely restricted participation in daily activities whereas persons with severe visual impairment were approximately 17 times more likely to experience limitations. A positive relationship between visual impairment and reduced cognitive function has been consistently shown in research studies addressing aging and cognition (Baker et al. 2009; Clay et al., 2009; Clemons et al., 2006; Gussekloo, de Craen, Oduber, Van Boxtel, & Westendorp, 2005; Lin et al., 2004; Pham, Kifley, Mitchell, & Wang, 2006; Tay et al., 2006, Valentijn et al., 2005). In those studies vision impairment was associated with slower processing speed and memory. Some investigators have suggested that the relationship between vision



impairment and cognitive impairment occurs because of a shared pathological decline in physiological function of the brain (Baker et al., 2009; Clemons et al., 2006; Pham, Kifley, Mitchell, & Wang, 2006). Other investigations have suggested that the difficulty seeing visual details that accompanies low vision reduces processing speed and memory (Clay et al., 2009; Lin et al., 2004; Valentijn et al., 2005).

Although studies have shown educational attainment to be a predictor of cognitive ability in older adults (Yaffe et al., 2009) research has also shown that reading ability (literacy) is a better predictor of cognitive ability than educational attainment (Baird, Ford, & Podell, 2007; Dotson, Kitner-Triolo, Evans, & Zonderman, 2009; Johnson, Flicker, & Litchenberg, 2006; Manly, Jacobs, Touradji, Small, & Stern, 2002; Manly, Schupf, Tang, & Stern, 2005). Yaffe et al. (2009) found that persons with a high school education or greater were almost three times more likely to experience less cognitive decline with age, whereas persons with a 9<sup>th</sup> grade *literacy* level or greater were almost five times more likely to experience the same protective benefit. The strength of literacy over education as a predictor of cognitive ability might be because more accurately reflected the quality of the education received by the person (Manly, Jacobs, Touradji, Small, & Stern, 2002; Morgan, Marsiske, & Whitfield, 2008). Manly, Schupf, Tang, and Stern (2005) argued that educational quality is a significant environmental factor influencing cognitive performance in ethnically diverse older adults and should be considered “a mediator of the interactions of biological and environmental factors on cognitive decline” (p. 213). Looking at literacy levels rather than educational attainment is therefore important in studies that include participants with minority and SES diversity (Baird, Ford, & Podell, 2007; Karlamangla et al., 2009).

Nearly 2.5 million older Americans have dementia (Plassman et al., 2008). The diagnostic criteria dementia includes cognitive decline severe enough to limit the ability to participate in routine daily activities, memory impairment beyond what would be expected for age, and impairment of at least one other cognitive domain (Kelley & Peterson, 2007). Alzheimer's dementia is the most prevalent form accounting for approximately 75% of all dementias. However, there are several other types including vascular dementia, fronto-temporal, Lewy body, and Parkinson disease dementia (Meyer, Huang, & Chowdhury, 2007; Riedel et al., 2008). Dementia also increases following stroke (Mackowiak-Cordoliani, Bombois, Memin, Henon, & Pasquier, 2005). Merino and Hachinski (2002) found that 25-30% of post stroke survivors demonstrated dementia within three months of stroke onset. The risk of developing dementia is even greater for stroke survivors over age 75 (Lowery et al., 2002). In addition, stroke survivors without dementia may experience persistent cognitive impairment. Patel, Coshall, Rudd, & Wolfe, (2003) studied cognitive impairment following stroke and found impairment rates of 35%, 30% and 32%, respectively, in the first three years following stroke demonstrating only minimal recovery of cognitive function.

Multiple risk factors have been identified for cognitive decline in older adults. Plassman et al. (2010) completed a systematic review of 127 observational studies, 22 randomized control trials, and 16 systematic reviews to examine the risk factors associated with cognitive decline in older adults. The investigators identified six risk factors: presence of the apolipoprotein E e4 genotype (associated with accelerated cognitive decline), low plasma selenium level, depression, diabetes, metabolic syndrome, and current tobacco use. The quality of evidence for each of these factors was considered

low. Metabolic syndrome is comprised of six components: abdominal obesity, high blood pressure, insulin resistance, elevated c-reactive protein, elevated triglyceride levels, and a prothrombotic state (Grundy et al., 2004). It is considered a significant risk factor for development of cardiovascular disease, which has been found to be associated with cognitive decline (Barnes, Alexopoulos, Lopez, Williamson, & Yaffe, 2006; Vinkers et al., 2005). The risk factor of depression deserves special consideration because of the high prevalence of depression in older adults in general and the very high rate of depression in older adults with low vision. Studies have found depression rates as high as 35% in community dwelling older adults (Kohler et al., 2010) and nearly 70% among older adults with low vision (Crews et al., 2006; Rovner & Ganguli, 1998). Studies have consistently shown depression to be associated with cognitive decline in older adults (Barnes et al., 2006; Ganguli, Du, Dodge, Ratcliff, & Chang, 2006; Thomas & O'Brien, 2008; Vinkers et al., 2005). However, it is not clear if depression independently influenced cognitive decline (Kohler et al., 2010) or was associated with another stronger underlying risk factor for cognitive decline such as cardiovascular disease (Ng, Niti, Zaw, & Kua, 2009).

#### *Age-Related Decline in Reading Performance*

Reading ability appears to change with age in two distinct but related areas: reading speed which reflects the person's print skills and fluency, and reading comprehension which reflects the person's meaning skills.

*Reading speed.* Research consistently has shown that older adults read more slowly than younger adults (DeBeni, Borella, & Carretti, 2007; Haegerstrom-Portnoy, 2005; Legge, 2007; Lott et al., 2001; Rayner, Reichle, Stroud, & Williams, 2006). Sass, Legge, and Lee (2006) found that older adults read text at a rate that averaged 67% of that of younger participants in the study. Rayner et al. (2006) found that older adults fixated longer on individual words suggesting that it took older adults longer to comprehend words. The investigators also found that older readers skipped words more often compared to younger readers and committed more regressions where they reread words, suggesting that they did not comprehend the word the first time it was read. Rayner et al. (2006) speculated that older readers might purposely adopt a “riskier” strategy of skipping words to increase reading speed, but did so at the expense of comprehension (p. 462). But not all studies have shown slower reading speeds in older adults compared to younger adults. This finding prompted Legge (2007) to argue that observed changes in reading speed in older adults may represent the influence of subtle individual changes in vision and oculomotor control in addition to cognition. These vision changes are found at higher rates in older adults and cannot be detected without in-depth vision screening.

*Reading comprehension.* Numerous studies have reported distinct declines in age-related reading comprehension attributed to changes in cognitive abilities that underlie reading performance (DeBeni, Palladino, Borella, & Lo Presti, 2003; Liu, Kemper, & Bovaird, 2009; Rayner, Reichle, Stroud, & Williams, 2006; Stine-Morrow, Gagne, Morrow, & DeWall, 2004; Stine-Morrow, Soederberg Miller, Gagne, & Hertzog, 2008). The declines have been found specifically in the ability to comprehend expository text,

which is text that explains something. Older adults may experience greater difficulty comprehending expository text because of age-related declines in working memory and metacognition (De Beni, Borella, & Carretti, 2007; Liu, Kemper, & Bovaird, 2009). Working memory is the ability to hold information temporarily in memory in order to examine it for meaning and determine whether and how to use it (De Beni, Borella, & Carretti, 2007; Goldberg, 2009). Metacognition is the conscious awareness of the learning process; it is dependent on the cognitive ability to monitor one's progress in reading text and modify a learning strategy that is not working. For example, when reading challenging material, a person with good metacognition may employ a strategy of re-reading difficult or unfamiliar parts of text or use a highlighter to underline important concepts. Both cognitive abilities require significant allocation of attentional resources within the central nervous system, which are vulnerable to the aging process (Goldberg, 2009). Older adults demonstrate less skill in employing metacognition skills during reading (Bann, Bayen, McCormack, & Uhrig, 2006; De Beni, Borella, & Carretti, 2007) and greater limitations in working memory (Brown & Park, 2002; De Beni et al., 2007; Liu, Kemper, & Bovaird, 2009). Expository text is particularly challenging to comprehend because it is more content laden and therefore requires more attentional resources. In addition, the material may be less familiar and the structure less coherent. In contrast, research has found little difference between older and younger adults in the ability to comprehend narrative text, which tells a story. Older adults are able to read narrative text more quickly than expository text and demonstrate greater recall possibly because narrative text is more familiar and predictable and typically has a more defined structure (De Beni et al., 2007). De Beni et al. (2007) found a more pronounced decline

in reading comprehension on expository text in adults aged 75 years and older compared to adults aged 65-74 years. Other studies have found a similar age effect suggesting that comprehension may decline with advanced age (Brown & Park, 2002; Liu, Kemper, & Bovaird, 2009). However, while the older groups in the De Beni et al. (2009) study performed more poorly than the younger adult group aged 18-30 years, reading comprehension remained within the normal range for all three groups.

The research on older adult readers has suggested that they put more effort into reading and understanding written text, especially expository text (Stine-Morrow, Milinder, Pullara, & Herman, 2001). Because printed health information is generally written in an expository style, older adults may shy away from reading health-related materials as it requires more effort. Finucane et al. (2002) investigated the ability of adults to comprehend varying health care plans. Older participants in the study rated themselves as less competent in deciphering tables and charts and reported a significantly greater desire to delegate responsibility for decision-making on the health plans to another person. However, research has also shown that self-perception of competence, verbal ability, and accumulated reading experience may influence reading comprehension in older adults (Bann, Bayen, McCormack, & Uhrig, 2006; Liu, Kemper, & Bovaird, 2009). Liu, Kempe, and Bovaird (2009) found that older adults with high verbal ability demonstrated greater comprehension of health-related written materials. Familiarity with health subjects and materials may also influence reading performance. These investigators also found that experience working in a health field was associated with increased comprehension of health materials. However, Brown and Park (2002) found that prior knowledge of a medical condition did not improve comprehension of new

medical information on the same subject among young or older adults. A regular habit of reading daily may also mediate reading performance on health materials and improve comprehension. Bann, Bayen, McCormack, and Uhrig (2006) found that older adults who read more frequently, regardless of the types of materials read, demonstrated greater understanding of Medicare documents. Wister, Malloy-Weir, Rootman, and Desjardins (2010) also found that older adults who regularly engaged in reading to learn new information demonstrated higher health literacy levels. These research findings suggest that many factors influence the ability of older adults to comprehend written health materials including just making a regular habit of reading daily. In addition, an age-related decline in reading comprehension among older adults may not translate into a functional impairment unless other factors are present such as being given a short period of time to read lengthy materials that describe a complex concept using unfamiliar words (DeBeni, Palladino, Borella, & Presti, 2003).

#### Variables Associated with Low Vision Reading Performance

In a series of studies, Gordon Legge and his colleagues at the University of Minnesota Reading Laboratory systematically examined the factors that influence reading performance in persons with low vision. Twenty studies were published between 1985 and 2001, culminating in a 2007 book published by Legge, the *Psychophysics of Reading in Normal and Low Vision*. The studies were primarily conducted on persons with AMD and showed that impairment in five visual functions accounted for most of the reading deficiencies experienced by persons with low vision. The visual functions were

reading acuity, contrast sensitivity, critical print size, reading speed, and central visual field deficit (e.g. scotoma) (Legge, 2007).

Eye diseases characterized by development of central scotoma in the foveal region of the retina disrupt the eye movements used for reading (Legge, Ahn, Klitz, & Luebker, 1997). While glaucoma and diabetic retinopathy can cause central scotoma in the advanced stages of the disease, it is the central clinical feature of AMD. The effect of central scotoma on reading performance has been thoroughly studied and delineated in multiple research studies on AMD (Cacho, Dickinson, Smith & Harper, 2010; Cheong, Legge, Lawrence, Cheung & Ruff, 2007; Crossland, Culham, & Rubin, 2005; Fletcher, Schuchard, & Watson, 1999; Legge, 2007; Lovie-Kitchin, Bowers, & Woods, 2000; Whittaker & Lovie-Kitchen, 1993). The process by which the disease disrupts reading has also been determined (Battista, Kalloniatis & Metha, 2005). Death of retinal photoreceptor cells in the central field and the resulting scotoma causes a cascade of changes in visual functions that interact synergistically to impair reading performance (Battista, Kalloniatis, & Metha, 2005). As the disease progresses, the scotoma increases in size and eventually forces the person to begin using areas of the retina that are eccentric to the fovea to read. Every shift in fixation away from the fovea towards the peripheral areas of the retinal field causes an incremental decline in visual resolution (acuity and contrast sensitivity) because the photoreceptor cells have less ability to resolve small and faint visual details. Reduced acuity and contrast sensitivity causes text to appear blurry. The shift to the peripheral retina also causes a crowding effect where letters within words fall into each other making it difficult to identifying specific letters or numbers. In addition, the visual span for reading, which is the area where letters are



clearly seen, is reduced in size causing the person to see fewer letters with each fixation. When the scotoma impinges on the visual span, the reader may not see the beginnings or ending of words, which can cause mis-identification of words with similar letter construction (e.g. “black” might be read as “lack”) and a reduction in reading accuracy (Cheong, Legge, Lawrence, Cheung, & Ruff, 2007; Fletcher, Schuchard, & Watson, 1999; Legge, 2007; Watson, Baldasare, & Whittaker, 1990; Watson & Whittaker, 1994). The combined result of the central field disruption and shift to peripheral retina is a reduction in acuity and contrast sensitivity, an increase in critical print size and a decrease in reading speed. Although magnifying devices can enlarge images and additional light can bolster contrast sensitivity, these tools cannot restore vision or reading to normal levels (Legge, 2007).

### *Acuity*

Acuity is the ability to see small details at a specified distance. Longitudinal studies have shown that older adults may experience mild declines in reading acuity with aging, but are able to retain the ability to read most print using lenses if needed (Brabyn, Schneck, Haegerstrom-Portnoy, & Lott, 2001). Older people begin to experience noticeable difficulty reading print when visual acuity reaches a moderate level of impairment (20/60 Snellen acuity) and typically begin using magnifiers to read standard and smaller print sizes. They are often able to achieve near normal reading speeds using these devices. Persons with severe vision impairment can read with magnifiers, but reading speed is slower than normal and the person puts more effort into reading

(Colenbrander & Fletcher, 1995). When visual acuity reaches the profound impairment range, the ability to read continuous text (e.g. paragraphs of material) generally requires too much effort to be practical as a daily activity (Colenbrander & Fletcher, 1995).

Persons with profound visual impairment use high-powered magnification, limit reading to essential information such as food and medication labels, and acquire most information through auditory or tactual senses.

### *Contrast Sensitivity*

Contrast sensitivity was defined earlier as the ability to distinguish objects (in this case letters) as they degrade in contrast from the background. Persons with normal contrast sensitivity are able to tolerate a ten fold decrease in contrast levels in print before reading speed is diminished (Legge, 2007). Older adults experience a decline in contrast sensitivity with aging (Brabyn, Schneek, Haegerstrom-Portnoy, & Lott, 2001) but are typically able to minimize the effect by adding lighting when reading. AMD readers with reduced contrast sensitivity require higher levels of letter contrast to maintain reading speed than normally sighted readers and often use additional lighting and magnification to compensate for limited contrast sensitivity (Bowers, Meek, & Stewart, 2001; Legge, 2007; Watson, 2001; Whittaker & Lovie-Kitchin, 1993; Yager, Aquilante & Plass, 1998).

Another function of contrast sensitivity is to provide *contrast reserve* for reading. Contrast reserve is the ability to read text of varying levels of contrast for extended periods of time. Persons with low vision require 80% contrast in text to be able to read fluently, whereas normally sighted persons can maintain fluency with reductions of

contrast as low as 10% (Barstow & Crossland, 2011; Legge, 2007). Low vision readers generally require larger text size and good contrast between the letters and the page to read for extended periods of time without fatiguing. Impaired contrast discrimination also affects the low vision reader's ability to see shading on printed materials and to distinguish features where gradations of color have been overlaid on each other, for example, a brochure that has light grey printing on a white background.

### *Critical Print Size*

Reading speed also declines as persons reach their critical print size. Legge (2007) defined critical print size as the smallest print size at which a person can still achieve maximum reading speed. Persons with normal vision have a wide range of print sizes they can read with maximum speed. Persons with low vision have a much narrower range of print sizes that they can read and although critical print size varies among low vision readers can be much larger than that of a reader with normal sight (Legge, 2007). One benefit of using magnification to read is that it moves the print closer to the critical print size for the low vision reader and increases reading speed. This benefit can be negated by the time consumed in manipulating the magnifier and combining eye movement with hand movement (Bowers, 2000). However, Legge (2007) reported that when persons with AMD are trained to use a magnifier, the increased print size neutralized the influence of page navigation on reading speed, and any slowness in reading could be attributed to central scotoma.

### *Reading Speed*

Reading speed is the primary psychophysical measure used to define reading performance in persons with normal and low vision (Legge, 2007; Rayner, 1998). Multiple research studies on AMD readers have shown that reading speed decreased as scotomas increased in size and affected both eyes (Cacho, Dickinson, Smith, & Harper, 2010; Crossland, Culham, & Rubin, 2005; Lovie-Kitchin, Bowers, & Woods, 2000; Whittaker & Lovie-Kitchen, 1993; Legge, 2007). Fletcher, Schuchard, and Watson (1999) found that AMD readers with bilateral scotomas read at approximately one-half the reading rate of persons with intact central fields. Other studies found reading rates that varied between 69 and 121 words per minute in persons with macular scotoma (Crossland, Culham, & Rubin, 2005; Barstow & Crossland, 2011).

### *Reading Comprehension*

There have been no definitive studies showing a reduction in reading comprehension in AMD readers. A few studies on AMD readers have included non-standardized reading comprehension measures and shown that macular scotoma can increase effort and slow processing speed in persons with AMD (Cheong, Legge, Lawrence, Cheung, & Ruff, 2007; Deruaz, Goldschmidt, Mermoud, Whatham, & Safran, 2005; Falkenberg, Rubin, & Bex, 2007). Cheong et al. (2007) compared participants with AMD with normally sighted controls and found that reduced processing speed associated with use of peripheral vision accounted for 30% of the difference in reading speeds

between the two groups. However, Legge (2007) has found that AMD readers with reading rates as slow as 10 words per minute were able to demonstrate normal comprehension levels on reading material. Legge attributed the lack of association between reading speed and comprehension to the wide variation in comprehension among normally sighted readers and the fact that many factors influence comprehension including cognition, language, age, and education.

### Functional Health Literacy Measures

Functional health literacy was the dependent variable in this study. It is a component of general literacy, and therefore, relies on the ability to read and interpret prose and numbers and complete routine mathematical calculations (Rudd, 2007). Several standardized literacy assessments have been developed to measure general literacy abilities in adults including reading comprehension and numeracy. The most commonly used assessments include the Peabody Individual Assessment Test (PIAT), the Slosson Oral Reading Test-Revised (SORT-R), and the Wide Range Achievement Test-Revised (WRAT-R) (Andrus & Roth, 2002; Hanson-Divers, 1997). The tests use a word recognition and/or reading comprehension format and produce a reading grade level. Of the tests, the WRAT-R, a nationally standardized achievement test, is widely used as an adult literacy test to measure reading recognition, spelling, and arithmetic (Andrus & Roth, 2002). The format of these general literacy assessments was used to develop assessments measuring functional health literacy in adults in either clinical settings or for research studies (Andrus & Roth, 2002).

### *Clinical Measures*

Health literacy assessments designed for clinical use generally require less than 15 minutes to administer to a patient and are quick and easy to score. Most use a word recognition format, assuming that a person unable to accurately complete this beginning level reading skill will also have difficulty comprehending text (Andrus & Roth, 2002). The Medical Terminology Achievement Reading Test (MART) was modeled after the WRAT. The test uses 42 commonly used medical words printed on a glossy label in a small print font size similar to that found on a prescription label. The Medical Term Recognition Test (METER) is another standardized short clinical health literacy test that takes approximately two minutes to administer (Rawson et al., 2009). The patient is given a list of items and asked to check off the ones that he or she recognizes. The Newest Vital Sign uses a nutrition label on a pint of ice cream and asks six questions that assess both reading comprehension and numeracy. The test is available in English and Spanish and can be completed within three minutes (Weiss et al., 2005). The psychometric properties of the three tests have been carefully analyzed and all three demonstrate good reliability and validity. However, the three assessments were designed only for clinical use and have not been used in research studies.

### *Research Measures*

Investigators have primarily used two tests to study functional health literacy levels in adults (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). The tests are

the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). Both tests were developed in the 1990s (Davis et al., 1993; Parker, Baker, Williams, & Nurss, 1995) and they have been used in multiple research studies (DeWalt et al., 2004; Nielsen-Bohlman, Panzer, & Kindig, 2004).

Paasche-Orlow et al. (2005) identified 85 studies conducted on functional health literacy in the United States between 1963 and 2005. The REALM and the TOFHLA were the most frequently used health literacy measurements in the reviewed studies. Forty-one of the studies used the REALM, and 17 used the TOFHLA. DeWalt et al. (2004) conducted a systematic review of the research literature on literacy and health outcomes roughly during the same period and confirmed the prevalent use of the REALM and TOFHLA for research investigations.

*Rapid Estimate of Adult Literacy in Medicine.* The REALM assesses the ability to recognize medical terminology. The participant is handed a laminated card with 66 common words including medical terms and laymen terms for parts of the body and illnesses. The words are arranged in three columns in order of difficulty. The person reads each word out loud and receives one point for each correctly pronounced word (Davis et al., 1993). Scores are converted into four reading grade levels: 0-3rd grade (0-18 correctly read words); 4<sup>th</sup>-6<sup>th</sup> grade (19-44 correctly read words); 7<sup>th</sup>-8<sup>th</sup> grade (45-60 correctly read words) and 9<sup>th</sup> grade and above (61-66 correctly read words). The test has demonstrated high intra-subject reliability and correlation with three standardized reading measures (Andrus & Roth, 2002). It can be conducted in less than 5 minutes, making it useful for clinical application. However, it does not measure two important aspects of

functional health literacy for persons with low vision: reading comprehension for written instructions and numeracy.

*Test of Functional Health Literacy in Adults.* The TOFHLA, widely considered as the gold standard test (Mancuso, 2009), was the first test developed to specifically to measure functional health literacy in adults by evaluating reading comprehension and numeracy using real world examples of health materials (Parker et al., 1995). The test is divided into two sections: a reading comprehension test that measures the person's understanding of printed materials and a numeracy portion that measures the ability to complete simple math computations. The text for the reading comprehension section consists of three separate passages taken from actual hospital and medical texts. The passages include instructions for preparing for an upper gastrointestinal procedure, an excerpt from the patient rights and responsibilities section of a Medicaid application form, and a standard hospital consent form for a medical procedure. The three passages are written at elementary, high school, and college reading grade levels respectively. The passages are presented using a cloze format where every fifth to seventh word in a passage is removed, creating a 50-item test. The person is required to identify the most appropriate word to fill in the blank from 4 possible choices. The 17 item numeracy portion of the assessment tests the person's ability to complete up to 9<sup>th</sup>-grade level math calculations to interpret instructions on six different prescription labels; determine if a stated blood glucose level is within normal limits; identify when to come to a clinic appointment; and determine whether the person qualifies for financial assistance. The information for the numeracy items is printed on prompts (e.g., an appointment slip, a prescription bottle, a medical test result) and handed to the participant to read. The



examiner asks the participant questions about the information on the prompt and records the answers. A key feature of the test is that it is timed. Participants are allowed 12 minutes to complete the reading comprehension section and 10 minutes for the numeracy section. The examiner stops the test when the time limit is reached and unanswered items are scored as errors. This creates the potential for slow reading speed to produce a lower score on the test. The scores from the two sections are weighted to ensure an equal contribution of 50 points from each section and added together to provide a composite score with a range from 1-100. The composite score can then be categorized into three levels of proficiency in health literacy: inadequate 0-59; marginal 60-74; adequate 75-100 points. Persons in the adequate category should be able to comprehend most health related materials; those with marginal or inadequate levels will experience difficulty reading, understanding, and interpreting all but very simple health materials.

There are two versions of the TOFHLA. The original or long version of the test, was developed first and takes up to 22 minutes to administer (Parker, Baker, Williams, & Nurss, 1995). The short version of the test, the S-TOFHLA was developed in 1999 and takes approximately 12 minutes to administer (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Both versions of the tests are available in Spanish and in a standard print size (12 point) and large print (14 point). The investigators state that the large print version accommodates readers with acuity between 20/70 and 20/100, which would permit testing a reader with moderate low vision.

A literacy expert reviewed more than 30 examples of common texts used in hospitals to develop the content for the test (Parker, Baker, Williams, & Nurss, 1995). Pilot studies were conducted on the English and Spanish versions simultaneously using

large, racially diverse samples from two large urban hospitals, one in Atlanta and the other in Los Angeles. Participants were administered the TOHFLA, the REALM, and the WRAT-R. The REALM and the WRAT-R do not have Spanish versions and were administered only to the English-speaking participants. The Cronbach coefficient alpha measure was used to measure internal consistency (Cronbach's  $\alpha = .98$  for the English and Spanish versions); a Spearman-Brown formula was used to measure test-retest reliability (Cronbach's  $\alpha = .92$  for the English version and Cronbach's  $\alpha = .84$  for the Spanish version) (Parker, Baker, Williams, & Nurss, 1995). Inter-correlations between the reading comprehension and the numeracy tests were also completed and were .79 for the English version and .70 for the Spanish version. Good correlations were found between the TOHFLA scores and scores on the REALM (.84) and the WRAT-R (.74) for the English version. These scores indicate that the test has good internal and inter-rater reliability and validity.

Both versions of the TOFHLA have been used extensively in studies measuring the associations between health literacy and health outcomes, health status, knowledge of chronic disease, use of health care services, and self-management skills. The authors of the TOFHLA state that the short version can be used for clinical screening, developing reading appropriate materials for a health education program, and measuring literacy level as a general descriptive variable in research study (Nurss, Parker, & Baker, 1995). The long version of the test should be used when health literacy is included as a "dependent or independent variable in research" (Nurss, Parker, Baker, 1995, p. v).

## Theory

To understand how proficiency in functional health literacy might influence successful management of chronic diseases among older adults with low vision, required an understanding of the role of health literacy in the self-management of chronic disease and the influence of low vision on the ability to be health literate and acquire the information needed for self-management. To obtain this perspective, two theories were necessary: one that delineated the role of health literacy in chronic care and one that delineated the influence of low vision on acquiring information from the environment. The chronic care model (CCM) provided a model for understanding how health literacy fit into the larger framework of providing effective health care to persons with chronic diseases (Schillinger & Davis, 2005). The ecology of human performance model (EHP) (Dunn, Brown, & McGuigan, 1994), an occupational therapy model delineating how the interaction between person and environment influences engagement in daily occupations, provided a framework for understanding the influence of low vision on reading performance and subsequent engagement in health behaviors.

### *Chronic Care Model*

The CCM is a widely used model for treating chronic illness in the United States (Coleman, Austin, Brach, & Wagner, 2009; Schillinger & Davis, 2005). The model, portrayed in Figure 1 was developed in the early 1990s to provide an all-encompassing framework for the management of chronic illnesses among varying target populations within a variety of health care settings (Improving Chronic Illness Care, n.d.). The goal of

the CCM is to prevent or minimize the progression of chronic illness and disability by providing ongoing coordinated health care services that empower the patient and family to successfully manage chronic condition(s). Figure 1 illustrates the six components of the framework. These components have been shown to be critical in preventing disability and death from chronic diseases (Coleman, Austin, Brach, & Wagner, 2009). Two of the components, the *community* and the *health system*, provide an overarching framework for the model. Figure 1 shows the health system residing partly within the larger community component, acknowledging that the support and resources offered by the community are critical to reinforcing the changes in health behavior needed to successfully manage chronic conditions. The figure shows that four additional components reside within the health system: self-management support, delivery system design, decision support, and clinical information systems.

The focus of the framework is on improving individual patient outcomes by ensuring a productive interaction between the patient and health care providers. This essential component of effective chronic care management is depicted at the bottom of the model. The model stipulates that successful chronic care depends on having an actively engaged patient who possesses sufficient health information to make informed decisions with the assistance of the health care team. The patient must also possess the skills, motivation, and self-efficacy to be empowered to play an active role in health management. The health care team must be prepared to work with the patient by providing evidence-based information to support decision-making and resources to design tailored interventions. A collaborative process must be used to ensure that the health care team, patient, and family set mutually acceptable goals.

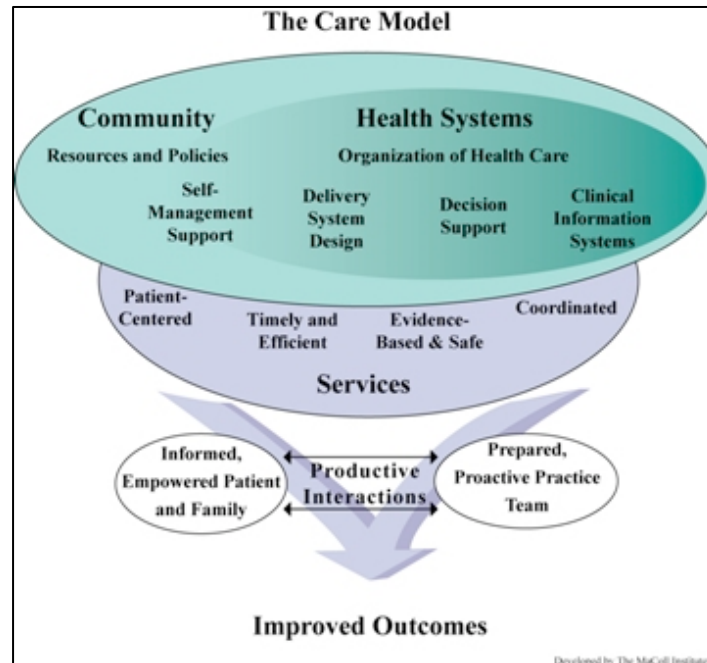


Figure 1. The Chronic Care Model.

Note: From: Chronic Disease Management: What Will it Take to Improve Care for Chronic Illness? By E. H. Wagner, 1998, *Effective Clinical Practice*, 1, p. 1. Copyright 1998 by the American College of Physicians. Reprinted with permission.

The other components in the model ensure that the health care team is able to deliver timely, coordinated, and evidence-based services. The delivery system design focuses on using planned visits and appropriate case management to monitor the patient's ability to carry out self-management skills. It also includes providing culturally sensitive care that can be understood by patients. Decision support integrates evidence-based practice guidelines into clinical care and includes using proven educational methods to ensure the patient understands the health material. The clinical information system ensures the health care team has access to databases to help plan interventions for specific patient populations. Community resources and policies provide non-medical resources

that assist the patient to make and sustain needed changes in health behavior. These resources include support groups, exercise facilities, weight loss, and healthy eating programs. The final component, health care organization, creates a culture and structure to incentivize organizations to make changes that support implementation of effective chronic care.

Although the chronic care model does not explicitly identify health literacy as an essential element within the framework, the importance of health literacy is clearly illustrated in the model. The patient's proficiency in health literacy affects the degree to which he or she can benefit from health education efforts and thus is important in enabling the patient to develop self-management skills. Health care providers frequently rely on printed materials to educate persons about their health and self-management procedures, thus making health literacy especially important (Parker, 2000). Proficiency in health literacy has been shown to bolster the patient's sense of self-efficacy and empower the patient to engage in self-management (von Wagner, Semmler, Good, & Wardle, 2009; White, Chen, & Atchison, 2008). The Institute of Medicine (IOM) 2003 report, *Priority Areas for National Action*, acknowledged the close relationship between health literacy and self-management by combining them into a single action priority area to improve the nation's health (Adams & Corrigan, 2003). The IOM report also designated self-management/health literacy as a "cross cutting" priority action area for the nation's health because improvement would affect most health care organizations and practitioners, impact all types of conditions, and improve health care for all Americans (Adams & Corrigan, p.46).

### *Ecology of Human Performance Model*

The EHP postulates that human performance (e.g. the person's ability to complete daily occupations such as reading) is a product of the interaction between the person, the task, and the context. The person in this dynamic triad possesses unique abilities that are the product of his or her sensory, motor, cognitive, and psychosocial skills. The task is the set of behaviors needed to accomplish a goal, and the context is comprised of the interdependent conditions that surround the person during task completion. The context includes temporal aspects such as the person's age, developmental stage, and disability status as well as the span of time during which the task is completed, when it takes place, and how often it occurs. Context also includes environmental aspects including physical elements (aspects of the built environment), social elements (norms, role expectation etc.) and cultural elements (customs, beliefs, activity patterns). The three variables continuously interact with one another in an ongoing daily process wherein the person engages in successive tasks within specific temporal and environment contexts. The variables are interdependent, and their interaction produces a performance range, comprised of the number and type of daily living tasks the person can successfully complete. When the three components are in balance, the person's performance range expands and the person is able to be self-sufficient and complete all needed activities of daily living. A negative change in any of the three components disrupts the balance among them with the effect of reducing the person's performance range and reducing the ability to engage in daily activities.

How the EHP model applies to the interplay between low vision and functional health literacy can be illustrated as follows. The reduction in visual ability that

accompanies low vision can cause the person attempting to read printed health information (representative of the physical environment) to take a long time (temporal environment) to complete the task and to inaccurately read some of the text. The additional effort involved in reading the text may convince the person that he or she lacks the ability to read health information. The person abandons the task and refrains from attempting to obtain information on his or her health condition by reading the printed materials provided by the physician. This narrows the person's performance range as it relates to health literacy. If the task involves identifying a medication dosage, the person may be under medicated or overmedicated and experience a serious health complication. Such an experience would also reduce the likelihood that the person would engage in further self-management tasks.

It was not the intent of the study to test the EHP model, but rather to use it to guide the selection of the measured and controlled variables for the study. The EHP model asserts that promoting change in human behavior is dependent on the ability to identify the variables that influence the relationship among the person, context, and task and then to manipulate those variables to ensure that an adequate performance range is maintained. The model directs the health care professional to observe and evaluate the person while engaged in the task to identify variables that may affect task performance. The variables influencing reading performance in persons with low vision from AMD have already been identified and include visual acuity, contrast sensitivity, critical print size, scotoma and reading speed (Legge, 2007). Research has not addressed how these variables may influence the ability to accurately read and interpret printed health information to establish proficiency in health literacy. However, the model suggests that



the limitations in reading caused by AMD may create an additional barrier that could influence the older adult's ability to understand and interpret health information, thus reducing health literacy levels beyond what would be expected to occur from the influence of age alone.

### Summary

This review of the literature identified multiple independent variables that influence reading fluency and therefore the dependent variable in this study, functional health literacy. The relationship between the independent variables and the dependent variable is illustrated in Figure 2. The column on the left side of the illustration shows the intrinsic variables that affect reading performance. These variables are innate to the individual and include older age, gender, race/ethnicity, and cognitive ability/reserve. The variable cognitive ability/reserve is also influenced by several innate factors including the person's genetics, chiefly innate intelligence, and the co-morbidities of depression and dementia. Reading frequency is included an intrinsic variable in this model because it reflects the person's motivation and desire, not advanced education or an intellectually-demanding occupation. Activity level is also included as an intrinsic variable that might influence maintenance of cognitive reserve in old age. Although activity level in older adults is associated with physical and sensory disabilities, as with reading, older adults can choose to remain actively engaged in their environments despite limitations.

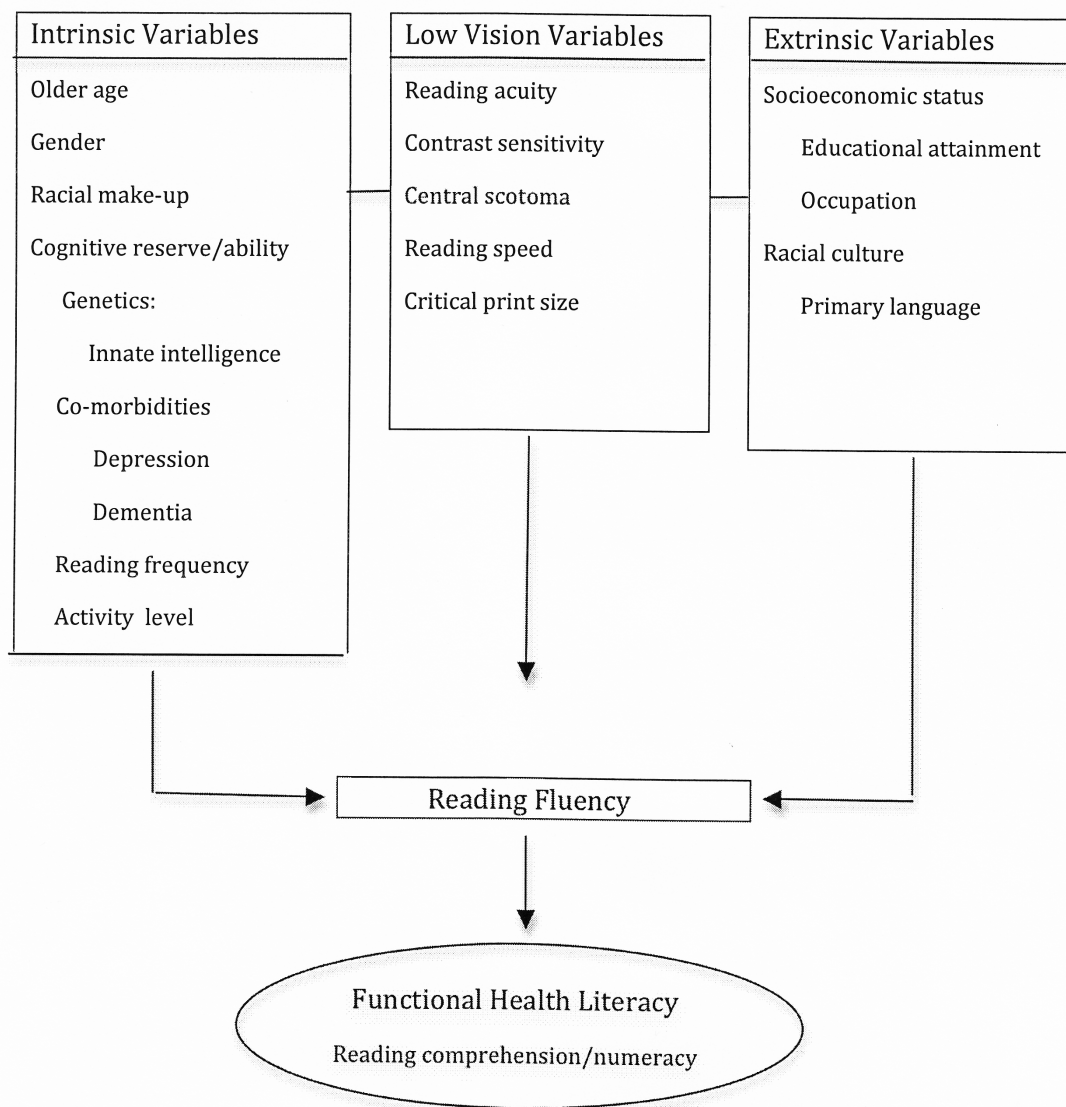


Figure 2. Variables Associated with Functional Health Literacy.

Extrinsic variables that influence reading performance are shown in the column on the right side of the illustration and include socioeconomic status (income), educational attainment, occupation, racial culture, and primary language. These variables influence reading fluency by creating environments that support activity and life-long learning. Educational attainment and occupation are listed under socioeconomic status

because SES, especially in childhood and early adulthood, can influence on both of these variables. Racial culture accounts for the social influences that surround persons due to their racial heritage. These influences determine the person's primary language and can shape the person's perception of health and health care.

The middle column describes the vision-related variables that influence reading fluency in persons with low vision. The variables include reading acuity, contrast sensitivity, central scotoma, reading speed and critical print size. Reading frequency is included in this middle column as a mediating variable that reflects the innate desire of the person to continue to read despite difficulty seeing print. Some persons with low vision continue to read even though it is difficult because they value this occupation; others will quickly limit reading because it is frustrating and seek out other ways to acquire information.

Because functional health literacy is a measure of reading and numeracy comprehension, each of the variables in the three columns may potentially influence functional health literacy through their associations with reading fluency. Although the model implies a linear relationship by neatly dividing the variables into columns, the research evidence has suggested an interactive, more cyclical relationship among the variables. For example, an older adult who was born into a minority racial culture and experienced low SES as a child may have received a limited and inferior quality education, resulting in fewer opportunities for cognitively challenging employment, which contributed to less cognitive reserve in aging and greater age-related cognitive decline that decreased reading and numeracy skills and ultimately led to a lower health literacy level. In contrast, an English-speaking Caucasian older adult with a high

childhood SES may have benefitted from better quality education, which led to a higher educational attainment, more intellectually stimulating jobs, more cognitive reserve and less age-related cognitive decline, better reading and numeracy skills, and subsequently, a higher health literacy level. However it was equally plausible that adverse economic circumstances in childhood and limited education would not automatically prevent an adult from seeking intellectual stimulation through reading and other activities. Likewise, adults who valued reading during their life and enjoyed intellectual pursuits are likely to work hard to continue these activities despite vision loss, and thus remain skilled readers (Legge, 2007; Watson, 2001). Although low vision has been shown to slow reading speed, researchers have failed to find a corollary reduction in reading comprehension especially in practiced readers (Legge, 2007; Watson, 2001). Therefore, it was important to acknowledge that multiple variables would be associated with reading performance, and thus functional health literacy in older adults with and without low vision. To ascertain whether low vision influenced health literacy levels in older adults, these variables had to be controlled for systematically within the study design.

## CHAPTER 3

### METHODS

The purpose of the study was to determine whether adults over age 65 years with low vision caused by age-related macular degeneration (AMD) experienced lower functional health literacy levels than normally sighted older adults. The investigation addressed a gap in the literature by examining the relationship between low vision and health literacy level in older adults. Although there was extensive research on functional health literacy levels in older adults, persons with low vision had been systematically excluded from most of the studies. As a result, there was no research examining whether low vision, through its influence on reading performance, added an additional barrier to proficiency in health literacy beyond factors associated with aging.

The study compared the performance of two groups of community dwelling adults between the ages of 65 and 94 years on the TOFHLA, a standardized test of functional health literacy. One group had moderate to severe visual impairment from AMD and the second group had normal vision. A review of the literature showed that multiple variables might potentially influence the performance of older adults on a test measuring functional health literacy by affecting reading performance. The research design attempted to control for potential confounding variables through inclusion criteria and closely matching the groups on variables shown to influence reading. The study also examined relationships among TOFHLA scores and vision-related and reading-related

variables in older adults with low vision and non-vision variables associated with reading performance of older adults in general. This chapter describes the population, recruitment, instruments, study procedures, and plan for data analyses.

The study investigated four research questions.

1. Do older adults with low vision differ from older adults with normal sight in vision-related variables including acuity, contrast sensitivity, reading speed, critical print size and scotoma, and reading-related variables including number of items typically read, reading frequency and perceived reading difficulty and satisfaction?
2. Do community-dwelling older adults with low vision score lower on the Test of Functional Health Literacy for Adults (TOFHLA) than community-dwelling older adults with normal sight.
3. Are vision-related variables-acuity, contrast sensitivity, reading speed, critical print size and scotoma associated with lower TOFHLA scores in older community-dwelling low vision?
4. Are variables associated with reading performance in older community-dwelling adults including age, gender, education, occupation, reading frequency and activity associated with TOFHLA scores?

## Participants

Non-institutionalized, community-dwelling older adults aged 65 years and older were recruited for the study. Fifty participants with moderate to severe visual impairment from age-related macular degeneration (AMD) were recruited for the low vision sample and matched with 50 participants without vision impairment for the control group.

Participants were required to meet the following inclusion criteria.

1. Person aged 65 years and older.
2. Persons who resided in a single-family dwelling or an apartment within a residential facility in the community.
3. Persons who possessed a minimum of a high school diploma or equivalency.
4. Persons who reported English as the primary language spoken and read.
5. Persons who reported a minimum average annual household income of \$20,000.
6. Persons who reported no medical history of dyslexia, brain injury, neurological disease, or other condition that might affect cognition or reading or a significant uncorrected hearing loss.
7. Persons who demonstrated adequate cognitive functioning using the Short Portable Mental Status Questionnaire (Pfeiffer, 1975): defined as a maximum of three errors for Caucasians with high school degrees; two errors for Caucasians with college degrees and four errors for African Americans.

8. Persons who demonstrated minimal risk of depression as defined by score of less than 10 on the Geriatric Depression Scale-Short Form (Shiekh & Yesavage, 1986).

9. Persons who reported reading a minimum average of 20 minutes on a daily basis.

Participants in the low vision sample met these additional criteria.

1. Persons with a diagnosis of AMD.

2. Persons with moderate to severe visual impairment defined as a Snellen distance visual acuity between 20/60 and 20/400 confirmed with the ETDRS chart wearing habitual correction.

Participants in the control group met the additional criteria of demonstrating distance visual acuity within the normal range (20/20 to 20/30 Snellen acuity) confirmed with the ETDRS distance acuity test chart wearing habitual correction.

### Recruitment

The Institutional Review Board of the University of Alabama at Birmingham approved the human subjects protocol for the study. The approval form is located within Appendix A.

Low vision participants were recruited from a research database of persons who had participated in a study on optical device use and reading at the University of



Alabama at Birmingham Center for Low Vision Rehabilitation (UABCLVR) and from patient caseload in the center. An additional nine low vision participants were recruited who had heard about the study from other participants and volunteered to participate. Participants for the control group were recruited mostly from the greater Birmingham metropolitan through flyers, personal contacts, and referrals provided by other participants in the study. Males were oversampled to assure a sample with at least 30% male representation.

Screened participants were contacted by telephone to ascertain their interest and eligibility for the study. Persons who expressed an interest in participating were sent a description of the study and the consent form. Verbal assent to participate was confirmed and a tentative interview date was scheduled 5 to 10 days after the initial telephone contact. The participant was re-contacted 3 to 5 days later to answer questions about the study, reaffirm assent to participate and confirm the interview date. Written consent was collected at the beginning of the scheduled appointment to conduct the study. Participants who enrolled and completed the appointment received a \$10 gift card to a local grocery store or Walmart as compensation for their participation.

### Instruments

Links to the standardized screening and study measures are found in Appendix B. The format and instructions, scoring, and validity and reliability of each of the standardized measures are summarized in Tables 1 and 2.

### *Screening Measures*

Four standardized measures were administered to the participants in both groups to screen for adequate cognitive functioning, risk for depression, distance acuity, and reading frequency. The measures included the Short Portable Mental Status Questionnaire, the Geriatric Depression Scale-Short form, the Early Treatment of Diabetic Retinopathy Study distance acuity chart, and the Reading Behavior Inventory. A structured social/medical history self-report questionnaire was also administered to obtain demographic and background information and to verify that participants met the inclusion criteria for the study.

*Social/medical history questionnaire.* The self-report questionnaire was developed for the study to solicit information to describe the sample. It was administered using an interview format and asked about marital status, living arrangement, income, educational level, occupation, years in retirement, health status, and co-morbid conditions including cardiovascular disease, high blood pressure, diabetes, arthritis, chronic lung disease, kidney or digestive disease, hearing impairment; whether they had received an intraocular lens replacement for cataract and the number of prescribed medications consumed on a regular basis. Three additional questions asked about participation in self-management tasks requiring functional health literacy. The participant was asked to identify whether he or she independently completed or received help from a family member, friend, or paid help to manage daily medications, make doctor's appointments, and review medical statements.

*Short Portable Mental Status Questionnaire (SPMSQ).* The SPMSQ (Pfeiffer, 1975) is a measure of global cognitive functioning. The test consists of ten short items that address different domains of memory functioning: short-term memory, long-term memory, orientation to surroundings, information about current events, and serial mathematics ability. The SPMSQ has been extensively used in research on older adults to screen for significant cognitive impairment and dementia (Welch & West, 1999) and specifically in studies of older adults with low vision because it does not have a vision component (Ringsdorf, McGwin, & Owsley, 2006; Tolman, Hill, Kleinschmidt, & Gregg, 2005; Whitson et al., 2007). To account for differences in educational attainment and race, Pfeiffer allowed one additional error for African Americans and persons with less than a high school education, and one less error for persons with education beyond high school (Pfeiffer, 1975). Erkinjuntti, Sulkava, Wikstrom, and Autio (1987) reported that a cut-off of three errors increased the sensitivity of the test to screen community-dwelling older adults with high school education or greater. Their guidelines were used in this study and are summarized in Table 1.

*Geriatric Depression Scale-Short Form (GDS-SF).* The GDS-SF (Shiekh & Yesavage, 1986) is a screening measure for assessing risk for depression among older adults. The person responds “yes” or “no” to 15 statements about how he or she felt during the past week to assess energy level, social interaction, mood, and hope for the future. The short version of the screening consists of the statements that demonstrated the highest correlation with depression symptoms on the original long version of the screen (Leshner & Berryhill, 1994). The GDS-SF is a widely used self-report assessment developed specifically to screen older adults for risk of depression (McDowell, 2006;

Nelson, Cho, Berk, Holland, & Roth, 2009). It has been used extensively in studies involving older adults with vision impairment (Galaria, Casten, & Rovner, 2000).

*Reading Behavior Inventory (RBI).* The RBI (Goodrich, Kirby, Wood, & Peters, 2006) is a self-report screening tool developed at the Western Blind Rehabilitation Center in the Palo Alto Veterans Affairs Health Care System to measure outcomes in reading related research on adults with low vision (Goodrich, Kirby, Wood, & Peters, 2006). The inventory consists of five questions that address the types of materials the person reads on a daily or weekly basis, approximate average time spent reading daily and perceived level of reading difficulty, satisfaction with reading performance, and current ability to read.

*Early Treatment of Diabetic Retinopathy Study (ETDRS) Visual Acuity Chart.* The EDTRS chart (Precision Vision, LaSalle, IL) is a logMAR chart used to measure distance acuity in persons with vision impairment. The chart was developed for a 1979 National Eye Institute funded randomized control trial. The chart design incorporated recommendations from the Committee on Vision of the National Academy of Science—National Research Council (Kniestedt, & Stamper, 2003). The chart is held at a standardized test distance. The examiner determines the test distance and whether the eyes will be tested separately or together and with or without spectacle correction. The chart provides letter-by-letter measurement of acuity and a more precise measurement of acuity than the standard Snellen chart and enables testing of very low acuity. It has been widely used to assess acuities in the low vision range of impairment (Kniestedt, & Stamper, 2003).

### *Study Measures*

Four standardized measures were administered to all qualified study participants: the Test of Functional Health Literacy for Adults (TOFHLA), the MNread acuity chart, the Mars Contrast Sensitivity Chart and the Leisure Activity Score Questionnaire. The investigator also conducted a chart review of microperimetry results on participants recruited from the UABCLVR to ascertain whether the participant had a central scotoma in one or both eyes and to characterize the scotoma.

*Test of Functional Health Literacy for Adults (TOFHLA).* The TOFHLA (Nurss, Parker, Williams & Baker, 1995) is a standardized measurement of functional health literacy for adults. The test uses real-life examples of health materials to measure comprehension of printed health information. The test has two sections, a numeracy test and a reading comprehension test. The numeracy test addresses understanding of dosage, timing and expiration of medications, results of medical tests, scheduling of medical appointment, and eligibility for financial aid. The reading comprehension addresses understanding of common health materials written at sequentially higher reading grade levels. The passages include instructions for preparing for an X-ray (4.3 grade reading level), a paragraph from the patient's rights and responsibilities section of a Medicaid document (10.4 grade reading level) and a paragraph from a standard hospital informed consent statement for surgery (19.5 grade reading level).

The TOFHLA has been used extensively in research on functional health literacy in older adults (Mancuso, 2009). The study used the long version of the TOFHLA, which was designed for use in research studies (Nurss, Parker, Williams, & Baker, 1995).

Peppercorn Books and Press, Inc., publisher of the TOFHLA, granted a license to reproduce the TOFHLA for the study (Appendix C). The 12-point English version of the test was used. Low vision participants were allowed to use magnifying devices to complete the test.

*MNREAD Acuity Chart 1.* The MNREAD Acuity Chart (University of Minnesota Board of Regents, 1994) is a clinical and research instrument used to measure reading acuity and determine how print size influences reading performance through measurement of maximum reading speed (in words per minute) and critical print size. The chart was designed to simulate a real world reading experience based on extensive research on print size and resolution, typeface properties, text properties, and sentence composition (Legge, 2007). It has been used extensively in low vision reading research (Bowers, Meek, & Stewart, 2001; Bowers, Cheong, & Lovie-Kitchin, 2007; Cacho, Dickinson, Smith, & Harper, 2010; Crossland, Culham, & Rubin, 2005; Fletcher, Schuchard, & Watson, 1999; Lovie-Kitchin, Bowers, & Woods, 2000; Legge, 2007).

Various methods for scoring reading speed and critical print size have been introduced in the literature and there is no one agreed upon method (Patel, Chen, Da Cruz, Rubin, & Tufail, 2011). Recently, Patel et al. presented a simple alternative method for calculating critical print and maximum reading speed (WPM). The investigators examined the test-retest variability of their method on a sample of persons with early and stable AMD and found acceptable coefficients of repeatability. Because the Patel et al. population was similar to the AMD sample in this study, their scoring method was used in this study.

*Mars Letter Contrast Sensitivity Chart.* The Mars chart (Arditi, 2005) is a logarithmic letter chart used to measure peak contrast sensitivity. The chart design was based on the widely used gold standard Peli-Robson contrast sensitivity chart and conforms to the recommendations of the Committee on Vision, U.S. National Academy of Sciences and National Research Council (Arditi, 2005). The chart was selected for this study because research comparing the Mars chart to the Peli-Robson showed that it demonstrated improved precision over the Peli-Robson test from refinement of the contrast values and also had a simplified and more defined scoring procedure (Arditi, 2005; Haymes et al., 2006). The smaller size of the chart compared to the Peli Robson made it easier to ensure that it was fully illuminated and the chart was more durable and portable making it more appropriate than the Peli Robson for testing in the participant's home.

*Leisure Activity Score Questionnaire.* The Leisure Activity Score Questionnaire (Bull, 1982) is a short self-report structured questionnaire used to identify leisure activities completed by community-dwelling older adults. The questionnaire was developed as part of a large population study on leisure patterns in community dwelling healthy older adults (Bull, 1982). The person is asked to rate participation in 12 common leisure activities ranging from sedentary activities like reading and arts and crafts to more strenuous activities such as gardening and travel. To capture individual differences, the person also identifies and rates participation level for up to four additional leisure activities of his or her choosing. The measure was selected for the study because it was developed specifically for older adults and their interests, provided a brief screening that could be administered orally with a sufficient range in activities to capture diverse

interests, and yielded a continuous score to provide an index of activity involvement. The participant's level of involvement in leisure activities on the form was used as a measure of activity level for the study.

*Chart review of microperimetry results.* Microperimetry is a form of fundus perimetry that provides a discrete measurement of scotoma within the central 20 degrees of the visual field (Rohrschneider, 2007). Fundus perimetry images the retina in real time correcting for errors in position and stability. This enables precise imaging of scotoma less than five degrees and microperimetry is considered the gold standard for locating scotoma and fixation within the central field (Barstow & Crossland, 2011). The perimetry testing was completed by one of three optometrists in the UABCLVR. Thirty-three of the participants recruited from the UABCLVR had microperimetry results for each eye. The participants signed a HIPPA waiver to permit review of the microperimetry results. The investigator recorded whether a central scotoma was present in one or both eyes based on documentation by the optometrist. The investigator then measured and recorded the distance in degrees between fixation and the horizontal scotoma border in the eye with the best acuity using a formula described by Timberlake, Sharman, Gobert, and Maino, (2003). This provided a quantitative index of the location of the scotoma within the central field.



Table 1

*Description of Standardized Screening Measures*

Measure	Format/Directions	Scoring	Reliability/Validity
Short Portable Mental Status Questionnaire (Pfeiffer, 1975)	10 questions, self-report format, orally administered.	1 point per item; cutoff for significant cognitive impairment: high school >3 errors; college >2 errors; African-American >4 errors.	Compared against 6 cognitive screenings with correlations between .69-.88. Test-retest reliability of .82-.85 in 3 studies (McDowell, 2006). Sensitivity of 88 to 92% for identification of dementia in older adults of mixed race (Nelson, Fogel, & Faust, 1986).
Geriatric Depression Scale-Short form (Shiekh & Yesavage, 1986)	15 “yes “or “no” questions, self-report, orally administered.	1 point for each negative response. Score: 0-4-non-depressed, 5-10-mild depressive symptoms, 11-15 severe depressive symptoms.	Correlation of .85 with Beck Depression Inventory and comparable sensitivity between 84-92% in studies (McDowell, 2006). Met guidelines as depression measure for older adults, including test-retest reliability >.70; internal consistency, Cronbach $\alpha$ >.70, content, construct and predictive validity (Nelson et al, 2010).
Reading Behavior Inventory (Goodrich, Kirby, Wood, & Peters, 2006)	5 questions, self-report, orally administered	Combination of Likert and ordinal scales. Questions scored separately and not summed.	Reliability and validity studies have not been conducted. One published study (Goodrich, Kirby, Wood, & Peters, 2006).
Early Treatment of Diabetic Retinopathy Study (ETDRS) Visual Acuity Chart (Precision Vision)	70 letters arranged in descending rows, 5 letters per line. Each line .01 logMar < previous row. Last accurately identified letter is recorded.  Participants were tested binocularly wearing habitual correction at 1 meter. Chart was evenly illuminated with	Total number of correctly identified letters was converted into a logMAR value and a Snellen equivalent value using a standardized formula.	Considered a gold standard test of distance acuity and used in multiple studies to establish validity of other acuity charts (Kniestedt, & Stamper, 2003). Chart test-retest variability range of +/- .10 and +/- .18 logMar (Arditi, & Cagenello, 1993; Laidlaw & Murdoch, 2001; Lim, Frost, Powell,

task lighting. Back lighting was not possible; light level was not measured.

& Hewson, 2010).

Table 2

*Description of Standardized Study Measures*

Measure	Format/Directions	Scoring	Reliability/Validity
Test of Functional Health Literacy for Adults (Nurss, Parker, Williams & Baker, 1995)	<p>Scripted directions to ensure uniform administration.</p> <p>Numeracy section has 17 orally administered questions. Participant is given a prompts (<i>e.g.</i> prescription bottles) answers questions about the information contained on the prompt. Examiner records answer.</p> <p>Reading comprehension section consists of 3 sequential passages divided into 32 lines of print and 16 sentences. 1-2 words removed from each sentence and replaced with a blank line. Participant silently reads and chooses the best word to fill in the blank from a list of four options by circling the correct word. 50 word choices are tested.</p> <p>Test was administered with 2 timing conditions: standard time 10 minutes and unlimited time. The test was evenly illuminated; participants used habitual correction or magnifying devices.</p>	<p>Unanswered items counted as errors.</p> <p>Numeracy section: 1 point for each correct answer. Raw score converted to a weighted score 0-50.</p> <p>Reading comprehension section: 1 point for each correct word choice. Score 0-50 points.</p> <p>Numeracy and reading scores summed for composite score of 0-100 points. Composite score can be converted into ordinal scale to provide a health literacy level ranking of inadequate (0-59 points); marginal (60-74), and adequate (75-100).</p> <p>Two scoring methods were used for each section:</p> <ol style="list-style-type: none"> <li>1. Standard time-score recorded for all answered and unanswered items using standard cut off of 10 or 12 minutes.</li> <li>2. Unlimited time- score recorded for all answered and unanswered items when the test was completed.</li> </ol>	<p>Validity studies conducted on large, racially diverse samples from urban hospitals in Atlanta and Los Angeles and included representative samples of adults over age 65 years. Correlation of .82 with REALM of .74 with (WRAT-R). Reliability coefficient of .92 for Equal Length Spearman-Brown and Cronbach <math>\alpha</math> of .98 (Nurss, Parker, Williams, &amp; Baker, 1995).</p>

<p>MNREAD Acuity Chart 1 (University of Minnesota Regents, 1994)</p>	<p>Logarithmic chart contains 19 short (10 word) sentences with 3<sup>rd</sup> grade reading level arraigned in descending order from 1.3 logMAR (8M) to .13 logMar .13M (.13M). Participant reads each sentence aloud beginning at 8M and continues until unable to see the text. Examiner times reading speed on each sentence and records time.</p> <p>2 chart versions (1 and 2) with same format, but different sentences and 2 color formats: black print on a white background and white print on a black background.</p> <p>Chart 1 with white print/black background format was used. Participants were tested binocularly wearing habitual correction for near distances and allowed to hold the chart in their preferred location. Magnifying devices were not used. Chart was evenly illuminated with task lighting; light level was not measured.</p>	<p>Maximum reading speed was calculated as the mean of the 3 fastest reading speeds recorded during the test, and converted into WPM using a standardized conversion chart.</p> <p>Critical print size was calculated as the smallest logMAR print size that supported reading at 90% of the maximum reading speed. The maximum reading speed was multiplied by .9 and the closest chart logMAR CPS and Munit values to the mean reading speed were recorded</p>	<p>Repeatability co-efficient for persons with stable AMD for scoring methods used in the study was .22 log reading speed and .44logMAR critical print size. (Patel, Chen, Cruz, Rubin, &amp; Tufail, 2011).</p>
<p>Mars Letter Contrast Sensitivity chart (Arditi, 2005)</p>	<p>Logarithmic chart of 48 Sloan letters arranged in 8 rows in descending order from 100 -1% contrast value; letters decrease in value by 0.04. Participant reads chart until unable to see letters; the test is concluded after 2 consecutive errors.</p> <p>Participants were tested at 50cm binocularly wearing their habitual correction for near distances. Chart was evenly illuminated</p>	<p>Scored letter by letter. The logContrast score is recorded as the value of the final correct letter minus 0.04 for each incorrectly read letter prior to the two final consecutive errors.</p> <p>The test produces a linear log contrast value between .04 and 1.92. The test is normed for persons over age 60 years. Contrast values can be converted into ordinal scale of normal, moderate, severe</p>	<p>Correlation of .83 with Peli Robson test for normally sighted and persons with AMD (Haymes et al., 2006). Chart test-retest variability range of <math>\pm 0.13</math> logContrast for normal and <math>\pm 0.33</math> for AMD. (Haymes et al., 2006). Coefficient of repeatability of .121 log units for persons with low vision (Thayaparan, Crossland, &amp; Rubin, 2007).</p>

	with task lighting; light level was not measured.	and profoundly impaired contrast sensitivity levels.	
Leisure Activity Score Questionnaire (Bull, 1982)	Orally administered Likert self-report format. Participants rate their level of participation in 12 leisure activities responding “often,” “sometimes,” or “never.” Examiner probes for 4 additional activities of the person’s choosing and participant rates those activities.	Ratings of “often” and “sometimes” are scored as 1 and “never” scored as 0 to provide an index of participation between 0 and 16.	The questionnaire was administered to 1200 older adults 2 times over a 2-year period (Bull 1982). Reliability data was not published.

### Study Procedures

The primary investigator completed all recruitment, data collection, and analysis. The study was conducted either in the participant’s residence or workplace, a private room in the UABCLVR or a private room in the UAB School of Health Professions building. Data were collected during one 60 to 90 minute session in a quiet, distraction-free environment. Additional task lighting was provided as needed to ensure that test materials were adequately illuminated. Frequent rest breaks were offered during the session to minimize the participant’s discomfort and fatigue.

Screening measures were administered in following order using the standardized instructions for each measure found in Table 1: social/medical history questionnaire, SPMSQ, GDS-SF, RBI, and visual acuity. Each assessment took approximately 5 minutes to complete.

The study assessments were administered in the following order using the standardized instructions described in Table 2: MARS Letter Contrast Sensitivity chart, MNread Acuity chart 1, Leisure Participant Activity Questionnaire, and TOFHLA. All assessments took 5 to 10 minutes to complete with the exception of the TOFHLA, which required up to an hour for a few participants. The TOFHLA was administered in two parts with a rest break in between sections. The numeracy section was administered first followed by the reading comprehension section.

#### *Modification of TOFHLA Scoring Procedures*

Extensive research on readers with AMD found that they read significantly slower than normally sighted adults (Cacho, Dickinson, Smith, & Harper, 2010; Cheong, Legge, Lawrence, Cheung, & Ruff, 2007; Falkenberg, Rubin, & Bex, 2007; Legge, 2007; Fletcher, Schuchard, & Watson, 1999). Standard TOFHLA procedures required stopping the test at 10 minutes for the numeracy section and at 12 minutes for the reading comprehension section. Questions left unanswered when the stop time was reached are counted as errors. This procedure had the potential to significantly inflate the number of errors committed by the low vision participants who read more slowly because of AMD but not necessarily provide an accurate depiction of their reading comprehension. Therefore, the timing procedure for the TOFHLA was modified to accommodate the effect of slow reading on test performance and permit examination of the influence of slow reading on test performance. Participants in both groups were permitted to take as much time as needed to complete both sections of the test and two scores were recorded:

the score based on the test item number the participant was on when the standard time minutes lapsed (T-standard score) and the score when the participant was permitted to answer all test questions (T-unlimited score). Two times (in minutes) were also recorded: the time the participant required to complete the test under the standard timing conditions (standard time) and the time the participant required to complete all test items (unlimited time). For participants who were able to complete the test within the standard allotted time, the scores and the time matched each other on the two timing conditions. For participants who required additional time to complete the test, the score and times did not match between the two timing conditions.

#### Statistical Plan for Data Analysis

The study represented a new area of inquiry, and the expected effect size was unknown because no previous research had been conducted. A sample size of 50 in each group enabled detection of a moderate effect size of 0.5 with a power of 0.8 on an independent samples *t*-test with equal samples (Portney & Watkins, 2004, p. 845). For correlations, a sample size of 50 in each group enabled detection of a .5 effect size with a power of .93 (Portney & Watkins, 2004, p. 850). SPSS PASW Statistics version 19 was used to complete the statistical analyses. A significance level of .05 was set for analysis. Table 3 provides a description of the variables, study measures and statistical tests used to establish sample equivalency and answer the research questions for the study.

Table 3

*Statistical Analysis Summary*

Variables	Measure	Statistical Test
Sample Demographics and Sample Equivalency Analyses		
Categorical and continuous demographic variables	Social/Medical History Questionnaire	Chi-square test of independence between groups.
		Descriptive statistics: number and percentage of each variable per group.
	Leisure Activity Questionnaire 16 items	Independent sample <i>t</i> -tests between groups.
Research Question 1		
Vision-Related Variables		
LogMar visual acuity	EDTRS Acuity Chart	Independent sample <i>t</i> -tests between groups
LogContrast	Mars Letter Contrast Chart	
LogCPS	MNread Acuity Test Chart	
Reading Speed		Descriptive statistics: number/percentages of each variables per group
Scotoma (low vision only)	Microperimetry print out	
Reading-Related Variables		
Number of items read	RBI Q1: 1-8 items	Independent sample <i>t</i> -test between groups
Reading difficulty	RBI Q2: 5 item Likert scale, collapsed to 2 items to ensure adequate cell count	Chi-square test of independence between groups
Reading frequency (time spent reading daily)	RBI Q3:10 item ordinal scale: collapsed to 3 items to ensure adequate cell count	
Reading satisfaction	RBI Q4: 5 item Likert scale collapsed to 2 items to ensure adequate cell count	
Research Question 2		
Differences in TOFHLA scores (composite and individual sections) for the two time conditions.	TOFHLA scores for low vision and control groups for standard time and unlimited time conditions	Independent samples <i>t</i> -test between groups
Differences in TOFHLA times (composite and individual sections) for the two time conditions.	TOFHLA times for low vision and control groups for standard time and unlimited time conditions	Independent samples <i>t</i> -test between groups

Differences in TOFHLA scores based on time condition	TOFHLA scores for standard and unlimited time conditions for low vision and control groups	Dependent samples <i>t</i> -tests  Descriptive statistics: number/percentage of TOFHLA health literacy level by group  Wilcoxin Signed Ranks test of difference in health literacy level by time condition
<i>Research Question 3</i>		
TOFHLA composite scores LogMar acuity Reading speed	TOFHLA ETDRS acuity chart MNread acuity chart 1	Pearson correlations Partial correlation
LogContrast LogCPS Scotoma	MARS chart MNread acuity chart 1 Microperimetry results	Spearman Rank correlations
<i>Research Question 4</i>		
TOFHLA composite scores Age Gender Activity Level	TOFHLA  Social/Medical history questionnaire Leisure Activity Questionnaire Index	Spearman Rank correlations
Education Occupation Reading frequency	Social/Medical history questionnaire RBI Q3 10 item ordinal scale: collapsed to 3 items for analysis	One way ANOVA



## CHAPTER 4

### RESULTS

The aim of this study was to investigate whether older adults with low vision from AMD experienced lower functional health literacy levels than older adults with normal eyesight as measured by the TOFHLA. A sample of 50 older adults with AMD was compared to a group of 50 older adults without low vision. The two groups were matched on variables that were associated with reading performance in older adults including age, gender and education level. Other variables associated with reading performance were controlled through inclusion criteria that included a minimum level of high school education and \$20,000 annual income, English as the primary language, absence of dementia and minimal risk for depression. The TOHFLA was administered to both groups under two timing conditions (a) using the standard cut off time specified by the test manual and (b) allowing unlimited time to complete the test. A second aim of the study was to explore the associations among vision-related variables in the low vision group and test performance and the associations among reading related variables and test performance in the entire sample to gain a better understanding of the relationship of these variables to participant performance on the TOFHLA.

This chapter presents the results of the study data analyses. Screening and recruitment is discussed first, followed by a description of the sample demographics and baseline equivalency analyses between the two groups. Next analyses addressing the

specific research questions are presented in the following order: (1) differences between the two groups in vision-related and reading performance variables to address research question one; (2) differences in TOHFLA scores between the groups to address research question two; (3) correlations among the vision-related variables and TOHFLA scores to address research question three and (4) correlations and comparison of means on reading performance variables and TOHFLA scores to address research question four.

The analyses tested four primary null hypotheses and alternative hypothesis:

1. *Null hypothesis*. There is no difference between the low vision and control groups on vision-related variables (acuity, contrast sensitivity, reading speed and critical print size) and on reading related variables (number of items typically read, perceived reading difficulty and satisfaction and time spent reading. *Alternative hypothesis*: Older adults with low vision will demonstrate greater impairment on one or more vision related or reading performance variables compared to older adults with normal vision

2. *Null hypothesis*: There is no difference between TOFHLA scores of older adults with low vision and without low vision. *Alternative hypothesis*: Older adults with low vision demonstrate lower TOFHLA scores than older adults with normal vision.

3. *Null hypothesis*: There are no associations among vision-related variables including acuity, contrast sensitivity, reading speed, critical print size and scotoma in older adults with low vision and TOFHLA scores. *Alternative hypothesis*: One or more vision and/or reading related variables are associated with lower TOFHLA scores in older adults with low vision.

4. *Null hypothesis:* There are no associations among the reading performance variables including age, gender, education level, occupation, activity level, and reading frequency and the standard composite TOHFLA score in the sample. *Alternative hypothesis:* Higher standard composite scores on the TOFHLA in both groups are associated with younger age, female gender, higher education level, professional level occupation, and higher activity level and greater time spent reading in the sample

### Recruitment and Screening

One hundred and two participants were recruited for the study and tested between January and August 2011. After consenting to participate in the study, two male participants did not meet the screening criteria established for the study. One male participant in the low vision group did not meet the criteria for acuity following a recent significant vision loss and the other participant in the control group did not meet the criteria for dementia. The remaining 100 participants, 50 low vision and 50 controls, completed the study.

### Sample Demographics

The demographic characteristics of the low vision and control groups are shown in Tables 4 and 5. The participants ranged in age between 65 and 94 years with a mean age of 81 years. All but two participants were Caucasian. Women comprised 70% of the sample, which was consistent with the typical gender distribution for older adults with

macular degeneration (Javitt, Zhou, Maguire, Fine & Willke, 2003). Most of the participants were widowed however, women outnumbered men in this category. Nearly two-thirds of the female participants were widowed compared to 20% of male participants. Most of the participants lived in their own homes with slightly more participants in the low vision group living in their home. Nearly two-thirds of the women in the sample lived alone compared to one-third of the men. Most participants had some college or a college degree. Among those who had careers outside the home, the majority had worked in skilled or professional occupations, and half of the participants had been retired for over 15 years. Most of the female participants who provided unskilled labor were homemakers. The participants reported an average of three co-morbidities and consumed an average of seven medications on a daily basis. Most participants independently completed three reading-dependent self-management tasks dependent needed to maintain their health. They reported engaging in an average of nine leisure activities on a regular basis. Most had average incomes above \$40,000 per year.

Table 4

*Demographics and Equivalency Analyses for Categorical Variables*

Characteristic	Low Vision (N = 50)		Control (N=50)		Test Statistic
	Number (Frequency %)				p
<i>Gender</i>					1.0
Male	15	(30)	15	(30)	
Female	35	(70)	35	(70)	
<i>Marital Status</i>					.62
Married	20	(40)	18	(36)	
Widowed	26	(52)	25	(50)	
Single	4	(8)	7	(14)	
<i>Living Arrangement</i>					.07
Own home	37	(74)	31	(62)	
Residential facility	9	(18)	18	(36)	
With family	4	(8)	1	(2)	
<i>Education</i>					1.0
High school	15	(30)	15	(30)	
Some college	13	(26)	13	(26)	
College degree	22	(44)	22	(44)	
<i>Occupation</i>					.58
Professional	22	(44)	17	(34)	
Skilled	13	(26)	16	(32)	
Non-skilled	30	(15)	17	(34)	
<i>Average Income</i>					.16
\$20-39,999	23	(46)	21	(42)	
\$40-50,000	10	(20)	18	(36)	
> \$50,000	17	(34)	11	(22)	
<i>Retirement Years</i>					.63
0/active retirement	12	(24)	12	(24)	
1-15 years	11	(22)	15	(30)	
> 15 years	27	(54)	23	(46)	
<i>Co-morbidities</i>					

Arthritis	33	(66)	34	(68)	.83
Cardiovascular	31	(62)	31	(62)	1.0
High blood pressure	29	(58)	33	(66)	.41
Hearing	12	(24)	19	(38)	.13
Diabetes	9	(16)	7	(14)	.78
Lung	8	(18)	6	(12)	.40
Kidney/digestive	12	(24)	9	(18)	.46
IOL for cataract	45	(86)	32	(64)	<b>.01</b>
<i>Self-manage tasks</i>					
Medications					.23
Yes	43	(90)	49	(98)	
No	5	(10)	2	(2)	
Medical appointment					.09
Yes	45	(90)	49	(98)	
No	5	(10)	1	(2)	
Medical statements					<b>.006</b>
Yes	43	(86)	50	(100)	
No	7	(14)	0	(0)	

*Note.* IOL = intra ocular lens replacement. Self manage = completion of self-management tasks to maintain health. Medical appoint = setting doctor's appointments. Statistically significant results are shown in boldface

Table 5

*Demographics and Equivalency Analyses for Continuous Variables*

Characteristic	Low Vision (N = 50)			Control (N = 50)			p
	M	Range	SD	M	Range	SD	
Age (in years)	81.9	65-94	6.09	80.6	65-91	5.6	.27
# co-morbidities	2.7	0-5	1.24	2.7	0-5	1.24	.87
# prescribed medications	5.6	0-16	3.41	5.2	1-19	3.58	.59
# leisure activities	9.2	4-13	2.3	9.7	4-14	2.6	.27

*Note.* # = number

### Sample Equivalencies for Demographic Variables

Chi-square analysis was used to test the equivalency of the low vision and control groups along the categorical demographic variables and *t*-tests were used to compare scale variables to ensure that the two groups were matched for variables that might be associated with reading performance. All of the categorical variables had five or greater respondents in each cell. These variables included gender, marital status, living arrangement, education level, income, occupation, years in retirement, types of co-morbidities, whether cataract extraction with intraocular lens replacement had been completed and completion of three reading dependent self-management tasks. The assumptions for independent *t*-tests including homogeneity were met for comparison between the groups on age and number of co-morbidities, medications and leisure activities.

The *p* values for the Chi-square analyses presented in Table 4 showed that there were no statistically significant differences between the groups on all of the categorical variables except prevalence of IOL replacement for cataract and independent completion of the self-management task of reading medical statements. Participants with low vision reported a higher prevalence of intra ocular lens (IOL) replacement surgery for cataracts,  $\chi^2(2) = 6.453, p = .01, \Phi = .299$ , compared to the control group. The higher prevalence within the low vision group may have been due to research showing the potential benefit of this surgery in improving acuity for persons with AMD (Hooper et al., 2009). Participants with low vision also relied more on others to review and manage medical statements,  $\chi^2(1) = 7.527, p = .006, \Phi = .274$ . The increased reliance on others among low vision participants may have reflected their difficulty in completing the amount of

reading required to review medical documents; however, the phi coefficient suggested a relatively weak association.

In summary, there were no significant differences between the low vision and control groups on variables associated with reading performance in older adults: age, gender, marital status, living arrangement, income, education, occupation, years in retirement, number of co-morbidities, number of prescribed medications, and leisure participation. More low vision participants reported having intra-lens replacement for cataract and reported that they required help to read medical documents than the control group.

#### Differences in Vision-Related and Reading-Related Variables

Research Question One asked whether the two groups differed on vision-related variables (acuity, contrast sensitivity, reading speed, critical print size) and reading-related variables (number of items typically read, perceived reading difficulty and satisfaction and time spent reading). Tests of equivalency were used to answer the question and found in Table 6. *T*-tests were used on scale variables including the vision-related variables and reading items. Chi-square analyses were used for categorical variables including time spent reading and perceived reading difficulty and satisfaction. Categories were collapsed for reading difficulty and satisfaction and the variables recoded into dichotomous categories of “difficult” and “no difficulty” and “satisfied” and “dissatisfied” to obtain cells with larger respondents within the low vision group. The assumptions for independent *t*-tests were met for comparison between the groups with the



exception of homogeneity for acuity, contrast (LogContrast), critical print size (LogCPS) and reading speed (WPM). Levene's correction for unequal variance was applied to the *t*-tests conducted on these variables.

Table 6

*Equivalency Analyses for Vision-Related and Reading-Related Variables*

Variable	Low Vision (N=50)		Control (N=50)		Test Statistic		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	95% <i>CI</i>
Acuity	.69	.20	.06	.05	21.9 <sup>a</sup>	<.001	[.57, .69]
LogContrast	.91	.25	1.5	.13	15.3 <sup>a</sup>	<.001	[.52, .68]
LogCPS	.89	.29	.65	.17	5.3 <sup>a</sup>	<.001	[.16, .34]
WPM	173	66.4	258	40.4	7.75 <sup>a</sup>	<.001	[63, 107]
Scotoma	1.26	1.16	-	-	-	-	-
# Items read	6.1	1.4	7.4	.85	5.2 <sup>a</sup>	<.001	[.75, 1.7]
		Number (%)		Number (%)		<i>p</i>	
Read time						.01	
20-50 mins		14	(28)	4	(8)		
1-2 hrs		9	(18)	6	(12)		
> 2hrs		27	(54)	40	(80)		
Difficulty						<.001	
Not difficult		4	(8)	50	(100)		
Difficult		46	(92)	0	(0)		
Satisfaction						<.001	
Satisfied		15	(30)	50	(0)		
Dissatisfied		35	(70)	0	(100)		

*Note.* Scotoma is measured in degrees from fixation. LogCSF = contrast sensitivity. LogCPS = critical print size. WPM = words per minute. # = number. Read time = time spent reading. Mins = minutes.

<sup>a</sup>denotes Levene's correction for unequal variances

The difference between two groups in categorical levels of vision impairment was calculated to provide a more clinically relevant description. These findings are displayed as prevalence data (numbers and percentages) in Table 7. The impairment levels for acuity were based on Medicare guidelines for classifying visual impairment based on distance acuity (CMS, 2002); the levels for contrast sensitivity were based on categories developed from research on the MARS Contrast Sensitivity Chart (Arditi, 2005). Participant reading speeds obtained from the MNread acuity test were recoded to create a dichotomous ordinal variable based on Legge, Ross, Isenberg, and LaMay (1992) who reported a reading rate range of 169 to 273 words per minute (wpm) for normally sighted adults. Participants were classified as having either “low” reading rates (less than 169 wpm) or “normal” rates (169 or greater wpm). The Munit levels for critical print size were based on categories developed by the American Printing House for the Blind (Kitchel, n.d.). Scotoma categories were based on criteria described in Chapter 3.

Table 7

*Impairment Levels of Vision-Related Variables*

	Low Vision (N=50)		Control (N=50)	
Variable	Number (Frequency %)		Number (Frequency %)	
Visual Impairment (acuity)				
Normal	0	(0)	50	(100)
Moderate	48	(96)	0	(0)
Severe	2	(2)	0	(0)

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Contrast Sensitivity				
Impairment	0	(0)	26	(52)
Normal	17	(34)	24	(48)
Moderate	30	(60)	0	(0)
Severe	3	(6)	0	(0)
Profound				
Reading Speed				
Slow (0-168 wpm)	24	(48)	0	(0)
Normal (169-300 wpm)	26	(52)	50	(100)
Critical Print Size				
Normal .13-1.0M	8	(16)	31	(62)
Large print 1.3-2.5M	17	(34)	19	(38)
Extra Large Print 3.2-8M	25	(50)	0	(0)
Scotoma				
No scotoma either eye	0	(0)	50	(100)
1 eye	2	(6)		
2 eyes	31	(94)		

---

*Note.* wpm = words per minute.

### *Vision-Related Variables*

Statistically significant differences were found between the groups on all of the variables. Participants in the low vision group had significantly lower distance acuity, contrast sensitivity, critical print size and reading speed. As shown in Table 7, all but two low vision participants had moderate level visual impairment (Snellen acuities between 20/80 and 20/100) compared to normal Snellen acuities between 20/20 to 20/25 within the control group. Two low vision participants had acuities in the severe impairment range (20/200 and 20/400 Snellen acuity respectively). All of the participants in the control group had contrast sensitivities at normal or moderate impairment levels compared to a majority of low vision participants who were classified as severe-profound

impairment. Nearly half of the low vision participants were classified as having low reading speeds whereas all of the control participants had a normal reading speed. The low vision group also had a larger range of reading speeds (27-300 wpm) compared to narrower range for the control group (182-353 wpm) and five low vision participants had reading rates under 75 wpm. One-half of the low vision group had critical print sizes in the extra large print range and only 16% had a normal CPS. In contrast, nearly two-thirds of the control group had a CPS within the normal range. Presence and distance of the scotoma border from fixation in eye with better acuity was measured only for low vision participants. As shown in Table 6, an average of 1.3 degrees between fixation and scotoma border was found with a range of 0 (no scotoma) to 6.3 degrees in the better eye. Ninety-four percent of the sample had scotoma in both eyes.

### *Reading-Related Variables*

Reading-related variables were measured using the Reading Behavior Inventory and the results are reported in Table 6. Participants were asked to identify whether they regularly read eight common types of reading materials. The items included letters, bills, magazines, newspapers, medicine labels, recipes, novels, and package instructions. Participants in the control group read significantly more types of reading materials than the low vision participants. Eighty percent of the control group reported reading an average of more than two hours a day compared to just over one-half of the participants in the low vision group. Participants in the low vision group reported greater difficulty and less satisfaction with their ability to read compared to the control group who reported

no difficulty or dissatisfaction with reading ability. In addition, two-thirds of the low vision participants used an optical device to read and 30% used extra task lighting. Only four low vision participants were able to read using typical lighting alone whereas all of the participants in the control group relied on typical lighting.

In summary, low vision participants had significantly lower acuity, contrast sensitivity function and reading speed as well as higher critical print size than the control group. The low vision group reported significantly lower reading frequency, read fewer items, and reported more difficulty and less satisfaction with reading than the control group.

#### *Differences in TOFHLA Scores*

To answer Research Question Two regarding whether a difference existed between the two groups on the TOFHA, *t*-tests were conducted on the composite scores and section scores of the TOHFLA for the two timing conditions: standard time (reading-12 minutes; numeracy-10 minutes) and unlimited time where the participant was allowed as much time as needed to complete the test as shown in Table 8. Visual inspection of the distribution of scores showed skewing of the data for test scores and time under both timing conditions. The sample showed a positive skewing towards higher TOFHLA scores and longer times. A Shapiro-Wilk test of normality showed statistically significant skewing of the distribution for the composite and section scores under both timing conditions. However, this test has been acknowledged to produce conservative values and *t*-tests and ANOVA have been considered robust enough to withstand some violation of

normality in the data if the sample sizes were equal and of sufficient size (Green & Salkind, 2011; Tabachnick & Fidel, 2007). In addition, a comparison of means, trimmed means, and medians for the composite scores and reading and numeracy section scores for the two timing conditions showed a difference of only 0.5 - 3 points except on the composite score under the standard timing condition. A difference of six points was found for the composite score on standard timing but with a skewing of only -.562, which was considered sufficient to allow for quantitative analysis of the data (Green & Salkind, 2011). A significance level of .05 was set for analysis.

Table 8

*Differences in TOHFLA Scores for Standard and Unlimited Time Conditions*

	Low Vision (N=50)		Control (N=50)		Test Statistic		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	<i>95% CI</i>
TOHFLA Score							
<i>Composite</i>							
Standard	77.9	16.3	93.2	7.2	6.12 <sup>a</sup>	<.001	[10.3, 20.2]
Unlimited	91.3	6.5	94.7	5.2	2.89	.005	[1.07, 5.8]
<i>Reading Comp</i>							
Standard	32.9	12.3	46.4	4.9	7.19 <sup>a</sup>	<.001	[9.7, 17.2]
	45.2	4.0	47.8	2.8	3.69 <sup>a</sup>	<.001	[1.2, 3.9]
Unlimited							
<i>Numeracy</i>							
Standard	44.1	8.02	46.8	3.9	2.14 <sup>a</sup>	.036	[-.19, 5.2]
Unlimited	45.4	6.01	46.9	3.8	1.27	.207	[-.72, 3.3]

*Note:* Reading Comp = reading comprehension section. Standard = standard timing condition. Unlimited = unlimited time to complete the test.

<sup>a</sup> denotes Levene's correction for unequal variances.

A significant difference was found between the composite scores of low vision and control group on the test for both timing conditions. Participants with low vision had composite scores that were significantly lower on the TOFHLA than the control group under the standard timing condition and when given unlimited time to complete the test. To determine if the differences between the two groups might be due to much poorer performance on either the reading comprehension or numeracy section, *t*-tests were conducted to test differences between the groups on each section under the two timing conditions. On the reading comprehension section of the test, low vision participants had significantly lower scores than the control group on both timing conditions. However, on the numeracy section of the test, low vision participants scored significantly lower than controls on the standard timing condition but there was no significant difference in the scores when participants were given unlimited time to complete the test.

Because the results of the *t*-tests on differences in score indicated that time may be a factor in test performance, *t*-tests were completed to test the differences between the two groups on the time required for completion of the test under the two timing conditions. The results of the *t*-tests found in Table 9 showed that low vision participants took significantly more time than the control group to complete the test on the standard and unlimited timing conditions for the composite test and individual sections.

Table 9

*Differences in Time Needed to Complete the TOFHLA*

	Low Vision (N=50)		Control (N=50)		Test Statistic		
TOFHLA time	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>	<i>p</i>	95% <i>CI</i>
<i>Composite</i>							
Standard	19.1	2.6	15.02	3.4	6.78 <sup>a</sup>	<.001	[2.9, 5.3]
Unlimited	26.8	10.4	15.7	4.7	6.89 <sup>a</sup>	<.001	[7.9, 14.4]
<i>Reading</i>							
<i>Comp</i>							
Standard	11.5	1.3	9.24	2.3	6.03 <sup>a</sup>	<.001	[1.5, 2.97]
Unlimited	18.5	7.9	9.86	3.6	7.02 <sup>a</sup>	<.001	[6.2, 11.2]
<i>Numeracy</i>							
Standard	7.48	1.7	5.74	1.5	5.49	<.001	[1.1, 2.4]
Unlimited	8.32	3.5	5.78	1.5	4.73 <sup>a</sup>	<.001	[1.5, 3.6]

*Note:* TOFHLA time is reported in minutes. Standard = standard time condition.

Unlimited = unlimited time condition.

<sup>a</sup> denotes Levene's correction for unequal variances.

To investigate whether the additional time provided in the unlimited timing condition improved test scores overall for each group, paired *t*-tests were conducted to examine the difference in scores on the composite test between the two timing conditions. A statistically significant improvement in the composite scores was found for the low vision group,  $t(49) = 6.45$ ,  $p = <.001$  with the unlimited timing condition. Scores also improved for the control group with extra time,  $t(49) = 2.2$ ,  $p = .03$ . A cross tabulation analysis of the number and percentages of participants classified as having adequate, marginal, or inadequate health literacy levels displayed in Table 10 showed that the unlimited timing condition also improved the classification levels for health literacy in the participants in the low vision group. On the standard timing condition, 30 (60%) of



the low vision participants were classified as having adequate health literacy skills, 14 (28%) as marginal, and 6 (12%) as inadequate based on their composite score. Under the unlimited timing condition, 49 (98%) of the low vision participants were classified as having adequate health literacy and one (2%) as having marginal health literacy. A Wilcoxin Signed Ranks test of the difference in the health literacy levels between the two timing conditions showed a statistically significant increase in the participants' health literacy ranking,  $z = -4.13$ ,  $p = <.001$ . No difference was found in health literacy level for the control group between the two timing conditions.

Table 10

*Health Literacy Levels for Standard and Unlimited Time Conditions*

	Low Vision (N=50)		Control (N=50)	
Health Literacy Level	Number (Frequency %)		Number (Frequency %)	
Standard Timing				
Adequate	30	(60)	48	(96)
Marginal	14	(26)	2	(4)
Inadequate	6	(12)	0	(0)
Unlimited Timing				
Adequate	49	(98)	50	(100)
Marginal	1	(2)	0	(0)
Inadequate	0	(0)	0	(0)

In summary, the low vision group scored significantly lower on the TOFHLA for the standard time and unlimited time conditions compared to the control group. The low vision participants took significantly longer to complete the TOFHLA than the control

group. Both groups showed statistically significantly higher scores on the unlimited time condition but the scores in the low vision group increased an average of 13 points on this condition compared to an average increase of 1.5 points for the control group. The low vision group also improved significantly in health literacy level with unlimited time to complete the test.

#### Associations Among Vision-Related Variables and TOFHLA Scores in Low Vision Group

To answer Research Question Three, whether vision-related variable were associated with TOFHLA scores in the low vision group, scatterplots were used to examine the linearity for each the five vision-related variables--acuity, contrast sensitivity, reading speed, critical print size, scotoma--and composite TOFHLA scores for the standard and unlimited timing conditions. The sample size was 50 for all variables except scotoma, which had a sample size of 33. Visual inspection of the scatterplots showed acceptable linearity for acuity and reading speed (WPM) permitting interpretation of a Pearson correlation for both timing conditions. Values for contrast (LogCSF), critical print size (LogCPS), and scotoma clustered toward one side of the regression line, and were not linear. Variables that divided contrast, critical print size and scotoma into ordinal rankings were used to calculate Spearman Rank correlations and examine the associations among these variables and TOHFLA scores for the two timing conditions and are shown Table 11.

Table 11

*Bivariate Correlations Among Vision-Related Variables and TOFHLA Scores for the Low Vision Group (N=50)*

TOFHLA score	Acuity	WPM	Critical Print Size	Contrast Sensitivity	Scotoma <sup>a</sup>
Standard time	-.55***	.61***	-.40**	—	—
Unlimited time	-.45**	—	—		

*Note:* WPM = words per minute

<sup>a</sup>  $n = 33$

\*\*  $p < .01$

\*\*\*  $p < .001$

The results of the analysis showed statistically significant associations among acuity, reading speed, and TOFHLA score for the standard time condition. Lower acuity was associated with lower test scores on the standard time condition. Higher reading speed was associated with higher test scores on the standard time condition. A statistically significant negative correlation was also found for critical print size where larger critical print size was associated with lower test scores. Non-significant associations were found among contrast sensitivity, scotoma, and TOFHLA score for the standard time condition. On the unlimited timing condition, a statistically significant negative correlation was found only for acuity and TOFHLA score. Lower acuity was associated with lower TOFHLA scores.

The statistically significant linear correlations among acuity, reading speed and TOFHLA scores permitted completion of partial correlation to clarify the relationship

between these variables and the TOFHLA score on the standard time condition. When acuity was held constant, the correlation between the TOFHLA composite score and reading speed remained statistically significant,  $r = .45, p = .001$ . When reading speed was held constant the correlation between TOFHLA and acuity remained significant.  $r = -.34, p = .017$ . These findings indicated that both variables contributed to the TOFHLA score under the standard timing condition.

In summary, significant associations were found in the low vision group among TOFHLA scores and acuity, reading speed and critical print size for the standard time condition. Lower acuity and lower reading speed were associated with lower test scores. Higher critical print was associated with lower test scores. Acuity and reading speed both contributed to TOFHLA scores. On the unlimited time condition, only acuity was significantly correlated with test scores: lower acuity was associated with lower test scores.

#### Associations Among Reading Performance Variables and TOFHLA Scores

Research Question Four asked whether variables shown in research to be associated with reading performance in older adults were associated with or related to the composite TOHFLA scores under the standard timing condition for the total sample. The variables, from Figure 2 in Chapter 2, included intrinsic variables--age, gender, reading frequency (e.g. time spent reading daily)--and extrinsic variables, education, occupation, and activity level. One-way analyses of variance (ANOVA) were conducted to determine whether TOHFLA scores varied by education, occupation and reading frequency (Tables

12 and 13). The assumptions for independence were met for conducting the analysis.

Descriptive statistics for the variables are shown in Table 11. Correlations were calculated to examine the associations among age, gender, activity and TOFHLA scores

Table 12

*Descriptive Statistics: TOHLA scores for Education, Occupation and Reading Frequency*

Variables	Descriptive Statistics			
<i>N</i> = 100	<i>n</i>	<i>M</i>	<i>SD</i>	<i>SEM</i>
Education				
High school	30	82.4	15.46	2.82
Some college	26	85.5	15.09	2.96
College	44	87.8	13.62	2.06
Occupation				
Non-skilled/Homemaker	32	81.87	15.32	2.71
Skilled	29	89.23	13.31	2.47
Professional	39	85.92	14.55	2.33
Reading Frequency (daily)				
> 2 hours	67	88.34	12.64	1.54
1-2 hours	15	88.8	12.18	3.15
20-50 minutes	18	72.56	16.75	3.95

Table 13

*One-Way ANOVA of Reading Performance Variables and TOFHLA Scores*

<i>N</i> = 100	<i>Source</i>	<i>SS</i>	<i>df</i>	<i>MS</i>	<i>F</i>	<i>p</i>	$\eta^2$
Education	Between groups	534.685	2	267.343	1.259	.288	
Occupation	Between groups	839.938	2	419.969	2.008	.140	
Reading Frequency	Between groups	3737.245	2	1868.623	<b>10.423</b>	<.001	.177

*Note:* Statistically significant results are in boldface.

A Levene's test of equality of error variances was conducted for each ANOVA. The alpha level was not significant indicating that the error of variance was equal across groups for all analyses. F values for education and occupation were not statistically significant indicating that there was no relationship between TOFHLA scores and these variables. The F value for reading frequency was statistically significant indicating that TOHFLA scores changed depending on the amount of time spent reading on a daily basis. The strength of the relationship indicated by the  $\eta^2$  value showed that reading frequency accounted for approximately 18% of the variance in the TOHFLA scores. A post hoc analysis was conducted to examine the interaction between time and score. The Tukey HSD was used for the analysis because there were uneven sample sizes between the three reading frequency levels and it was considered to provide good protection against Type I error (Portney & Watkins, 2009, p. 483). The results of the Tukey HSD showed that participants who read less than 1 hour daily had lower mean scores than those who read either 1 to 2 hours or more than 2 hours daily.

Visual inspection of the scatterplots for age, activity level and TOFHLA score showed nonlinear relationships among the variables precluding interpretation of a Pearson correlation. Therefore Spearman Rank correlations were calculated to examine the associations among these variables, gender and TOFHLA score. A weak but statistically significant positive association was found for activity level and TOHFLA score,  $r_s = .29, p = .003$ . Participants who were more active had higher scores on the TOFHLA. No associations were found among age, gender and TOFHLA score.

In summary, reading frequency was related to TOFHLA scores in the sample as whole. Participants who read between 20 to 50 minutes daily had lower TOFHLA scores

than those who read one or more hours each day. Activity was also statistically associated with TOFHLA scores. Participants who reported higher activity levels also had higher test scores.

## CHAPTER 5

### KEY FINDINGS, DISCUSSION AND RECOMMENDATIONS

The purpose of this study was to investigate whether older adults with low vision from age-related macular degeneration (AMD) experienced lower functional health literacy levels than normally sighted older adults as measured by the Test of Functional Health Literacy for Adults (TOFHLA). The investigation addressed a gap in the literature by examining the potential relationship between low vision and lower health literacy levels in older adults. Although extensive research had examined health literacy levels in older adults, persons with low vision were excluded from much of this research because of their lower acuity. No studies had been completed that specifically examined functional health literacy levels in visually impaired older adults who were still capable of reading printed materials using magnifying devices. As a result, there was no research evidence on whether low vision added an additional barrier to proficiency in health literacy beyond factors associated with aging.

Functional health literacy is the ability to read and understand printed health information and complete simple math calculations. It is a sub-category of general adult literacy and the variables that influence literacy levels also influence functional health literacy levels. These variables include educational attainment, primary language, race and culture, and reading performance. Persons with less education, who are minorities, and whose primary language is not English demonstrate lower functional health literacy



levels as measured by standardized functional health literacy tests. Older adults also demonstrate lower health literacy levels than other age groups. Besides the variables associated with reading performance for all age groups, older adults may also experience age-related decline in reading performance. The resulting combination of variables may contribute to the lower levels of functional health literacy observed in older adults.

Research has shown that adequate levels of functional health literacy are critical to the older adult's ability to safely consume medications, follow medical instructions to manage chronic diseases, and navigate the health care system (Nielsen-Bohlman, Panzer & Kindig, 2004). Low vision has been shown to reduce reading speed and accuracy and increase the amount of effort required to complete reading tasks (Legge, 2007). Difficulty acquiring health information from printed sources may lessen the visually impaired older adult's ability to manage eye disease and other chronic diseases and potentially increase activity limitations, vision loss, and morbidity. The limited research that has been conducted on adults with low vision has found associations among low health literacy and poorer vision outcomes (Muir et al., 2006; Schillinger et al., 2002).

Four hypotheses were tested in the study: (a) that participants with low vision would differ significantly from normally sighted participants in vision-related variables that influence reading performance, including acuity, contrast sensitivity, critical print size, reading speed and central field scotoma and in reading related variables including the number of printed items typically read, the amount of time spent reading daily and perception of reading difficulty and reading satisfaction (b) that community-dwelling older adults with low vision from AMD would score lower on the TOFHLA compared to community-dwelling adults with normal sight, (c) that at least some of the vision-related

would be associated with TOFHLA scores in the low vision group, and (d) that at least some non-vision-related variables associated with reading performance in older adults would also be associated with test performance for all participants. To test the hypotheses, the TOFHLA, and vision and reading measures were administered to a group of older adults with low vision from AMD and a control group of normally sighted older adults. The two groups were closely matched on some non-vision variables that might influence reading performance including age, gender and education. Inclusion criteria were set to control for other variables including minimum educational attainment and income, English proficiency, reading frequency and risk for dementia and depression. All of the participants were community dwelling and responsible for self-management of their chronic medical conditions. Two sets of scores were recorded on the TOFHLA (a) the score received on the standard timing condition where the test was stopped at a pre-set time and unanswered test items were scored as errors, and (b) the score on the untimed condition where participants were given as much time as needed to answer all test items. Differences between the groups on the TOHFLA were examined for the two timing conditions and associations were explored among vision-related and reading-related variables and TOFHLA scores.

### Key Findings

The results of the study supported the four study hypotheses. Low vision participants differed significantly from controls in vision-related and reading-related variables. Low vision participants had significantly lower scores on the TOFHLA than

than participants in the control group. Associations were found among vision-related variables and TOFHLA scores in the low vision group showing that lower acuity and reading speed was significantly associated with lower TOFHLA scores. Associations were found among non-vision reading performance variables and TOFHLA scores for the entire sample showing that higher reading frequency and higher activity levels were associated with higher TOFHLA scores.

The primary key finding was that low vision participants demonstrated significantly lower composite scores on the TOFHLA compared to the control group. The difference in scores was greatest under the standard time condition and decreased substantially when participants had unlimited time to complete the test. However, the difference between the groups remained statistically significant even with unlimited time and this finding suggested that variables besides time influenced scores in the low vision sample and differentiated between the two groups.

A second key finding is that although the two groups were closely matched on most demographic variables, they differed significantly on all vision-related variables and on reading-related variables. Participants with low vision demonstrated central field disruption from scotoma, poorer acuity and contrast sensitivity levels, lower reading speeds and also required larger critical print sizes for reading than the control group. In addition, they read fewer types of printed materials, spent less time reading on a daily basis and reported greater difficulty and less satisfaction with reading. This was not an unexpected finding in that the research evidence on AMD and reading indicated that the disease process significantly impairs visual functions and reading performance.

A third key finding was that within the low vision sample, statistically significant associations were found among TOHFLA scores, and the vision-related variables of acuity and reading speed. Low vision participants with lower acuity and those with slower reading speed performed more poorly on the test under the standard timing condition. Although reading speed showed the strongest correlation with test scores on the standard timing condition, lower acuity was the only variable to show a statistically significant association with TOFHLA scores on the standard and unlimited timing conditions. This finding suggested that lower acuity might contribute to test performance separately from reading speed by influencing reading accuracy and reading fatigue.

The final key study finding was that associations were found among TOFHLA scores and non-vision variables associated with cognitive reserve and reading performance in older adults for the sample as a whole. The variables included time spent reading daily and activity level. Participants who devoted more time to reading each day and who participated in a greater number of activities had higher TOFHLA scores.

## Discussion

### *Equivalency Between Groups on Reading Performance Variables*

A primary concern of the study was to control as many of the non-vision variables associated with reading performance as possible so that the influence of low vision could be studied. Inclusion criteria were put in place to ensure that all participants had a minimum of a high school education, a reported minimum yearly average household income of \$20,000, spoke English as their primary language, read a minimum of 20

minutes daily, and presented a minimal risk for depression or dementia. In addition participants in the groups were closely matched on age, gender and educational attainment. An unintended outcome from applying strict inclusion criteria and close matching was equivalency between the groups on other variables including occupation, average yearly reported income, marital status, living arrangement, years in retirement and activity level as measured by number of reported leisure activities.

### *Differences in Vision-Related Variables*

While the groups closely resembled one another in demographic and character traits, their visual capabilities were significantly different (Tables 5 and 6). There were statistically significant differences between the groups on all of the visual variables associated with reading performance in adults with low vision including: acuity, contrast sensitivity, reading speed, and critical print size. Participants in the control group demonstrated mild declines in visual functions that were consistent with older age (Brabyn, Schneck, Haegerstrom-Portnoy, & Lott, 2001). The majority of the control group had moderately impaired contrast sensitivity and 60% had a Snellen acuity of 20/25 rather than 20/20. Two-thirds of the group had a critical print size of 1.6M or smaller, which was consistent with research showing that CPS is typically at least two times larger than reading acuity in normally sighted adults (Legge & Bigelow, 2011). The observed declines in visual function within the control group did not negatively affect reading speed-100% of the control group demonstrated reading speeds within the normal range.

In contrast, the participants in the low vision group demonstrated significant declines in visual function. Two-thirds of the sample had severe or profound impairment in contrast sensitivity. The observed difference in mean log contrast sensitivity scores between the two groups was about 15 times greater than would be expected to occur due to random sampling fluctuation alone. The mean acuity measurement for the low vision group was .68 logMar, or approximately 20/100 Snellen acuity. The observed difference in average acuities between the two groups was almost 22 times greater than would be expected due to random sampling fluctuation alone. The average critical print size was significantly larger for the low vision group with 84% of the sample requiring large to extra large print sizes to obtain maximum reading speed. Control participants read an average of 85 more words per minute than the low vision group, which was statistically significant and almost 8 times greater than would be expected due to random sampling fluctuations. This finding was consistent with multiple studies showing slower reading speeds in persons with AMD compared to normally sighted persons (Cacho, Dickinson, Smith, & Harper, 2010; Cheong, Legge, Lawrence, Cheung & Ruff, 2007; Cheong, Legge, Crossland, Culham, & Rubin, 2005; Falkenberg, Rubin, & Bex, 2007; Legge, 2007; Fletcher, Schuchard, & Watson, 1999). Both groups demonstrated variability in reading speed evidenced by large standard deviations ( $\pm 66.4$  wpm for low vision and  $\pm 40.4$  wpm for controls). Multiple studies have also reported significant variance in reading speeds among normally sighted and low vision adults, a finding attributed to the wide range of factors that influence reading speed including cognitive and perceptual abilities, education, and age (Akutsu, Legge, Ross, & Schuebel, 1991; Legge, 2007; Legge & Bigelow, 2011; Sass, Legge & Lee, 2006). Although some low vision

participants were able to achieve normal reading speeds of greater than 169 words per minute (Legge, Ross, Isenberg & LaMay, 1992), on average their reading speed was 30% slower than the control group and some participants demonstrated very slow speeds. The slowest reader in the low vision group had a maximum reading speed of 27 wpm compared to the slowest reader in the low vision group who read at a normal rate of 182 wpm. The only variable that the two groups did not share was the presence of a macular scotoma within the central visual field. Central scotoma is the primary clinical feature of AMD. All of the low vision participants with microperimetry results had a central scotoma in at least one eye and 94% had scotoma in both eyes. The observation that the low vision group showed declines in all of the vision-related variables most likely reflected the unique disease process of AMD. AMD causes photoreceptor cell death and subsequent development of scotoma in the central field; the expanding scotoma in the central field causes acuity and contrast sensitivity to decrease and critical print size to increase as fixation is shifted to the peripheral retina (Battista, Kalloniatis, & Metha, 2005). Reading speed subsequently declines as it takes the person longer to decode text (Battista, Kalloniatis, & Metha, 2005; Fletcher, Schuchard & Watson, 1999; Legge, 2007). As a result, persons with AMD do not experience deficits in just one visual component of reading, but rather experience deficits in multiple components (Cacho, Dickinson, Smith, & Harper, 2010; Legge, 2007).

### *Differences in Reading-Related Variables*

Although all of the participants in the both groups engaged in reading on a daily basis, their responses on the Reading Behavior Inventory showed significant differences in reading behaviors. The control participants read for a longer period of time each day and read a larger variety of materials than the low vision participants (Table 6). Although the differences were statistically significant, it is important to note that a majority of participants in both groups reported reading more than two hours daily and that control participants read on average only one more type of reading material than the low vision participants. However some low vision participants restricted reading to just two items as shown by the range of reading materials reported by the groups in response to question 1 on the Reading Behavior Inventory. The range for the low vision group was 2 to 8 items compared to 5 to 8 items in the control group. In addition, statistically significant negative associations were found within the low vision groups among the quantity of items read and reported difficulty in reading,  $r_s = -.34$ ,  $p = .017$ , and the amount of time spent reading,  $r_s = -.36$ ,  $p = .011$ . Low vision participants who reported difficulty in reading also read fewer items and also spent less time reading. Although squaring of the  $r$  values showed that they accounted for only 12% and 13% of the variance respectively, the finding suggested that some low vision participants might have restricted their reading performance because reading was difficult to complete.

In summary, research question one asked whether the two groups differed on vision-related and reading-related variables. The answer to the question is that the visual abilities of the two groups were significantly different. Low vision participants demonstrated significantly greater levels of impairment on all vision-related variables



compared to the control group. They also differed in the number of materials read and the amount of time spent reading each day. Overall, low vision participants read nearly as many types of reading materials as the control participants but there were some participants who limited their reading to just a few items.

### *Differences in TOFHLA Scores*

There were significant differences in the TOFHLA scores between the low vision and control groups on both time conditions (Table 8). Participants with low vision scored an average of 15 points lower than the control group on the composite test under the standard time condition. The observed difference was approximately six times the amount that would be expected to occur due to random sampling fluctuations. The mean difference in scores between the groups was reduced to only about three points on the unlimited time condition but the difference remained statistically significant and was almost three times the amount that would be expected to occur due to random sampling fluctuations.

These results suggested that the time required to complete the test influenced scores in the low vision group. Low vision participants took a significantly longer time to complete the test under both time conditions. Low vision participants averaged four minutes longer to complete the test under standard time condition and 11 minutes longer to complete it on the untimed condition. These differences were approximately seven times greater than would be expected due to random sampling fluctuation. Scores for both groups also improved when given additional time to complete the test. The results of

paired *t*-tests on the differences between scores on the standard and unlimited time conditions (Table 9) showed that low vision participants gained an average of 13 points on the unlimited time condition compared to the standard condition, and control participants gained an average of 1.2 points. Both results were statistically significant. The difference was nearly eight times more than would be expected due to random sampling fluctuations for the low vision group and nearly three times more than expected for the control group.

The additional time on the unlimited time condition resulted in an average increase of 1.5 points in composite test scores for the control group. This difference was sufficient to improve the health literacy level of the control group by four percent and elevated all participants to the adequate health literacy category (Table 10). In contrast, unlimited time to complete the test improved test scores by approximately 13 points in the low vision group and resulted in reclassification of 19 low vision participants-38% of the sample-to the category of adequate health literacy level. This gain increased the percentage of low vision participants with adequate health literacy by 50% and brought the percentage of low vision participants classified as having adequate health literacy to 98%, nearly matching the 100% achieved by the control group. This finding suggested that low vision participants may not have differed from their sighted counterparts in the ability to comprehend health related materials as in the amount of time they required to achieve an adequate comprehension level. This is consistent with Legge's (2007) perspective that slow reading speed in AMD readers does not necessarily reduce reading comprehension.

The benefit of additional time in slightly increasing the scores in the control group may be explained by research that has shown small declines in reading speed in older adults associated with age-related cognitive changes in reading (DeBeni, Borella, & Carretti, 2007; Haegerstrom-Portnoy, 2005; Legge, 2007; Lott et al., 2001; Rayner, Reichle, Stroud, & Williams, 2006). However, the much larger increase in scores in the low vision group suggested that factors in addition to age-related changes influenced the time they needed to complete the test. Low vision participants had significantly slower reading speeds than the control group and this difference likely reduced test scores on the standard time condition because questions left unanswered after the time limit was reached were scored as errors. But even with unlimited time, the difference in TOHFLA scores remained statistically significant between the groups and almost three times the amount that would be expected to occur due to random sampling fluctuation. This finding indicated that low vision participants made significantly more mistakes on the test than their normally sighted counterparts regardless of time.

Based on these findings, the answer to research question two on whether low vision participants scored lower on the TOFHLA than the control group was yes, older adults with low vision scored significantly lower on the TOHFLA than older adults without low vision. The differences between the groups on the amount of time that participants required to complete the test in the unlimited time condition suggested that reading speed was a significant factor in test performance for both groups and especially for the low vision participants. However, other factors appeared to influence test performance in the low vision group.

*Associations Among Vision-Related Variables and TOFHLA Scores in the Low Vision Group*

Among the five vision-related variables, acuity, reading speed, and critical print size were statistically associated with TOFHLA composite scores on the standard time condition in the low vision group (Table 11). Lower reading speeds and lower acuities were associated with lower TOFHLA scores. Larger critical print sizes were also associated with lower TOFHLA scores. Computation of a partial correlation for the linear variables of acuity and reading speed showed that both variables contributed to TOFHLA scores in the standard time condition. Squaring of the  $r$  value showed that reading speed accounted for more of the variance in the scores—approximately 20%—compared to approximately 12% for acuity. However, no association was found among reading speed and TOFHLA scores on the unlimited time condition while acuity continued to show a significant negative association with TOFHLA scores. Participants with lower acuity also had lower composite scores on the TOFHLA.

Intuitively, it would be expected that a slower reading speed might reduce scores on a timed test where unanswered items were counted as errors. This assumption would be true especially if the time limit was determined using populations with normal acuity as was done in the development of the TOFHLA (Parker, Baker, Williams & Nurss, 1995). The finding that scores for both groups, and especially the low vision group, increased significantly on the unlimited time condition supported the importance of reading speed as a variable influencing test performance. However, the correlation between acuity and TOFHLA score remained statistically significant after suppressing reading speed under the standard time condition and lower acuity was the only variable statistically correlated with lower TOFHLA scores in the untimed condition. This finding

suggested that acuity also influenced test scores possibly by reducing reading accuracy and inducing fatigue.

Research has shown that AMD readers are able to decode letters and words when provided adequate magnification; however, reading is not restored to normal levels (Falkenberg, Rubin & Bex, 2006; Legge, 2007; Lovie-Kitchin, Bowers & Woods, 2000). When forced to use peripheral retina, AMD readers demonstrate lower acuity, slower reading speed, reduced eye movement control, visual blur and crowding, and a reduced visual span that may permit as few as 1-2 letters to be seen at a time (Battista, Kalloniatis & Metha, 2005; Cheong, Legge, Lawrence, Cheung & Ruff, 2007; Crossland & Rubin, 2006). Crowding, blurriness and reduced visual span make it more difficult to accurately distinguish between letters and misreading words is a common occurrence in AMD readers with scotoma (Legge, 2007; Watson, Baldasare & Whittaker, 1990; Watson & Whittaker, 1994; Watson, Wright, Long & Del'Aune, 1996). Seventeen of the low vision participants in this study were observed to make at least one error on the test because they incorrectly read a word. While it was unlikely that these errors were sufficient to make a significant difference in test scores, they may have contributed to the difference of 3.4 points in TOFHLA scores observed between the two groups on the unlimited time condition.

Most of the errors made by both groups on the TOFHLA occurred on the comprehension section. Low vision participants scored an average of almost 14 points lower on this section than the control group under the standard time condition. Again, the low vision group was able to close the gap to about 2.5 points with unlimited time, but the difference remained statistically significant and was almost four times greater than

expected due to random sampling fluctuations. On the numeracy section, low vision participants scored about three points lower on average than the control group on the standard time condition, a difference approximately two times greater than would be expected due to random sampling fluctuation. However, that difference decreased to just over one point with unlimited time, and the difference between the groups was no longer statistically significant. Thus, low vision participants were able to complete basic numeracy tasks as accurately as the control group when given additional time.

One possible explanation for why additional time negated the differences between the groups on the numeracy section but not the reading comprehension section of the test might be the different demands placed on reading in each section. The two test sections are matched in reading grade level but differ substantially in text characteristics and format. Text characteristics such as print size, font type and letter contrast have been shown to influence the reading speed and comprehension levels of both normally sighted and AMD readers (Legge, 2007; Legge & Bigelow, 2011). Persons with normal vision can read a wide range of print sizes from small to large whereas AMD readers have a much smaller range of print that they can read accurately (Barstow & Crossland, 2011; Legge & Bigelow, 2011). Maximum reading speed for both groups occurs at critical print size, which generally is much larger for persons with low vision as shown in this study and others (Cacho, Dickinson, Smith & Harper, 2010; Legge, 2007; Lovie-Kitchin, Bowers & Woods, 2000). The ability to read a wide range of print sizes equips the reader with acuity reserve, which is the ability to read for prolonged periods of time without experiencing fatigue.

The formatting of the text so that it requires either continuous text or spot reading has also been shown to affect acuity reserve (Whittaker & Lovie-Kitchin, 1993). Continuous text reading requires readers to read through multiple sentences or paragraphs to grasp the required information. The quantity and close proximity of letters in continuous text requires low vision readers to put more effort into decoding words, which can reduce reading speed and increase fatigue (Legge, 2007; Whittaker & Lovie-Kitchin, 1993). In contrast spot reading requires the reader to decode a single word, number or short phrase to locate the needed information. Spot reading has less word density and is completed in short bursts. Spot reading requires no acuity reserve, whereas reading continuous paragraphs of text requires an acuity reserve of 5:1 (Barstow & Crossland, 2011; Whittaker & Lovie-Kitchin, 1993). Whittaker and Lovie-Kitchin (1993) showed that AMD readers typically have acuity reserves of 3:1 or less. Legge (2007) speculated that text characteristics that strain acuity reserves might reduce the amount of time that a person can sustain good reading speed and comprehension by causing fatigue.

The reading comprehension section of the TOFHLA required the participant to read through a paragraph of print, often using information in a previously read sentence to select answers for the next sentence. In contrast, the numeracy section required spot reading; participants were asked to answer a question by looking for a number or decoding a short phrase on a prescription bottle or a card. Although acuity reserve was not measured in this study, the low vision participants with greater acuity loss most likely had lower acuity reserves. Reading demands and subsequent fatigue might explain the finding that the low vision participants scored lower on the reading comprehension

section than controls even when given unlimited time whereas unlimited time erased the statistical difference between the groups on the numeracy section.

Research question three asked whether vision-related variables in older adults with low vision were associated with lower test scores on the TOFHLA. The results of the study indicated that reading speed influenced test performance especially in the low vision group but did not account for all of the variance observed between the scores. Visual acuity also appeared to have contributed to test performance especially on the reading comprehension section of the test.

#### *Associations Among Non-Vision Reading Performance Variables and TOFHLA Scores*

Sass, Legge and Lee (2006) cautioned that visual deficits interact with lifelong cognitive ability and age-related changes in cognition and reading performance and these factors must be considered when interpreting reading performance in older adults with low vision. Research question four therefore asked whether there were associations among non-vision variables and TOFHLA scores for the sample as a whole. Analyses were completed to investigate the relationships between TOFHLA scores and six non-vision variables shown to be associated with reading performance in older adults: age, gender, education level, occupation, reading frequency and activity level.

Statistically significant results were found for only two of the variables: reading frequency and activity level. Participants who reported reading more than one hour daily scored higher on the TOHFLA under the standard time condition than those who read less than one hour daily. The difference in scores was nearly 10 times greater than would



be expected due to random sampling fluctuation. Participants who reported regularly engaging in a larger number of leisure activities also tended to score higher on the TOFHLA ( $r_s = .29, p = .003$ ). These findings, when combined with those showing no associations among education and occupation and TOFHLA scores, suggested that the activities currently completed by participants might have been more important than past accomplishments in attaining an adequate level of health literacy.

These findings were consistent with studies showing associations among engagement in intellectual pursuits and other activities and better cognitive performance in older adults (Agahi, Ahacic, & Parker, 2006; Dellenbach & Zimrich, 2008; Gatz, Prescott, & Pedersen, 2006; Newson & Kemps, 2005; Scarmeas, Levy, Tang, Manly, & Stern, 2001; Schumacher & Martin, 2009; Wilson et. al., 2002; Wilson, Barnes, & Bennett, 2003). Participation in intellectually stimulating activities such as reading books and newspapers has been consistently associated with better cognitive performance in older adults (Agahi, Ahacic, & Parker, 2006; Dellenbach & Zimprich, 2008; Gatz, Prescott, & Pedersen, 2006; Newson & Kemps, 2005; Schumacher & Martin, 2009; Wilson et. al., 2002; Wilson, Barnes, & Bennett, 2003). It has also been shown to help bolster cognitive function in older adults with less education (Lachman, Agrigoroaei, Murphy, & Tun, 2010). Lachman, Agrigoroaei, Murphy, and Tun (2010) found that older adults with lower education levels who regularly engaged in reading and other cognitive activities demonstrated memory performance comparable to older adults with college and post-graduate degrees. Likewise, higher levels of participation in everyday leisure activities such as socializing with family and friends, exercising, and completing craft activities (e.g. knitting), have also been associated with less cognitive decline (Agahi,

Ahacic, & Parker, 2006; Newson & Kemps, 2005; Scarneas, Levy, Tang, Manly, & Stern, 2001).

This finding was also consistent with research showing that regular engagement in reading was associated with better understanding of health materials. Bann, Bayen, McCormack, and Uhrig (2006) found that older adults, who read more frequently regardless of the types of materials read, demonstrated greater understanding of Medicare documents. Wister, Malloy-Weir, Rootman, and Desjardins (2010) examined the performance of older adults on the health literacy scales of the Canadian version of the 2003 International Adult Literacy and Life Skills Survey. They found that older adults, who regularly engaged in reading books, manuals and other references materials to learn new information, were more likely to be classified as having adequate health literacy than those who did not engage in these activities. Baker, Gazmararian, Sudano, and Patterson (2000) observed that regular reading was specifically associated with TOFHLA test performance in older adults. The investigators administered the short version of the TOFHLA to adults over age 65 years and found that those who reported reading the newspaper at least 4 times a week averaged 18 points better on the test than older adults who never read the newspaper.

For older adults with low vision, the study findings underscore the importance of providing rehabilitation services to enable the person to continue to read using magnifiers and to remain actively engaged in daily pursuits. The majority of low vision participants in this study had received low vision rehabilitation services including the prescription of a magnifier by a low vision optometrist. Overall, they had been able to maintain adequate levels of reading and activity despite vision impairment which contradicted the finding by

O'Connor, Lamoureux, and Keefe (2008) that persons with moderate visual impairment were approximately four times more likely to experience severely restricted participation in daily activities. Unfortunately, low vision rehabilitation services are significantly underutilized in the United States and other countries and many visual impaired persons are never prescribed magnifying devices or trained to use them (Matti, Pesudovs, Daly, Brown, & Chen, 2011; Laitinen et al., 2008; O'Connor, Mu, & Keefe, 2008; Overbury & Wittich, 2011; Pollard, Simpson, Lamoureux, & Keefe, 2003).

The finding that education was not associated with TOFHLA scores even though other research has shown associations most likely reflected the high education level of the participants. Much of the research using the TOFHLA to measure health literacy has been conducted on large populations of educationally and socioeconomically diverse participants (Baker, Parker, Williams, & Clark, 1998; Baker, Gazmararian, & Williams, 2002; Baker et al., 2007; Gazmararian, Baker, & Williams, 1999 b; Williams et al., 1995; Williams, Baker, Parker, & Nurss, 1998). Seventy percent of the participants in this study were college educated and over half had engaged in skilled or professional occupations. Their high level of engagement in activities and reading may have bolstered cognitive reserve and scores.

Age also did not correlate with TOFHLA scores in the sample although research had shown older age to be associated with lower health literacy levels (Billek-Sawbney & Reichert, 2005; Cordasco, Asch, Franco, & Mangione, 2009; Cutilli, 2007; Downey & Zun, 2008; Kutner, Greenberg, Jin, & Paulsen, 2006) and TOFHLA scores (Baker, Gazmararian, Sudano, & Patterson, 2000; Benson & Forman, 2002; Gazmararian, Baker, & Williams, 1999b); Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd,

2005). Most studies have investigated the relationship between age and health literacy performance by comparing adults over age 65 to adults under age 65 rather than studying the influence of advancing age within a sample of older adults. However, Baker, Gazmararian, Sudano and Patterson (2000) explicitly studied the effect of advancing age on scores for the short version of the TOHFLA. They stratified a sample of 3,000 older adults by 10-year age increments (e.g. 65-74, 75-84, and 85-94 years) and by three education levels-less than 12 years, high school (12 years) and more than 12 years. They then compared TOFHLA scores after controlling for dementia, physical function, visual acuity and comorbidities. They found a decline of almost ten points on the S-TOFHLA for every decade after age 65. Participants with 12 years or greater education showed a smaller decline between ages 65 and 75 but an overall decline of nearly 25 points between ages 65 and 85. However, the study did not specify the number of participants with some college or college degrees in the sample with 12 years or greater education and they did not include data on occupation or consider other factors associated with cognitive reserve in older adults other than reading the newspaper.

Based on these findings, the answer to the final research question on whether associations were found among non-vision variables associated with reading performance and TOFHLA scores was that reading frequency and activity level were associated with test performance. Participants who spent more time reading daily or who had higher activity levels scored higher on the test under the standard time condition. Both of these variables have been associated with cognitive reserve in older adults and it may be that some participants benefitted from higher cognitive reserve in completing the test.

### Implications for Health Education and Recommendations

Both low health literacy and low vision are expected to dramatically increase as baby boomers enter old age. Concerns about low health literacy levels in older adults arise from the increasing complexity of health management and need for the patient to be an active participant in the management of chronic diseases (Nielsen-Bohlman et al., 2004). The inability of medical science to find cures or restore vision for the leading causes of low vision in older adults has been projected to create a “tsunami” in the number of older adults experiencing low vision within the next 20 years (Gordon, 2009, p. 2). This study’s significance stems from the confluence of these two events, which together have the potential to significantly and adversely affect health outcomes in a large population of older Americans.

According to the ecology of human performance model (Dunn, Brown, & McGuigan, 1994) persons who struggle to complete a task because they have difficulty gathering sufficient information from the environment often avoid or drop the difficult task from their repertoire of daily activities. This behavior has been well documented in research showing that persons with low vision significantly reduce their activity levels as vision declines (Crews, 2000; Jones, Rovner, Crews, & Danielson, 2009; Lamoureux, Hassell, & Keeffe, 2004; Lindo & Nordholm, 1999; Travis, Boerner, Reinhardt, & Horowitz, 2004). This study found that low vision participants struggled more with reading and had difficulty quickly comprehending health information. Some low participants in the study reduced the number and types of printed materials they read and they were less likely to read medical bills and statements formatted in continuous text. But overall the low vision group did not shy away from completing basic self-

management tasks including medication management and making doctor's appointments and reported that they participated in self-management of their health conditions on a daily basis. Thus, they did not reduce the repertoire self-management activities they completed despite their visual difficulties. However it must be noted that the low vision participants in this study were also not representative of the population of older Americans as a whole. The participants were better educated than average Americans; 70 percent had been to college, which exceeded a national prevalence of about 20% for this age group (Administration on Aging, 2010). They also had more intellectually demanding occupations compared to average Americans (Administration on Aging, 2010) and the median income of the sample was higher than the national average. They were above average in all of the traits that promote cognitive reserve in older adults. Those traits may have likely equipped them with skills they could use to compensate for their limited vision and continue to maintain activity levels.

Yet, the affluence and education of the low vision participants did not protect them from experiencing greater difficulty in reading and comprehending health information than the participants without low vision. This finding suggested that low vision does add an additional barrier to functional health literacy through its effect on reading performance. Although visually impaired older adults-like those in this study--with good cognitive reserve, financial resources, and access to low vision rehabilitation may experience only small declines in health as a result of limited health literacy, the same cannot be said for the majority of visually impaired older adults. Low vision is a condition caused by multiple eye diseases that affects all races and cuts across all socioeconomic levels in the United States. Minorities including African Americans,

Hispanic Americans and Native Americans experience higher rates of vision impairment than Caucasian Americans (Congdon et al., 2004). These racial groups as a whole have been shown to have less education, less income and poorer health than Caucasian Americans (CDC, 2010). English may not be their primary language (Cordasco, Asch, Franco, & Mangione, 2009) The quality of their education may be less and they may have completed high school without being able to read at a 12<sup>th</sup> grade reading level (Neilson-Bohlman, Panzer, & Kindig, 2004). These traits have been shown to increase vulnerability to age-related cognitive decline (Manly, Schupf, Tang, & Stern, 2005) and lower health literacy levels (Baker, Jeppesen, Coyle, & Miser, 2009). In addition, it is likely that only a small number of these persons have received low vision rehabilitation services. As a result if this study were repeated using a sample of older adults more representative of the population of visually impaired older Americans, significantly greater limitations in health literacy would probably be found along with greater activity limitations and poorer health outcomes.

Research has found that, like other older adults, older adults with low vision wanted to receive health information that will enable them to manage all of their medical conditions and they wanted this information delivered using methods that enhanced their understanding of the material (Harrison, Mackert, & Watkins, 2010; O'Day, Killeen, & Iezzoni, 2004; Pollard, Simpson, Lamoureux, & Keefee, 2003; Williams, 2002). They specifically cited the need for the information to be presented in visually accessible formats (Harrison, Mackert, & Watkins, 2010; O'Day, Killeen, & Lezzoni, 2004). Several national organizations have launched initiatives to help health care professionals improve their ability to effectively communicate health information to low literacy

patients. Three of these initiatives, the National Institutes of Health Plain Language Clear Communication Initiative (NIH, n.d.), the Pfizer Pharmaceutical Clear Health Communication Initiative (Pfizer Public Health Group, 2008) and the Group Health Center for Health Studies Readability Toolkit (Ridpath, Greene, & Wiese, 2007) have Internet sites with extensive information and tools for health professionals to improve written and verbal communication. The guidelines and tools these organizations provide are readily applicable to older adults with low vision. They focus on simplifying language and sentence structure and creating materials that avoid medical jargon, use common words, active voice, and simple, short sentences. In addition, organizations that advocate for persons with vision impairment such as the American Printing House for the Blind and Lighthouse International also have Internet sites that provide specific guidelines for improving the visibility of printed materials. Their guidelines focus on increasing the size of text and the spacing between words and sentences, bolding text, color contrast, and avoiding contractions and other language conventions that can reduce reading accuracy. Combining guidelines from these two sources could assist health educators to design print materials in accessible formats for visually impaired older adults.

Another significant study finding was that low vision participants required a longer time to comprehend printed text. Sass, Legge, and Lee (2006) found that older adults with low vision read more slowly than those with normal vision, and they also read more slowly than younger adults with low vision. According to Legge (2007) the combined effect of aging and low vision delivers a double blow to the older reader because low vision places demands on attentional ability to decode difficult-to-see text at the same time that aging reduces attentional capacity. Legge suggested that low vision



readers might deliberately slow down reading speed in order to improve comprehension. If so older adults should be encouraged to take as much time as needed to read and understand printed materials. Printed materials should also be provided in formats that minimize reading time to reduce the effect of fatigue on reading. These formats are the same as those recommended for improving text readability for low literacy and include using bullet points instead paragraphs, simplifying language and using common everyday words that are more easily decoded.

### Study Limitations

Study limitations included a smaller sample size due to the exploratory nature of the study. Racial diversity within the sample was also limited because the study was restricted to persons with AMD. Persons with AMD also experience changes in reading performance because of the presence of central scotoma that may not accompany other visual conditions such as glaucoma and diabetic retinopathy. As a result, the associations found among vision variables and TOHFLA performance may not be replicated in populations with other eye diseases. The large number of controlled variables in the research design ensured that differences between groups could be attributed to low vision, but also created a sample atypical of older Americans in many respects. Because of the location of the study, the participants shared a southern heritage. All of these study criteria limited the generalization of the findings to less educated and lower income populations and populations residing outside of the southeastern United States and to persons with eye conditions other than AMD. In addition, most of the visually impaired

participants had received low vision rehabilitation and all were proficient in using a magnifier to read and this may have improved the low vision sample's performance on the TOFHLA. This also limited the generalization of study findings to visually impaired older adults as only a small fraction of this population receive low vision rehabilitation services and are trained to use magnifying devices.

Measurement limitations included incomplete and possibly inaccurate data on scotoma in the low vision participants. Microperimetry results documenting the presence and location of the scotoma were available for only 33 of the low vision participants. Results were not available for the rest of the sample either because the participant could not be tested due to difficulty imaging the retina or the participant had not been recruited from the UABCLVR clinic. In addition, microperimetry results might have been inaccurate for those participants who had been tested because the test was completed several weeks up to two years before the participant was evaluated in the study. Scotoma can increase in size and change shape as the disease progresses; had this occurred in some of the participants, it would have changed how the scotoma influenced reading performance. To accurately measure the influence of scotoma on reading, microperimetry should have been completed on the same day as data collection for the study, which was not financially feasible for this study. Finally, the addition of a brief validated and reliable intelligence test for older adults would have enabled a more indepth analysis of the relationship among non-vision variables and TOFHLA scores.

### Future Research

This study provided an initial investigation of the relationship between low vision and functional health literacy. Replication of the study with a larger sample that is more representative of older adults with low vision must be conducted to determine the full effect of low vision on health literacy levels among older visual impaired adults. However, the study findings suggest that low vision might potentially influence health outcomes by interfering with the persons' ability to understand health information and restricting their ability to fully participate and complete self-management of chronic disease. This suggests a need for future research to investigate methods to provide effective health education to older adults with low vision. The findings also questioned how health literacy should be measured in persons with low vision to accurately determine their ability to comprehend health information. Of particular concern is the efficacy of using timed tests to measure health literacy in older adults with low vision. Future research should address the best test design to measure health literacy in persons with low vision.

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## APPENDIX A

### INSTITUTIONAL REVIEW BOARD APPROVAL FOR THE STUDY



Form 4: IRB Approval Form  
Identification and Certification of Research  
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on September 29, 2013. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: WARREN, MARY

Co-Investigator(s):

Protocol Number: **X101130012**

Protocol Title: *Difference in Functional Health Literacy Level in Older Adults with and without Low Vision*

The IRB reviewed and approved the above named project on 1/5/11. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 1-5-11

Date IRB Approval Issued: 1/5/11

Marilyn Doss, M.A.

Vice Chair of the Institutional Review  
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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## APPENDIX B

### STANDARDIZED STUDY MEASURES

### **Early Treatment of Diabetic Retinopathy Study (ETDRS) Visual Acuity Chart**

Manufactured by:

Precision Vision  
944 First Street  
LaSalle, IL 61301

Illustrations of the chart can be found at:

<http://precision-vision.com/index.cfm/category/34/etdrs-charts.cfm>

### **Geriatric Depression Scale Short Form**

The form is freely available from the Center for Gerontology and Health Care Research-Brown University: [http://www.chcr.brown.edu/GDS\\_SHORT\\_FORM.PDF](http://www.chcr.brown.edu/GDS_SHORT_FORM.PDF)

### **Leisure Activity Score Questionnaire**

Test and description can be found in:

Bull, C.N. (1982). Leisure activities. In D.J. Mangen & W.A. Peterson (Eds.). *Research instruments in social gerontology volume 2: Social roles and social responsibility*. (pp.477-538). Minneapolis MN: University of Minneapolis Press.

### **Mars Letter Contrast Sensitivity Chart**

Manufactured by:

The Mars Perceptrix Corporation  
49 Valley View Rd  
Chappaqua, NY 10514-2533

Illustrations of the chart can be found at: <http://www.marsperceptrix.com/>

### **MNread Acuity Chart 1**

Developed by:

Minnesota Laboratory for Low Vision Research, University of Minnesota  
<http://gandalf.psych.umn.edu/groups/gellab/MNREAD/>

Manufactured by:

Precision Vision  
9 44 First Street  
LaSalle, IL 61301

Illustrations of the chart can be found at:

<http://precision-vision.com/index.cfm/category/116/reading-cards.cfm>

### **Reading Behavior Inventory**

Test and description found in

Goodrich, G. L., Kirby, J., Wood, J., & Peters, L. (2006). The reading behavior inventory: An outcome assessment tool. *Journal of Visual Impairment & Blindness*, 100(3), 164-168.

<http://www.eric.ed.gov/PDFS/EJ732710.pdf>

### **Short Portable Mental Status Questionnaire**

The questionnaire is freely available from the National Palliative Care Research Center:

[http://www.npcrc.org/usr\\_doc/adhoc/psychosocial/SPMSQ.pdf](http://www.npcrc.org/usr_doc/adhoc/psychosocial/SPMSQ.pdf)

### **Test of Functional Health Literacy for Adults-Long Form**

Sample items from the test are available at National Academies Press:

[http://www.nap.edu/openbook.php?record\\_id=10883&page=305](http://www.nap.edu/openbook.php?record_id=10883&page=305)