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Developing An Assessment Of Reading Impairment And Its Impact On Occupational Performance In Older Adults With Glaucoma In A Metropolitan Area Of The Southeastern Us: A Mixed Methods Approach

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DEVELOPING AN ASSESSMENT OF READING IMPAIRMENT AND ITS IMPACT ON OCCUPATIONAL PERFORMANCE IN OLDER ADULTS WITH GLAUCOMA IN A METROPOLITAN AREA OF THE SOUTHEASTERN US: A MIXED METHODS APPROACH

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ABSTRACT

According to the United States Administration on Aging (AOA, 2014), the population of individuals over 65 will be 98 million by the year 2060, doubling its 2014 estimates. As our population ages, the prevalence of glaucoma increases. Vision loss resulting from glaucoma can limit participation in valued occupations including engagement in reading. It has long been thought that mobility issues and glare sensitivity were the main factors that characterized glaucoma. In the late 1990s and early 2000s researchers began to examine quality of life (QoL) in those with glaucoma. It was during these early QoL studies that the first reports of central vision issues were reported among adults with glaucoma.

The QoL studies show that the concerns of those with glaucoma are associated with the vulnerability of central vision as the disease progresses, and not with the consequences of visual field loss that are commonly thought to characterize the disease. The most frequently reported problems with vision from many of the QoL questionnaires have been related to lighting and glare. These factors have been assessed as less important by patients when judged within the context of several vision-related factors. The findings that patients are concerned about the vulnerability of central vision (reading and near tasks) rather than the characteristic features of visual field loss (mobility)

suggests that the focus of rehabilitation should not simply be on mobility, as it is only addressing part of the problem.

Some studies have been completed with the goal of identifying the components of reading that are affected by glaucoma (i.e., contrast sensitivity function), most significantly reading endurance. There are very few studies that have explored how these changes in reading affect the person's ability to perform specific occupations. These studies have also not examined the perspectives of persons with glaucoma of how their occupational performance is affected by reading loss.

The purpose of this exploratory mixed methods research study was to develop a new, reliable and content validated instrument to measure the effects of reading impairment associated with glaucoma on occupational performance in older adults in a metropolitan area of a Southeastern state. The product of the study was a newly developed, initially validated and reliable instrument to assess reading changes associated with glaucoma and the effect on occupational performance. The insights gained from the data aided in understanding the problems that arise from an inability to read and the effects on occupational performance. This information could be used to determine treatment interventions that can be designed to reduce the effects of inability to read on occupational performance.

DEDICATION

I would like to dedicate this dissertation project to my life partner, Victor Deacy. Victor has provided me with undying support in unimaginable ways. From my first semester of undergraduate studies through the end of this time-consuming, resource depleting, life-changing and perseverance test of a dissertation, he has been my number one support and fan. He has supported me financially, physically, emotionally and spiritually. I would not have been able to go on this journey without him, nor would I want to. Thank you for everything, my love, but mostly for your support. It truly means more to me than words can express.

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ADVS	Activities of Daily Vision Scale
AI	Activity Inventory
CS	Contrast Sensitivity
GDS-SF	Geriatric Depression Scale – Short Form
EBD	Evidence based dentistry
IADL	Instrumental Activities of Daily Living
IVF	Integrated Visual Fields
NEI	National Eye Institute
NEI VFQ-25	National Eye Institute Visual Function Questionnaire 25
OA	Occupational Adaptation Framework
OCT	Optical Coherence Tomography
OT	Occupational Therapy
POAG	Primary Open Angle Glaucoma
QoL	Quality of Life
REALM-SF	Rapid Estimate of Adult Literacy in Medicine Short Form
RGC	Retinal Ganglion Cell
RNFL	Retinal Nerve Fiber Layer
SEE Project	Salisbury Eye Evaluation Project
SPMSQ	Short Portable Mental Status Questionnaire
VA	Visual Acuity

VF	Visual Field
VS	Visual Span

CHAPTER ONE

INTRODUCTION

Glaucoma is the most common cause of irreversible blindness worldwide (National Institute on Health Statistics, 2010; Quigley and Broman, 2006). It is a collection of progressive neurodegenerative diseases of the retinal ganglion cells (RGCs) that are characterized by visual field loss secondary to axon degeneration in the optic nerve (Buckingham et al., 2008). Glaucoma also affects the central visual pathways, which leads to degenerative changes in the retina and ultimately the visual cortex (Chang & Goldberg, 2012). The gradual loss of visual ability occurs as optic nerve damage results in loss of the visual field. It is often asymptomatic in early stages. Once it occurs, loss of vision is irreversible (Green et al., 2002).

Glaucoma currently affects approximately 2% of the population of adults over the age of 40 in the United States (US). It is considered an age-related eye disease because its prevalence steadily rises with increasing age (National Eye Institute [NEI], 2010). As the population over age 65 increases in the US, it is expected that the number of persons with glaucoma will also increase. Persons with glaucoma typically experience limitations in mobility because of the early degeneration of the peripheral visual field. However, as the disease progresses and further optic nerve damage occurs, acuity in the central visual field also declines which may significantly impair reading performance. Reading is an integral part of many activities of daily living (ADLs). People read directions and recipes to complete meal preparation, financial statements for financial management, pill bottles

to ensure safety with medication management and many other labels and such to function independently. Reading is essential to daily function. Reading is the most frequently mentioned complaint amongst individuals with glaucoma (Ramulu, 2013) and is often the reason that persons seek low vision rehabilitation (Brown, Goldstein, Chan, Massof & Ramulu, 2014).

Purpose of the Study

The purpose of this exploratory design mixed methods study was to develop an instrument with evidence of internal consistency reliability, face validity and content validity that could potentially be useful in examining the effects of reading impairment on occupational performance in older adults with glaucoma. The study was conducted in two sequential phases. The first phase sought to examine the beliefs among older adults about reading changes associated with glaucoma and how this affects the completion of occupations. This information was gathered via semi-structured, qualitative interviews with twelve older adults with a diagnosis of glaucoma. The findings from the qualitative interviews informed the instrument development and quantitative exploration of the psychometric properties of the instrument in the second phase.

Research Questions

In this study, the researcher sought to answer the following research questions:

Phase I Qualitative Exploration of Reading Changes and Occupational Performance

The study was guided by the following research questions:

1. What beliefs do older adults with glaucoma living in a SE metropolitan area have about the changes in reading they experience?

2. What strategies do older adults with glaucoma employ to compensate for and cope with reading deficits experienced during occupational performance?

Phase II Quantitative Exploration of Reading Changes and Occupational Performance

1. What is the estimated face validity, content validity and internal consistency reliability of items to measure the impact of reading changes from glaucoma on occupational performance?
2. How do the items within the scale correlate to measure reading performance in older adults with glaucoma?

Mixed Methods Questions

1. In what ways does the information obtained in the qualitative phase help to develop a new psychometrically sound quantitative instrument?
2. What do the qualitative and quantitative data together reveal about the relationship between changes in reading associated with vision loss from glaucoma and occupational performance in older adults with glaucoma living in a metropolitan area in a SE state.

Theoretical Framework

This study was guided by the Occupational Adaptation (OA) framework, originally developed by Schkade and Schultz (2009). This framework focuses on improving adaptiveness and this is a critical part of occupational therapy assessment and intervention planning. For older adults with glaucoma to be successful at overcoming the

reading difficulties they experience causing deficits in occupational performance, adaptation is key.

Significance of the Study

It is important to note that prior studies have not sought to determine whether engagement in reading is impacted by glaucomatous vision loss. Nor have prior studies associated patient perceptions of reading changes and the impact on occupational performance. To conceptualize the dissertation study, the investigator has reviewed published literature retrieved from library databases including: PubMed, PsychInfo, Psychological Abstracts, CINAHAL, MEDLINE and OVID. Currently, there is little literature available on reading with glaucomatous visual field loss. The limitations in current knowledge of reading changes associated with glaucoma and how this effects occupational performance, presents a challenge to the rehabilitation professional trying to address the needs of this population.

The research related to reading and glaucoma has shown that those with glaucoma do have impaired reading (Ramulu et al., 2013a, 2013b; Nyugen et al., 2014). Findings of the research on reading performance show that persons with glaucoma read slower and fatigue earlier than age-matched controls on sustained reading tests (Ramulu et al, 2013). Persons with bilateral visual field loss experience difficulty completing activities of daily living that require sustained reading and as a result may avoid or limit their performance of these ADLs (Nguyen et al., 2014). Although studies have been completed that identify the components of reading that are affected by glaucoma, most significantly reading endurance, very few studies have explored how these changes in reading effect the person's ability to complete specific ADLs or the perspectives of persons with glaucoma

on their ADL performance. It is important to understand the person's perspective of how the reading changes affect their ability to complete daily activities in order to identify the most appropriate intervention strategies.

It is apparent that more research is needed in the glaucoma population to learn more about the effects of reading changes on completing ADLs and IADLs and how this effects their daily life. It is important to start with an understanding of the experiences of those who live with glaucoma and the effects on their lives. This understanding can potentially lead to rehabilitative methods to address the effects of the reading changes on daily life.

Definition of Key Terms

ADLs is an abbreviation for activities of daily living. ADLs are basic activities people do daily including self-care (i.e., dressing, bathing, eating).

Content Validity is the examining the extent to which an instrument samples items from a particular field.

Glaucoma a term used to describe a collection of progressive, neurodegenerative diseases that result in retinal ganglion cell axon degeneration and death. It is the most common irreversible cause of blindness worldwide.

IADLs is an abbreviation for instrumental activities of daily living. IADLs include activities that are more complex and require higher cognitive functioning than basic ADLs. These include activities such as medication management, financial management, and meal preparation.

Legitimation describes the process used in mixed methods research to make inferences that are credible, trustworthy, dependable, transferable, and/or confirmable.

Mixed methods research refers to a research design that combines collection and analysis of both qualitative and quantitative research in a single study. The research is "mixed" to attempt to better understand a new phenomenon or a research problem.

Occupations refers to activities that people engage in in their daily life. These activities can be as basic as toileting and dressing to more complex task, such as medication management and pet care.

Occupational performance is a combination of two terms found in the Occupational Therapy Practice Framework (3rd Edition, AOTA, 2014), occupation and performance skills. Occupational performance refers to performance of occupations.

Quality of Life is the standard of health, comfort and happiness of an individual or group.

Reliability is the extent to which an instrument produces a consistent result.

Study Assumptions

The following assumptions were made in this study:

1. All participants were able to participate in the study procedures.
2. All participants engaged in daily activities and occupations that require reading.
3. All participants expressed their experiences and thoughts about participation in daily tasks that require reading.
4. All participants honestly expressed their thoughts and beliefs on the methods used to cope with the difficulties they experience.

Limitations

The limitations of this study are identified as follows:

- Qualitative data analysis will reveal subjective data about individual perceptions of the phenomenon of interest to the researcher.
- Use of a mixed methods approach, which involves data collection through self-report, can lead to socially desirable responses from participants.
- The sampling methods, focusing on a metropolitan area of the Southeastern US, will not represent all older adults with glaucoma.
- Results of this first exploration of developing a new valid and reliable instrument to measure reading difficulty and the effects on occupational performance in older adults with glaucoma must be interpreted with caution due to small sample size.

Organization of the Study

The study discussion is organized into five chapters. Chapter One provides the reader with an introduction to the topic area including study purpose, review of research questions, discussion of the significance of the problem, outline of study assumptions and limitations and summary. Chapter Two provides a review of the relevant literature on the topics of quality of life among those with glaucoma; factors affecting reading; glaucoma and reading; occupations and reading and a brief review of mixed methods research, specifically the sequential exploratory design. Chapter Three provides an overview of the study methodology including the rationale for using a sequential exploratory design, identification of the study population, and procedures for qualitative and quantitative phases. Chapter Four describes the study results for both phases and describes the development of themes and how these were used to generate survey items. The chapter also includes results of the instrument piloting and exploratory factor analysis. Chapter

Five is a discussion of the integration of data from both phases, discussion of results organized by the research questions, limitations of the study, the plan for dissemination of results and recommendations for future research.

Summary

This chapter presented the background, statement of the problem, study assumptions and briefly described the theoretical framework. The purpose of the study and research questions were developed to explore thoughts and perceptions of older adults with glaucoma who experience reading difficulty and how these difficulties impact occupational performance. This study applied qualitative and quantitative methodology to better understand the effects of reading difficulties and the impact on occupational performance among older adults with glaucoma. The results of this study may aid in better understanding of the issues this population face and lead to effective interventions to reduce disability associated with glaucoma and improve occupational performance, especially with occupations that require reading.

CHAPTER TWO

REVIEW OF THE LITERATURE

Merriam-Webster (2015) defines the term *read* as to look at and understand the meaning of letters, words, symbols, etc. It is further defined as, "to read the words of a book or magazine; and to speak aloud the words of something written" (Merriam-Webster, 2015). The written language, while complex, is one of the most important sources of information in the workplace and at home. From medication management, recipes and instructions to reading an e-book on a tablet, reading is essential to many of the basic and instrumental activities of daily living (ADLs) that people perform. It would stand to reason that problems with reading constitute one of the most frequent visual complaints in ophthalmic and optometry practices ((Trauzettel-Klosinski, 2002).

Glaucoma is a common diagnosis seen in ophthalmic and optometry practices. It is the most common cause of irreversible blindness worldwide and the most common optic neuropathy (Quigley & Broman, 2009). It is a collection of progressive, neurodegenerative diseases that result in retinal ganglion cell (RGC) axon degeneration and death (Chang & Goldberg, 2012). The RGC axon degeneration results in corresponding psychophysical abnormalities, including visual field loss. This visual field loss typically begins in the peripheral visual field and progresses to the central visual field.

For more than a century, glaucoma treatment has been directed at lowering intraocular pressure (IOP), yet often disease progression continues to occur even in

patients with significant IOP reduction. This has been demonstrated in several randomized controlled trials (The Advanced Glaucoma Study, 2000; The AGIS Investigators, 1994; Lichter et al., 2001; Heijl et al., 2002). It has recently been reported that the entire visual pathway may be involved in glaucoma (Chang & Goldberg, 2012; Chen et al., 2013; Yucel et al., 2001; Gupta et al., 2001; Gupta et al., 2006; Boucard et al., 2009). Chen and colleagues (2013) reported on structural brain abnormalities in patients with primary open-angle glaucoma (POAG). This was a clinical observation study that included 15 participants with bilateral POAG and 15 healthy, normal control subjects. The researchers gathered optical coherence tomography (OCT) and 3-dimensional magnetic resonance imaging (MRI) data for each participant. The group measured the cross-sectional area of the optic nerve and optic chiasm and the gray matter volume of the brain. The participants in the POAG group compared to the control group showed a significant decrease in bilateral gray-matter volume in several areas of the brain and a significant increase in gray-matter volume in other areas of the brain. In addition, the cross-sectional are of the optic nerve and optic chiasm and the retinal nerve fiber layer (RNFL) were significantly decreased in the study group. The authors conclude that the study detected changes in the visual cortex of patients with advanced POAG, but these central nervous system changes extend well beyond the visual cortex. This study supports the hypothesis that glaucoma, specifically POAG not only is an ocular disorder, but a disease involving the entire visual pathway (Chen et al., 2013). This study provides evidence that glaucoma is more than an ocular condition; it is also a progressive neurological condition. In theory, this could account for some of the reading difficulty detected in some with early glaucoma.

Glaucoma and Quality of Life

A search of the literature was conducted using descriptors "glaucoma and reading," "glaucoma and reading impairment,' glaucoma and reading performance," "occupational performance," "occupation and reading," "quality of life and glaucoma" to identify studies examining reading performance in those with glaucoma and specifically to identify any studies in the area of reading, glaucoma and occupational performance. There were several studies identified that examined quality of life (QoL) in those with glaucoma. These early QoL studies were the first to identify complaints of central vision loss issues, such as reading and seeing detail, among those with glaucoma.

The QoL studies that began in the late 1990s examined vision-related QoL and clinical indicators (Sherwood et al., 1998). Sherwood and colleagues (1998) reported on a pilot study examining glaucoma's impact on QoL and its relation to clinical indicators. This group used a stratified cross-sectional study design to compare QoL between patients with glaucoma and control subjects. The study included 56 patients with glaucoma and this group was compared with 54 nonglaucomatous controls. They found that there were significant differences in QoL perception between a sample of participants with glaucoma and a control group. Differences in scores by race were found, with African American patients having lower general health scores than Caucasians. No differences were found in scores between males and females. In the glaucoma group, increasing severity of field loss and decreasing visual acuity correlated significantly with diminished quality of life. This was particularly evident with the Activities of Daily Vision Scale (ADVS). ADVS is a scale used to assess vision-related QoL in which scores are trichotomized into categories including the following: the least

difficulty with visual tasks, some difficulty, and the most difficulty. No previous study has documented subjective aspects of visual function and QoL in persons with glaucoma, nor had any correlation between QoL measures and clinical indicators ever been established. In this study, the researchers were among first to determine whether there are any differences in perceptions of QoL between a group of persons with glaucoma and a comparable sample of nonglaucomatous control subjects, exploring the correlations between QoL measures and commonly used clinical indicators in persons with glaucoma. These study results demonstrate the significance of using a QoL assessment when examining impact of this condition on their everyday life. The patients will be better informed about their disease process and how glaucoma impacts their ADLs.

Nelson, Aspinall, Papasouliotis, Worton and O'Brien (2003) also explored patients' self-reported visual disability resulting from glaucoma by means of a questionnaire developed by the research group to identify activities strongly associated with a measure of visual field loss. This questionnaire sought to quantify different psychophysical aspects of visual function and to assess the relationship between objective measures of visual function and patients' perception of their vision-related quality of life. This group identified five factors as main groups of difficulties encountered by glaucoma patients. These factors include near vision (reading and seeing faces), peripheral vision, dark adaptation and glare, personal care and household tasks, and outdoor mobility. These studies were the first to report that persons with glaucoma experienced changes in functional performance from central field loss. This challenged the notion that the central clinical features of glaucoma were mobility issues and glare sensitivity. This was groundbreaking in that it has long been thought that those with glaucoma suffer

peripheral visual field loss early in the disease. The results of this study challenge this notion and indicate that more research needs to investigate this new phenomenon.

Ringsdorf, McGwin and Owsley (2006) examined the relationship of visual field impairment to both vision-specific QoL and visual and nonvisual symptoms in a large cohort of persons with glaucoma. The study population was approximately 2/3 African American. The authors contend that previous literature has been somewhat limited in examining the association between field impairment from glaucoma and health-related QoL because most of the prior studies samples have been predominantly Caucasian despite that fact glaucoma is more prevalent in African Americans. They also note that previous studies have not had large study populations, regardless of race.

The study cohort consisted of individuals aged 55 and older, diagnosed with glaucoma and no other eye condition causing vision loss. There were 576 participants deemed eligible to participate. The data for this study was obtained from two sources, including medical record abstraction to confirm the diagnosis of glaucoma, best-corrected distance visual acuity for both eyes and visual fields for both eyes of each participant. The visual fields were used to calculate a visual field defect score for each eye based on the Advanced Glaucoma Intervention Study (AGIS) scoring system (Rinsgdorf, McGwin & Owsley, 2006). The second data collection method was a telephone survey. The group collected information on socio-demographic, self-reported medical conditions and cognition using the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). Vision-specific health-related QoL and glaucoma symptoms were measured using seven subscales of the 25-item National Eye Institute Visual Function Questionnaire (NEI VFQ-25) (Mangione et al., 2001). The seven subscales chosen were based on

functionality, ocular pain, general health and vision. The Glaucoma Symptom Scale [(GSS) (Lee et al., 1998)] was used to assess visual and nonvisual symptoms.

Ringsdorf, McGwin and Owsley (2006) reported results on 345 surveys with sixty-two percent of the respondents reporting African American race. The average age was 73 and slightly over half of the participants were female. The research showed that, regardless of race, the lowest NEI VFQ-25 subscales were for general health (50s) and general vision (60s) and the highest for social functioning and color vision (all averaging in the 80s). For the better seeing eye in African Americans, statistically significant correlations were observed for general vision, near activities (reading and seeing details such as faces), distance activities, social functioning and color vision; for the worse eye significant correlations were observed for general vision, near activities, distance activities, color vision and peripheral vision.

For the first time, this study provided information on the performance of NEI VFQ-25 subscales and the GSS for both African Americans and Whites diagnosed with glaucoma based on a large cohort. The results demonstrated that scores on the NEI VFQ-25 and the GSS are distributed similarly among African Americans and Caucasians with glaucoma.

Spaeth, Walt and Keener (2006) looked at the impact of glaucoma on ability to function and on QoL to guide therapeutic strategies for improved adherence to therapeutic regimens and to suggest alterations in environments to help the patient cope better with the effects of the disease. This group presented a discussion of the major instruments that were currently available to assess QoL, especially in patients with glaucoma and indicated the strengths and limitations of the various methods. This

research supports the importance of doctors doing a careful evaluation of the patients in their care. It also supports the practice of assessing QoL as being a critical part of understanding how glaucoma affects the patient. Spaeth, Walt and Keener (2006) contend that degradation of visual ability that is associated with glaucoma can impair a patient's ability to perform many common activities, even though acuity in central vision is retained mostly during early and middle stages of the disease. Some of these activities include tasks such as following a line of type while reading adjusting to changing in light conditions and activities that are dependent on peripheral vision or perception of contrast. They contend that QoL information can guide therapeutic choices and lead to suggestions to alter the person's home environment to minimize problems with obstacles, lighting or performance of household and reading tasks. They further state that such adaptations might permit more years of unassisted living for elderly patients, which would be a significant benefit. Adaptations to increase or improve reading to complete IADLs could be one such adaptation that could increase the years of unassisted living for older adults.

The authors conclude their discussion by stating that QoL research in glaucoma has shown considerable progress and has provided important insights over recent years. For clinicians these insights can help focus the dialog with the patient as they seek the most therapeutic regimen. They further conclude that continued efforts to improve the methods for collecting and analyzing data are expected to further the understanding of the impact of glaucoma.

Aspinall and colleagues (2008) sought to examine the quality of life and priorities of those with glaucoma and found that the two main priorities reported were "reading and seeing detail" and "outdoor mobility." Aspinall and colleagues contend that most

conventional QoL measures are useful in identifying the presence, absence or severity or frequency of symptoms, impairments and disabilities, they do not assess the relative importance or priority of different symptoms and disabilities that may give a better idea of when to intervene.

Aspinall and colleagues (2008) used standardized, functional questionnaires to explore the relationship between the different QoL scales and clinical and functional data. Not only did the participants report the importance of reading, but they also reported "a lot of difficulty with reading" (p. 1911). The results of this study show that the concerns of a group of patients with glaucoma are primarily associated with the vulnerability of central vision as the disease progresses, and not with the consequences of visual field loss that are commonly thought to characterize the disease. For example, the most frequently reported problems with vision from many of the QoL questionnaires have been related to lighting and glare. While this factor has been assessed as less important by patients when judged within the context of several vision-related factors. The findings that patients are concerned about the vulnerability of central vision (reading and near tasks) rather than the characteristic features of visual field loss (mobility) also suggest that the focus of rehabilitation should not simply be on mobility, as it is only addressing part of the problem.

These findings have practical implications for the clinical management of glaucoma, as well as the low vision rehabilitation management of persons with resultant vision loss from the disease. From the point of view of low vision rehabilitation, the present findings emphasize the importance of not relying on a patient's stated concerns in isolation of other aspects of vision-related QoL (Aspinall et al., 2008). For example,

whereas the most frequently reported problems with vision from the QoL questionnaire were related to lighting and glare, this factor was assessed as less important when judged within the context of several other vision-related factors (i.e., "reading or seeing detail" and "getting about outside the house").

Another research group associated with the Salisbury Eye Evaluation (SEE) project, examined the relationship between glaucoma status and measures of visual function. The researchers looked at how the factors affected by glaucoma are associated with self-reported difficulty with vision-intensive tasks (Freeman, Munoz, West, Jampel & Friedman, 2008). This study was part of a larger, population-based project. This group used clinical examination data and self-report of visual difficulty data with the Activities of Daily Vision Scale (ADVS). The authors found that bilateral glaucoma was associated with greater odds of having difficulty on the overall ADVS. Bilateral glaucoma was also associated with having some difficulty on ADVS subscales. Another interesting finding in this population-based study is bilateral glaucoma was associated with the most difficulty on the near vision subscale while unilateral glaucoma was not associated in a statistically significant manner with any of the ADVS subscales.

Freeman and colleagues (2008) found that individuals who had glaucoma in both eyes reported the most difficulty on the ADVS QoL questionnaire than those without glaucoma. Conversely, those with unilateral glaucoma were no more likely than those without glaucoma to report the most difficulty on the ADVS. It is interesting to note that this was the first of the QoL studies to associate more self-reported difficulty in those with bilateral glaucoma.

Medeiros and colleagues (2015) examined the association between longitudinal changes in QoL and the rates of progressive visual field loss in persons with glaucoma. Moreover, they looked at the significance of the relationship between standard automated perimetry (SAP) and patient-reported outcomes in the form of questionnaires. In this study, the group used the National Eye Institute Visual Function Questionnaire (NEI VFQ) – 25 (Mangione et al., 1998) for patient-reported outcomes. This study had 161 participants, who underwent monocular and binocular SAP, along with administration of socioeconomic and clinical questionnaires. This data was collected initially for baseline data and then at 6-month intervals for a total of 2 years.

Medeiros and colleagues found that changes in bilateral visual field sensitivity as assessed by SAP were significantly associated with changes over time in patient-reported QoL outcomes in glaucoma. This group examined this relationship further by evaluating the association between rates of progressive loss in different regions of the visual field and longitudinal changes in QoL (Abe et al., 2015). The researchers contend that it is important to investigate the impact that change in different regions of the visual field can have on QoL. One supporting argument is that loss of sensitivity in central areas of the visual field may carry a larger impact of QoL than loss of sensitivity in peripheral areas. The methods for this study are similar to their previous study, including perimetry testing and Rasch Analysis of the NEI VFQ-25. This study included 236 patients with glaucoma who were followed for an average of 4.3+/-1.5 years. The participants had an average of six NEI VFQ-25 questionnaires given over this time period. The results demonstrated that loss of vision in the central inferior region corresponded to the greatest impact on NEI VFQ-25. They also found that change in NEI VFQ-25 scores was also associated

with severity of visual field loss at baseline. For the central inferior visual field, each 1 decibel (dB) lower mean sensitivity at baseline was associated with a 0.15-units/year greater decline in NEI VFQ-25 scores. The relationship between progressive field loss and change in NEI VFQ-25 scores was approximately two times stronger for the central inferior compared with the peripheral superior region of the visual field (Abe et al., 2016). This finding is not surprising because this central inferior area would carry a greater impact on the ability to perform daily activities such as reading. This is the first report of the association of visual field loss and QoL and the first study to quantify their magnitude.

The QoL studies demonstrated that those with glaucoma, in addition to mobility and glare/light sensitivity issues, are reporting difficulty with near or central vision tasks. The more recent QoL findings have provided interesting insight. This includes the development that those with peripheral vision loss, often significant, attach greater importance to their central vision tasks. Continued improvements in the collection and analysis of QoL data should assist health care and service providers with the effective therapies and treatment options for those with glaucoma.

Older Adults and Reading

As the number of adults ages 65 and older continues to rise steadily across the US (Administration on Aging, 2015), the issue of successful aging has become increasingly important. A common determinant of successful aging has been the ability of older adults to maintain their independence (Garfein & Herzog, 1995; Roos & Havens, 1991). Rowe and Kahn (1997) further explain successful aging as involving these three main components: low probability of disease and disease-related disability, high cognitive and

physical functional capacity, and active engagement with life. Older adults who remain independent often utilize fewer health care resources, thus putting less of a strain on the health care system (Roos & Havens, 1991). One way aging adults can maintain independence is through continuing to read. Several occupations, specifically instrumental activities of daily living (IADLs) require individuals to accurately read and comprehend information. These are necessary for tasks and activities such as that presented in a monthly bill or for administering a daily medication. Even successfully aging adults can have difficulty reading and understanding documents related to health information, such as informed consent documents (Baker, Gazmararian, Sudano, & Patterson, 2000).

As the aging population confronts new technology, increasing availability of health care information, and increasingly complex personal finance management systems (Harris, Rogers, & Qualls, 1998), their ability to read and to comprehend what they read is critical. In 2014, over 16% of Americans ages 65 and older remained part of the US labor force (Administration on Aging, 2015), contributing to their need and desire to maintain functional reading skills.

Any discussion of the likely changes in reading and writing skills with advanced age also must consider the cognitive and sensory changes that are pervasive among older adults. Older adults can continue to perform as well as younger adults in terms of attention tasks. Research has shown the older adults' performance on these attention tasks is typically slower (Legge et al., 2007). The connection between sensory function and cognition are apparent across the life span but become much more pronounced with advancing age (Baltes & Lindenberger, 1997; Schneider & Pichora-Fuller, 2000). The

most striking issue of deterioration in cognitive function with advancing age reported widely in the literature is the decline in working memory (Kemper, Kynette, Rash, O'Brien, & Sprott, 1989; Schneider & Pichora-Fuller, 2000). Working memory is a cognitive function involving the limited-capacity system used for holding multiple bits of material, while the material is manipulated in some way or combined with additional incoming material (Craik, Anderson, Kerr, & Li, 1995). Together with reading comprehension, working memory has been shown to have significant impact on language comprehension (Qualls & Harris, 2003).

Regardless of what one reads, there are several essential related abilities involved. Some of these reading abilities include the understanding of vocabulary, decoding, and reading fluency. These reading-related skills assist the reader in comprehension of what is read (Duke, Pressley, & Hilden, 2004; Kamhi & Catts, 1999). These areas, while widely studied in children, have not been studied in the aging population. Adults who report having difficulty reading have been shown to have poorer performance in sound segmenting and non-word reading tasks than children of comparable reading skill level (Greenberg, Ehri, & Perin, 1997).

One theory related to reading and literacy was posed by Goodman (1996), where he described reading as the process of deriving meaning from print. This perspective contends that reading is a transactional interaction between the individual reader and the text with the purpose of making meaning. That is, reading is more than verbally producing the letters on the printed page. In involves the reader's establishment of comprehensibility from an interaction with written symbols. This information is of importance to note when examining reading in those with visual field loss, visual acuity

and contrast sensitivity deficits as these readers are already at predisposition to struggle with reading.

Champley and colleagues (2008) sought to address the paucity of information available on aging adult readers. This group completed a preliminary study to gather information related to reading abilities of typically aging older adults, the strategies that older adults use to improve reading comprehension and the types and frequency of reading material older adults use. The study included 96 adults, mostly college-educated participants between the ages of 65 and 79 years. The participants had no history of neurological incident or disease. Because older adults can have declines in auditory and visual acuity, individuals were included if they had functional corrected vision and functional hearing.

As with the previous research on older adult reading, the Champley group found that participants performed significantly better reading expository text. The participants also were found to be fluent oral readers, with words correct ranging from 95 to 99%. The group also found a correlation between reading comprehension and reading-related skills (vocabulary, decoding and reading fluency). Overall, the participants in this study demonstrated reading comprehension and reading-related skills that were generally above average compared to the normative data for the standardized assessments used in the research (Champley et al., 2008).

One of the research questions sought to determine what types of materials and with what frequency older adults read. Nearly all of the participants in this study indicated that they read the newspaper on a regular basis. Three quarters of the participants indicated they used electronic mail. While previous studies have not

examined reading of electronic media despite research indicating that reading material by computer screen positively affects comprehension and recall in older adults (Moore & Zarbrucky, 1995). In this study, half of the participants reported that they accessed the internet on a regular basis (Champley et al., 2008).

While there are limitations to this study, including lack of ethnic diversity in sample, lack of diversity in educational levels and a disproportionately large number of female participants, this report provides some understanding of typical adult's abilities with regard to reading.

Summary

Reading is an important part of daily life for older adults. It is also important to understand older adult reading characteristics, including information related to reading abilities of typically aging older adults, the strategies that older adults use to improve reading comprehension and the types and frequency of reading material older adults use.

Normal Reading and Visual Function

Common visual tasks such as reading or finding the bathroom at a restaurant require us to analyze large amounts of information and at high rates. There are many basic visual processes that underlie the performance of these tasks. For reading, some of these visual processes include visual acuity, visual fields, contrast sensitivity, among others.

Visual Acuity

Visual acuity refers to the sharpness or clarity of vision at a distance (American Optometric Associations, AOA, 2016). Visual acuity is dependent on neural and optical factors. These factors include sharpness of the retinal focus, health and functioning of the

retina and sensitivity of the interpretative area of the brain (Colenbrander, 2001). Visual acuity (VA) is a measure of the spatial resolution of the visual processing system. VA is tested by requiring the person whose vision is being tested to identify optotypes – an example is the Tumbling E, developed by Snellen and is a variation of the Snellen E (Snellen, 1862). The optotypes are on a printed chart and are viewed from a set viewing distance. Optotypes are represented as black symbols against a white background, representing maximum contrast (Colenbrander, 2001).

Good spatial resolution is important for a variety of everyday tasks, but probably most critically for reading text. Visual acuity also plays a central role in discriminating and recognizing small objects or the detailed features of objects. The visual acuity demand for a given task depends on the size of the critical detail in the task and the observation distance. For example, a person with good visual acuity might be expected to recognize faces at about 20 meters. To recognize the same faces, a person with poor visual acuity would have to get significantly closer (Lennie & Van Hemel, 1994).

Visual Field

The visual field is the entire area that can be seen when the eye is directed forward, including that which is seen with peripheral vision. The normal field of vision is about 160 degrees horizontally and approximately 90 degrees vertically. The greatest sensitivity is found at the very center (central-most 15-20 degrees) of the field and this sensitivity decreases toward the periphery (Heijl & Patella, 2002). Defects in a person's visual field adversely affect the patient's ability to perform daily activities such as personal hygiene, reading and driving, as well as many others (Kedar, Ghate & Corbett, 2011).

Visual Span

The visual span is referred to as the range of letters, formatted as in text that can be recognized reliably without moving the eyes. Legge, Mansfield and Chung (2001) examined the relationship between letter recognition and reading speed. This research group contend that the size of the visual span varies with reading speed. Work in the Legge reading lab (discussed in more detail in the following sections) has shown that for adults with normal vision, manipulation of text contrast and print size (Legge, Cheung, Yu, Chung, Lee & Owens, 2007), character spacing (Yu, Cheung, Legge & Chung, 2007) and retinal eccentricity (Legge et al., 2001) produce highly correlated changes in reading speed, as well as the size of the visual span.

Kwon, Legge and Dubbels (2007) sought to determine the relationship between reading speed and the size of the visual span. They found that a larger visual span correlates with faster reading speed. This group contends that for eye-movement mediated reading of lines of text on a page or a screen, a larger visual span means that more letters can be recognized accurately on each fixation.

Contrast Sensitivity

The contrast of text letters refers to the luminance difference between the strokes (or pixels) making up a letter's features and the background. Contrast sensitivity (CS) is defined as the ability to distinguish objects (in this case letters) as they degrade in contrast from the background (Hall, Wang & McAnany, 2015). Contrast sensitivity is a fundamental aspect of vision. Its measurement provides useful independent information in relation to a patient's visual function, which may not be revealed by VA (Lovie-Kitchen & Brown, 2000; Rubin, West, Munoz et al., 1997). Research has shown contrast

sensitivity function is a strong predictor of real-world performance and can provide better insight into a patient's disability and quality of life than visual acuity (Owsley, 2003). Owsley and colleagues (1998) reported significant relationship between CS and driving (Owsley, Ball & McGwin, 1998). Studies have shown a strong relationship with CS among mobility and walking (Marron & Bailey, 1982)), face recognition (Bullimore, Bailey &Wacker, 1991)), reading speed (Whitaker & Lovie-Kitchen, 1993; Crossland, Cuhlam & Rubin, 2005), computer task accuracy (Scott, Feuer & Jacko, 2002) and ability to perform activities of daily living (Haymes, Johnston & Heyes, 2002; West, Rubin & Bromann, 2002).

Factors Affecting Reading Performance

The traditional view on the functional impact of glaucoma is that the disruption is usually first noticed in peripheral vision. However, difficulties with central vision, including seeing details and difficulty with reading have consistently been reported as problems experienced by persons with glaucoma (Aspinall et al., 2008). Many questionnaire studies have found links between glaucoma and problems with reading (Parrish et al., 1997, Nelson, Aspinall & O'Brien, 1998, Aspinall et al., 2008, Freeman, 2008). There is little available in the literature about how the field loss that occurs in glaucoma affects reading performance and even less was found on how persons with glaucoma perceive the changes in their reading performance due to their disease.

Gordon Legge and colleagues from the University of Minnesota Reading Laboratory examined several factors that influence reading in persons with low vision and those with normal vision. This laboratory published 20 studies between 1985 and 2001. In 2007 the laboratory published the book, *The Psychophysics of Reading in*

Normal and Low Vision, Legge and colleagues' (1985) first paper detailed the vision requirements for reading with normal vision. Low vision reading, encompassing several diagnoses, including a small population with glaucoma has been studied for several years. Legge and his colleagues' series on factors that influence reading were primarily conducted on persons with age-related macular degeneration (AMD); they are the first to demonstrate the impact of the physiologic changes seen in many eye conditions, including glaucoma. The studies completed in the Legge reading lab reported on impairment in five visual functions and found that this accounted for many of the reading deficiencies experienced by persons with low vision. The visual functions included intermediate acuity, contrast sensitivity function, critical print size, reading speed, and central visual field deficit (Legge, 2007).

Glaucoma has historically been characterized by initial peripheral visual field loss, followed by visual field loss developing in the foveal region of the retina as the disease progresses. There is a growing body of evidence suggesting that early glaucomatous damage can involve the macula and central visual fields (Hood et al., 2013). Hood and colleagues (2013) examined retinal nerve fiber layers (RNFL) and retinal ganglion cells (RGC) in healthy controls and in those with glaucoma using optical coherence tomography (OCT). They compared the data obtained from OCT to testing using automated perimetry testing, which is part of the diagnostic criteria used to diagnose glaucoma. They found that there was detectable damage to the macula in those with early glaucoma that did not correspond to visual field loss in the static automated visual perimetry testing. They conclude that macular damage from glaucoma is common and can occur early in the disease.

Central field damage can cause disruption of eye movements that are used for reading (Legge, Ahn, Klitz, & Luebker, 1997). The effect of central field loss on reading performance has been thoroughly studied and delineated in multiple research studies (Cacho, Dickinson, Smith & Harper, 2010; Cheong, Legge, Lawrence, Cheung & Ruff, 2007; Crossland, Culham, & Rubin, 2005; Legge, 2007; Lovie-Kitchin, Bowers, & Woods, 2000). Death of retinal ganglion cells corresponding to retinal photoreceptor cells in the central visual field, which can occur in glaucoma, and the resulting field loss causes a cascade of changes in visual functions. These changes cause impairment in reading performance (Battista, Kalloniatis, & Metha, 2005). Reduced acuity and contrast sensitivity result in a blurry appearance of text with reading. The combined result of the visual field disruption and decreased contrast sensitivity leads to the need to increase print size and this can lead to a decrease in reading speed.

Visual Acuity and Its Effect on Reading Performance

Acuity, as previously mentioned, is the ability to see small details at a specified distance. Visual acuity can be reduced in many eye conditions, including glaucoma, macular degeneration, cataracts, diabetic retinopathy and several other conditions. While studies have shown that older adults are likely to experience mild declines in reading acuity as they age, if the older adult is free of pathology, they are able to retain the ability to read most print (Brabyn, Schneck, Haegerstrom-Portnoy & Lott, 2011).

Contrast Sensitivity and Its Effect on Reading Performance

Another finding from the Legge (2007) reading lab series of studies was that older adults experience a decline in contrast sensitivity with aging. Contrast sensitivity is reduced in many eye conditions, including macular degeneration, diabetic retinopathy

and glaucoma. Older adults without eye pathology are typically able to minimize the effect of reduced contrast sensitivity by adding lighting when reading (Brabyn, Schneck, Haegerstrom-Portnoy, & Lott, 2001). Low vision readers with reduced contrast sensitivity function do require higher levels of letter contrast to maintain reading speed than normally sighted readers. These readers often use additional lighting, such as a reading lamp and magnification to compensate for limited contrast sensitivity function (Bowers, Meek, & Stewart, 2001; Legge, 2007; Watson, 2001; Whittaker & Lovie-Kitchin, 1993).

As previously mentioned, contrast sensitivity is reduced in persons with glaucoma. Burton, Crabb, Smith, Glen and Garway-Heath (2012) examined the effects of lowering the contrast of text with reading in participants with glaucoma. The authors hypothesized that participants with glaucoma would have a greater change in reading speed than age-similar visually healthy people when letter contrast is reduced. This was a case-control study with subjects between 50 – 80 years of age with a range of bilateral, glaucomatous visual field loss.

The participants underwent visual and non-visual testing to include cognition, reading tests, computer-based reading ability test and an informal questionnaire to identify how much reading participants did in daily life. The primary outcome for this study was the change in reading speed demonstrated by each individual observer as a result of a decrease in letter contrast. The participants whose reading was most affected by lowering contrast had more severe visual field defects and poorer visual acuity. The participants most affected by lowering contrast also demonstrated poor contrast sensitivity function.

Visual Field and Its Effect on Reading Performance

Burton, Saunders and Crabb (2014) studied the effects of the visual field (VF) on reading. They contend that while a link between measured visual acuity (VA) and reading performance is well established, the relationship between VF loss and difficulty with reading is less understood. They contend that it is very likely that VF defects that occur close to fixation can potentially inhibit reading to a greater extent than VF defects in peripheral areas. The study included 54 patients with glaucoma and 38 visually healthy controls. Silent reading speeds were measured using non-scrolling text on a computer screen. The aim of this study was to investigate how different areas of the binocular VF compare in their associations to measured reading speed in clients with glaucoma and preserved VA. This information can be useful clinically because knowing this could facilitate a better understanding of which patients may have difficulty with this important everyday activity by interpreting their VF results.

The participants completed three cognitive assessments and evaluations of visual function, including the Humphrey 24-2 threshold VF test in each eye; the results were combined to produce binocular integrated VFs (IVFs). They found no statistically significant association between IVF and reading speed. Ranking individual thresholds indicated that the inferior left section of the IVF was most likely to be associated with reading speed. They conclude that certain regions of the binocular VF impairment may be associated with reading performance even in patients with preserved VA. They also noted that the inferior left region of patient's IVFs may be important for changing lines during reading.

Critical Print Size

As a reader approaches the critical print size, reading speed also decline. Legge (2007) described critical print size as "the smallest print size at which a person can still achieve maximum reading speed" (p.134). Those with normal vision have a wide range of print sizes they can read with maximum speed. Conversely, persons with low vision, this could be related to glaucoma or other eye pathology, have narrow ranges of print size that can be read at maximum speed. Although critical print size varies among low vision readers, the print can be much larger than that of a reader with normal sight (Legge, 2007).

Reading Speed

Reading speed is the primary measure used to define reading performance in persons with normal and low vision readers (Legge, 2007). Several research studies on low vision reading have shown that reading speed decreased as scotomas or central visual field loss increased in size and when these visual field changes affected both eyes (Cacho, Dickinson, Smith, & Harper, 2010; Crossland, Culham, & Rubin, 2005; Lovie-Kitchin, Bowers, & Woods, 2000; Whittaker & Lovie-Kitchen, 1993; Legge, 2007).

Reading and Vision Loss

It has been established that reading is an important communication skill for maintaining connections to the social world, carrying out essential everyday activities, and for overall quality of life. Ryan, Anas, Beamer and Bajorek (2003) reported on interviews that were completed with older adults with age-related vision loss and how they cope with this in everyday activities. They completed the in-depth interviews with 26 visually impaired seniors experiencing moderate to severe vision loss. The aim of the interviews was to clarify the role of reading for leisure in the lives of the participants.

Furthermore, they sought to learn how the participants dealt with the reading required for instrumental activities of daily living (IADLs). They addressed two main areas of reading, for leisure and for functional independence. The participants were asked about reading both before and after vision loss. They asked about the importance of reading, reasons for reading, materials read, time spent reading and how their vision loss had affected their ability to read for leisure. The researchers also asked questions about IADLs adapted from Lawton & Brody (1996) and included the ability to prepare meals, use the telephone, handle personal finances, travel within and outside of the community, shopping and medication management. For each task, the researchers inquired about the reading-related problems and strategies for dealing with them. The researchers wanted to identify barriers for adaptation and strategies for reducing the barriers (Ryan et al., 2003).

The results demonstrated that reading, including the aid of talking books, computers or another person, was just as important after vision loss as before. On average the interviewees reported approximately seven hours of reading per week, this was equivalent for both before and after vision loss. The authors also note that talking books were utilized by 58% of the participants to continue reading books for leisure. With regards to reading for IADLs, the barriers found included reading expiration dates and appliance dials with meal prep; identifying numbers on phones with telephone use; writing checks for financial management; and signage, maps and numbers on doors or buses for travel (Ryan et al., 2003). The authors also note the strategies reported by participants for compensation for dealing with the reading required of some IADLs. The strategies fell into the following categories: relinquish the activity altogether or continue a valued activity either by simplifying the activity, restricting the activity or developing

alternative techniques. Some compensation incorporating assistive devices included low-tech devices (i.e., felt pens, magnifiers, lamps) and high-tech devices (i.e., computers and closed-circuit televisions). Also, with coping strategies for IADLs researchers found that interviewees were flexible, persistent and creative in dealing with these reading barriers.

Glaucoma and Reading

It has only been since the QoL studies specifically looking at the glaucoma population were completed that reading performance and factors affecting reading have been studied. In the last two decades, several researchers have examined specific factors and the effect on reading in those with glaucoma. Freidman, Munoz & Rubin (1999) reported on the SEE project, which was a population-based evaluation. The SEE project was completed with the older adult residents of Salisbury, Maryland to directly test when age-related eye disease produces disability. They specifically looked at visual function and disability in older adults and examined self-reported reading difficulty compared to reading speed. They found that ninety percent of subjects who were asked about reading a newspaper and had their reading speed tested reported little or no difficulty reading a newspaper. Of this group, 10.8% read newsprint-sized text more slowly than 80 words/min (normal is 250-300 WPM), although they reported little or no difficulty reading small print.

Another group associated with the SEE study developed and validated a sustained silent reading assessment (Ramulu, Swenor & Jefferys, 2013). They determined that outloud tests of reading speed do not accurately reflect sustained silent reading and these reading assessments cannot capture change in reading speed over time. They found that the glaucoma group did not differ from controls on reading acuity but read slower on the

sustained reading performance. Those with bilateral glaucoma-related visual field deficits reported the most declines in reading speed. Ramulu states the following, "Reading speed decline may be a marker for 'reading fatigue,' which often is described among glaucoma patients in the clinical setting, and indicates that the effect of glaucoma on reading measured in the first minute of reading likely underestimates the true impact of the disease" (p. 671). Ramulu then suggests further studies are needed to corroborate the group's findings and to quantify reading fatigue through self-report. Moreover, more studies needed to examine the association between change in reading speed with reading over time and the patient report of reading fatigue.

Reading Ability

Nguyen, van Landingham, Massof, & Ramulu, (2014) examined reading ability and reading engagement in a research group of participants with glaucoma and a group of age-matched controls. This group used a validated assessment, the Activity Inventory (AI) to assess reading ability and reading engagement. The AI is a visual function questionnaire developed and validated by Massof, Ahmadian & Grover (2007) to measure visual ability in patients with low vision. This group used the following reading items of the AI: reading magazines, newspaper articles, bills, financial statements, handheld menus, religious texts, books, word puzzles, typed mail, written notes or mail. For each reading task of the AI, more glaucoma subjects described moderate-to-severe difficulty as compared to controls. Also, less reading ability was found for glaucoma patients as compared to controls. Nguyen and colleagues then concluded that having glaucoma made reading more difficult and this was seen across a broad range of reading tasks. Furthermore, overall reading is significantly affected by glaucoma. Participants

with glaucoma were more likely to avoid reading, with a trend showing greater restriction of tasks involving sustained reading, such as reading books and newspaper.

The research related to reading and glaucoma has shown that those with glaucoma do have impaired reading (Ramulu et al., 2013a, 2013b; Nyugen et al., 2014). Findings of the research on reading performance show persons with glaucoma read slower and fatigue earlier than age-matched normal on sustained reading tests (Ramulu et al, 2013). This is consistent with Ramulu and colleagues' findings in previous reading research (Ramulu, 2009, Ramulu et al., 2013a). Participants with glaucoma were also found to take longer in recovering once reading fatigue was present. After resting for a period of time, the readers with glaucoma were unable to return to their baseline reading speeds. Persons with bilateral glaucomatous visual field loss, experience difficulty completing activities of daily living that require sustained reading and as a result may avoid or limit their performance of these ADLS (Nguyen et al., 2014).

Burton, Crabb, Smith, Glen and Garway-Heath (2012) completed a case-control study. The aim of the study was to explore the hypothesis that persons with glaucoma will have a greater change in reading speed that age-similar visually healthy people when letter contrast is reduced. The study included patients with glaucoma between 50 and 80 years of age. The participants had a varying range of VF defects in both eyes. The participants completed binocular visual field testing, visual acuity and contrast sensitivity measurements. The participants also completed the Burt Reading Test (Scottish Council for Research in Education), which is a standardized reading test designed to measure reading abilities. This assessment has been previously used to assess reading skill in an adult population (Burton et al., 2012). The participants also completed cognitive tasks

and a reading experiment that involved reading short paragraphs. The paragraphs were adapted from an English fiction book, eight of the 16 paragraphs were printed at 100% contrast and the other eight were printed at 20% contrast. The participants read the paragraphs silently on a computer screen and ended the reading by pressing a button on the keyboard. The participants were also asked simple comprehension questions about the text.

The primary outcome for this study was the change in reading speed demonstrated by each observer. This change in reading speed was found to be the result of decrease in letter contrast. For the eight trials for each level of contrast, the median reading duration in seconds was calculated for each participant. The difference between these two median values determined the percent reduction for the individual.

The data analysis showed that median reading duration at the 100% contrast condition was 16.1 seconds in the patient sample and 16.4 in the control sample. Median reading duration at the 20% contrast condition was 19.2 seconds in the patient sample and 17.1 in the control sample. Patients with glaucoma read lower contrast text with a median speed that was 20% slower than higher contrast text. It was also noted that patients with impaired reading speed at lower letter contrast had worse visual acuities, contrast sensitivity and visual fields, when compared with those patients whose performance fell "within the normal limits." (Burton et al, 2012).

While there are few studies that have directly assessed reading performance in patients with glaucoma, this study provides evidence that low contrast between the text and background reduces reading speed in patients with glaucomatous VF defects in both

eyes. Previous research has demonstrated that difficulties with reading can lead to diminished QoL (Gallucci et al., 2011).

Kwon, Liu, Ptel and Girkin (2017) examined slow reading in persons with glaucoma and sought to determine if the change in reading speed was related to a shrinking visual span in central vision (Kwon et al., 2017). Kwon and colleagues describe the visual span as the size of the window in the visual field within which letters can be recognized reliably. The larger the visual span, the more likely there are smaller saccades and fixations required to read, thereby leading to faster reading.

The purpose of this study was to examine the impact of glaucomatous field loss on the size of visual span, visual acuity, contrast sensitivity and stereo-acuity. A secondary purpose was to determine which visual factors contribute significantly to slow reading in persons with glaucoma. The study included 38 participants, 17 with primary open-angle glaucoma and 21 normally sighted participants. The majority of the glaucoma participants were in the early or moderate stages of glaucoma. For each participant, the researchers measured binocular visual acuity, binocular contrast sensitivity, VF mean deviation and the visual span. The visual span was measured with a trigram letter-recognition task in which participants identify trigrams flashed at varying letter positions left and right of the fixation. Oral reading speed was also measured using short blocks of text presented on a computer monitor.

The results indicated a significant difference between glaucoma patients and age-similar normal controls in binocular visual acuity, binocular contrast sensitivity, stereo-acuity and better eye visual field mean deviation. They also noted that while the acuities

of those with glaucoma were not as good as that of age-similar normal controls, the visual acuities were considered near normal (Kwon et al., 2017).

In order to determine the factors that could best predict the reading speed of glaucoma patients, the researchers performed multiple regression analysis in which the size of the visual span, binocular visual acuity, binocular contrast sensitivity, stereo-acuity and visual field mean deviation were entered as independent variables and reading speed being the dependent variable in this model. The analysis revealed that the size of the visual span was the only factor that contributed significantly to the reading speed of glaucoma patients, while the other visual factors had no significant independent effect on reading speed. Furthermore, they found that the size of the visual span measured in the central 10° VF decreased by 11.02 bits for those with glaucoma, meaning that those with glaucoma tend to recognize an average of 2.3 letters less than the age-similar normal controls would recognize at one glance (Kwon et al., 2017).

The researchers demonstrated that reading speed was significantly slower in participants with glaucoma relative to age-similar normal controls. Considering that the majority of the participants with glaucoma are in either early or moderate stage of glaucoma, the objective evaluation of out loud reading rate further supports the view that reading difficulties are present even in relatively moderate stages of glaucoma.

Reading and ADLs

Although studies have been completed that identify the components of reading that are affected by glaucoma, most significantly reading endurance, very few studies have explored how these changes in reading affect the person's ability to complete specific ADLs nor the perspectives of person with glaucoma on their ADL performance.

Many questionnaires and self-report studies have found a link between glaucoma and problems with reading, but this has been corroborated by only a very few performance-based studies. One study, using performance-measures taken from proficiency in a spectrum of activities, concluded that reading small print is one of the most visually demanding tasks for persons with glaucoma (Burton, Saunders & Crabb, 2014). Another research group indicated that measured reading speed deficits only occur in patients with advanced bilateral VF loss and that these deficits are heightened when sustained silent reading instead of out loud reading is measured (Ramulu, 2013).

The conventional view of the functional impact of glaucoma is that it primarily disrupts peripheral vision. Yet difficulties with central vision, including seeing details and difficulty with reading, are consistently reported as problems experienced by patients with glaucoma (QoL studies). Ramulu (2009) evaluated reading and glaucoma to determine if, and at what point, glaucoma affects out loud reading speed. This group found that there were high rates of spoken reading impairment throughout the elderly sample. The presence of glaucoma was associated with slower reading rates and increased reading impairment was noted with advanced bilateral VF loss. It is important to understand the person's perspective of how the reading changes affect the ability of a person with glaucoma to complete daily activities in order to identify the most appropriate intervention strategies. An instrument that assesses the relationship between changes in reading performance and completion of reading dependent ADLs would be useful in understanding the person's perspective on vision changes and reading.

Effects of Low Vision on Activities of Daily Living

Older adults who experience low vision are often flanked between a state of dependence and independence in relation to their performance of routine tasks (Finger, et al., 2011). The older adult with low vision has to seek assistance from family members or others for some ADL and IADLs that they can longer perform, but still have the ability to safely complete some of the task they need to perform. An older adult, not living in an institution and suffering from low vision confronts emotional, as well as physical barriers that influence performance of daily tasks. In recent times, many studies discussing low vision have highlighted that an adult with low vision experiences an increase in complications with respect to his daily tasks (Finger et al., 2011). The presence of low vision in a non-institutionalized adult leads to complications in performing routine activities, such as walking in the community and home (Schinzel, et al., 2014).

These factors, when combined with visual impairments, lead to devastating impacts on the independence of a person. For example, the interaction of vision and hearing loss leads to substantial decrements in the performance of activities and social roles (Crews & Campbell, 2004; Kempen, Verbrugge, Merril & Ormel, 1998).

Additionally, low vision experienced late in life leads to reduced travelling, constrained physical activities, disruption in social interactions, and limits the independent mobility of a person (DeVries et al., 2012). It has been noted often that whenever an independent adult experiences low vision, it will result in is a decreased sense of self-worth and self-competency, particularly when the independency transforms into dependency.

Crews, Jones and Kim (2006) reported on use of national survey data to examine multiple effects of nine comorbid conditions on physical function, participation and health status among older adults with visual impairment. Some of these conditions included breathing problems, depression risk, diabetes, heart problems, hearing impairment, joint problems and stroke. The conditions were selected as they are common among older adults and most lend themselves to prevention or treatment. There were nine conditions that were examined in combination with vision loss. The study phenomenon was to illustrate the effects of the specified conditions on five outcome measures. The outcome measures included the following: walking, climbing stairs, shopping, socializing and self-reported health status.

The researchers compared older adults who had neither visual impairment nor these conditions with adults of similar age who had one of the nine conditions only, visual impairment only or both visual impairment and the condition. The results indicated older adults with visual impairment frequently experience comorbid conditions. Moreover, these conditions are associated with difficulties in walking, climbing steps, shopping and socializing and with significantly more self-reports of declining health. This group contended that these results underscore the importance of greater attention to addressing the multiple needs of older people who are visually impaired. Also, the results suggest that interventions by health care providers including rehabilitation services, have the potential to reduce or prevent the deleterious effects of comorbid conditions (Crews et al., 2006).

Various issues associated with daily activities confronted by adults experiencing low vision include difficulties in paying household bills, inability to read package

directions, difficulty in preparing meals, difficulties in using a telephone, accidentally burning themselves on a stove, and inability to differentiate between spoiled food and non-spoiled food (Lamoureux & Pesudovs, 2011). Additionally, adults suffering from low vision often are forced to exert more mental and physical energy to complete tasks that were once simple and required minimal energy to complete.

Summary

There have been several studies focused on occupational performance, including occupations that require reading and the psychometrics of reading and how low vision affects reading. There have also been studies examining QoL in those with glaucoma that revealed some themes or functional deficits related to central vision when it was long thought that glaucomatous vision changes were more aligned with mobility issues. The results of these studies lead to initial and emerging research on reading with glaucoma. However, it is clear that more research is needed to understand how changes in reading changes associated with glaucoma affects occupational performance. With the aging population, the prevalence of glaucoma will continue to increase in the coming years. Low vision rehabilitation practitioners will see more and more clients with glaucoma. It will be essential to understand how reading impairment affects occupational performance. Once the problem has been defined and is understood, more evaluation tools and intervention strategies can be developed to address the problems that those with glaucoma face when participating in occupations. This study will seek to understand the thoughts and beliefs of those with glaucoma on the effects of reading impairments on occupational performance. The primary goal of this proposed research is to develop an

instrument that seeks to reveal the effects of reading impairment associated with glaucoma on occupational performance.

Theoretical Framework

This study was guided by the theory of Occupational Adaptation (Schultz, 2009). This theory was first developed as a frame of reference in 1992 by Schkade and Schultz. The frame of reference further developed into a theory aimed at describing the link between the two fundamental constructs of occupational therapy: occupation and adaptation. One distinction between this theory and other occupation-based frameworks is that occupational adaption intervention focuses on improving adaptiveness, whereas others focus on improving functional skills. Adaptation has been a consistent area of interest for occupational therapist for several years. However, as Schultz and Schkade (1997) point out, there has been little effort to describe how persons generate an adaptive response.

The theory of OA is based on several assumptions about occupational performance and human adaptation. These include, 1) Competence in occupation as a lifelong process of adaptation to demands to perform; 2) Demands to perform occur naturally as part of the person- occupational environment interactions; 3) When demands for performance exceed person's ability to adapt, dysfunction occurs; 4) Adaptive capacity can be overwhelmed by disability, impairment and stress; 5) The greater the level of dysfunction, the greater the demand for change in adaptive process; and 6) Sufficient mastery and ability to adapt result in success in occupational performance (Schultz, 2009).

The OA process describes the interaction between three elements of occupational adaptation: the person, the environment and their interaction. Each element is fluid and dynamic. Change in one element influences other elements. The primary goal of the occupational adaptation process is to achieve mastery over the environment. This process is dynamic, self-organizing, complex and its elements are highly interactive. OA theory contends that personal adaptation is a human phenomenon that is constantly in a process characterized by disorder, order and reorganization. The desire, demand and press for mastery are constantly present within an occupational environment.

The focus of the element of person is on the internal factors. The occupational adaptation process in the element begins with a constant factor of desire for mastery. The person is made up of systems that are unique to the individual and these include sensorimotor, cognitive and psychosocial systems. All occupations involve the person systems. Moreover, the contribution of each system shifts depending on the circumstances surrounding the specific occupation. The element of the occupational environment focuses on the external factors of the OA process that affect the person. The process in the occupational environment begins with a constant demand for mastery. The occupational environment is dynamic. The occupational environment is also the experiential context within which the person engages in occupations and occupational roles. Schultz (2009) describes three types of occupational environment. These include self-care, leisure/play and work. Each are affected by the person's experiential context.

The element of interaction focuses on the interplay between the external and the internal factors that continuously interact through occupation. The constant factor is press for mastery that yields the occupational challenge. This press for mastery is created

by demand and desire for mastery. In response to this demand, the person creates an internal adaptive response to the situation and then an occupational response is produced. An occupational response is an observable outcome of the adaptive response, which refers to an action and behavior carried out in response to an occupational challenge.

Schultz contends that an imbalance between the desire and demand for mastery could lead to inability to adapt to an occupational challenge, leading to dysfunction. Furthermore, dysfunction also occurs when challenges exceed the person's capacity to adapt. Lastly, the more adaptive the individual, the more functional.

Some implications for occupational therapy (OT) practice using the theory of OA include the following, 1) the main goal – the client's ability to adapt is used to maximize effectiveness to adapt; 2) client is assisted in choosing occupational roles and these guide treatment; 3) OT manages the occupational environment to promote the client's ability to adapt; and 4) client is the agent of own change.

While no research was found using the OA Frame of Reference to describe adaptation via use of occupation in older adults specifically with visual impairment, at least two articles documenting use of the framework in OT practice were reviewed. Bontje, Kinebanian, Josephson and Tamura (2004) explore the experiences of occupational adaptation among a small number of older adults with physical disabilities. OA was defined as overcoming disabling influences on occupational functioning. The researchers, occupational therapists and professors, interviewed eight, community-dwelling older adult clients. The clients were found to recruit already familiar problem-solving strategies and personal resources as well as resources in their social and physical environments to identify prospects of potential solutions and to create solutions to

overcome constraints on occupational functioning. Furthermore, participants strived for finding satisfaction through occupations, a meaningful theme, which emerged as the object of occupational adaptation.

Another research group examined the shift from a biomechanical approach to an occupational adaptation approach in hand therapy (Jack & Estis, 2010). This group contended that investment of time and self to develop therapeutic relationships with clients appears incongruent with today's time-constrained health care system. They used the OA approach to improve therapists' interactions with clients and this led to improved outcomes. Moreover, bridging the gap of these incongruences is the challenge therapists face to provide high-quality, client-centered, occupation-based treatment. This case report illustrates a shift in approach from biomechanical to OA in an orthopedic outpatient clinic. The researchers concluded that an OA approach provides the bridge between the application of clinical expertise, client-centered, occupation-based therapy and the time constraints placed by payer sources (Jack & Estis, 2010).

Summary

In summary, this framework emphasizes the person's experience of self in relevant occupational contexts. Their holistic approach gives equal importance to the occupational environment, the person, and their interaction. Within this framework, the practitioner can identify OT interventions that are consonant with the patient's unique OA experience and that will promote the ability to perform occupations with greater efficiency, effectiveness, and satisfaction. Third, the occupational adaptation frame of reference focuses treatment on the patient's internal adaptation process and the use of

meaningful occupations to affect that phenomenon as opposed to outward measures of performance (Schultz & Schkade, 1992).

This framework is a good fit for the current study as it centers on OA, specifically OA in context of the occupational environment, the person and their interaction. Adaptation is necessary for completing any activity once vision loss is present. Moreover, each individual is unique and lives, works and participates in occupations in different environments. The person should be seen as an adaptive being and a being that desires mastery and will adapt to the environment and task demand in order to achieve mastery. The more adaptive an individual is, the more functional they will be.

Mixed Methods Research

This study used a mixed methods research approach. Mixed methods research has emerged as the "third" research paradigm (Creswell & Plano Clark, 2018). Mixed methods research is formally defined as a procedure for collecting, analyzing, and integrating both quantitative and qualitative data at a defined stage within a single study for the purpose of gaining a better understanding of the research problem (Creswell & Creswell, 2018; Tashakkori & Creswell, 2009; Tashakkori & Teddlie, 2003). The rationale for mixing qualitative and quantitative data within one study is grounded in the fact that neither quantitative nor qualitative methods alone are capable of conveying the trends and details of a situation. Thusly, the combination of both approaches yields richer data about the phenomenon of interest (Onwuegbuzie & Johnson, 2006).

Mixed methods research involves collecting, analyzing, and integrating both qualitative and quantitative data (Teddlie & Tashakkori, 2009). This approach contends that the combination of the qualitative and quantitative methods provides the best

approach to truly comprehend a phenomenon (Creswell, 2005). Creswell and Plano Clark (2018) describe the central premise of mixed methods as the use of quantitative and qualitative approaches, in combination, which provides a better understanding of research problems than either approach alone. The outcome of this approach is high-quality and complex meta-inferences. These meta-inferences emerge from the integration of the inferences from the results of the quantitative phase and the qualitative phase of a mixed methods study (Ivankova & Kawamura, 2010, Tashakkori & Teddlie, 2003). The following paragraphs will detail the quantitative and qualitative approaches that combined and integrated, make up the mixed methods approach.

One rationale for using the mixed methods research approach is instrument fidelity. Creswell and Plano Clark (2018) and Teddlie and Tashakkori (2009) both reported on the use of mixed research as a tool for developing quantitative instruments. They presented a 10-phase process for use of a mixed methods framework for optimizing the development of a quantitative instrument. The process starts with the concept of crossover analyses, which involves using one or more analysis types associated with one tradition (e.g., quantitative analysis) to analyze data associated with a different tradition (e.g., qualitative data). The authors also breakdown the concept of instrument development as it pertains to the construction of quantitative instruments. They describe a framework for developing and assessing the fidelity of a quantitative instrument via what is termed as areas of validity evidence and they further specify the types of crossover analyses that are pertinent for each of the multiple areas of validity evidence. The authors provide an outline for how qualitative and quantitative approaches can be

combined to enhance instrument fidelity at the different stages of the development process.

When developing a quantitative instrument, qualitative methodology is often used to inform the items and scales of the instrument, including question design and ensuring the content is correct. After instrument is developed and reviewed for content, it is tested using quantitative methods. Use of a mixed methods approach with emphasis on the qualitative phase for this study is a systematic way to develop a new instrument (Morgan, 2014). After a review of the relevant literature, no instrument was identified that would assess how changes in reading associated with glaucoma affect occupational performance among older adults. Integration of the qualitative data and quantitative data can enhance generating knowledge regarding this phenomenon. The newly-developed instrument, once reliable and valid, will allow practitioners to gain valuable knowledge about occupational performance and therefore develop effective intervention strategies.

Qualitative Methods

The qualitative approach is most commonly used in social and behavioral sciences. Qualitative research consists of a set of interpretive practices allowing researchers to study a central phenomenon in natural settings (Creswell & Poth, 2018). Researchers obtain qualitative data through methodology that yields detailed, thick description capturing personal perspectives (Creswell & Poth, 2018). Qualitative method is used to understand the study population's beliefs, experiences, attitudes, behavior, and interactions (Gibson et al., 2004). It generates narrative data. Answers to qualitative research questions are in narrative form (Teddlie and Tashakkori, 2009).

Quantitative Methods

The quantitative approach is typically deductive, objective and general. This approach is useful in describing trends and explaining relationships among variables. This research involves numerical data and analysis, where the research question guides investigations and are concerned with unknown aspects of a phenomenon of interest (Creswell & Plano Clark, 2018). To conduct quantitative research, the investigator specifies research questions, locates and/or develops instruments to gather data to answer the questions, and analyzes the numbers from the instruments using statistics. From the results of the analyses, the researcher interprets the data using prior predictions and research studies. The final report is presented in a standard format, which lacks bias and displays researcher objectivity (Creswell, 2012). This method is well known for the strength of producing results that apply to generalized processes and not specific individuals or settings (Creswell & Plano Clark, 2018).

Summary

Mixed methods research involves collecting, analyzing, and integrating both qualitative and quantitative methods (Teddlie & Tashakkori, 2009). This model provides the best approach by combining qualitative and quantitative methods to truly comprehend a phenomenon (Creswell, 2005).

The rationale for mixing both types of data within one study is grounded in the fact that neither quantitative nor qualitative methods alone are sufficient to capture the trends and details of a phenomenon. Rather, the integrated approach yields richer data about the phenomenon of interest (Onwuegbuzie & Johnson, 2006). The outcome of this approach is high-quality and complex meta-inferences. These meta-inferences emerge from the integration of the inferences from the results of the quantitative phase and the

qualitative phase of a mixed methods study (Ivankova & Kawamura, 2010, Tashakkori & Teddlie, 2003).

When developing a quantitative instrument, qualitative methodology is often used to inform the items and scales of the instrument, including question design and ensuring the content is correct. After instrument is developed and reviewed for content, it is tested using quantitative methods. Use of a mixed methods approach with emphasis on the qualitative phase for this study is a systematic way to develop a new instrument (Morgan, 2014). Integration of the qualitative data and quantitative data can enhance generating knowledge regarding this phenomenon.

CHAPTER THREE

METHODOLOGY

After an exploration of the relevant literature it was noted that there is not much understanding of reading related to visual changes associated with glaucoma in older adults. Presently, it is known that when those with glaucoma read they experience fatigue and decreased endurance (Ramulu et al., 2009, Ramulu et al., 2013). Additionally, glare sensitivity and some central visual field issues impact QoL for those with glaucoma, when these issues were thought to usually not impact functionality until late in the disease process (Aspinall et al., 1998). It can be difficult to compare results across studies that feature different approaches with varied data collection methods and data analyses. Furthermore, it can be a challenge to determine strength of association or influence of glaucoma on measured daily living variables, ranging from participation in reading to use of coping methods. Use of a mixed methods approach with emphasis on the quantitative phase for this study provided a systematic way to develop a new instrument. No instruments were identified from the literature to assess impact of reading changes associated with glaucoma on occupational performance; therefore, it is necessary to first explore the concept in depth.

Study Design

A sequential exploratory mixed methods design utilizing both qualitative and quantitative data collection methods across two sequential research phases was employed for the study (Creswell & Plano Clark, 2018). The purpose of this design is to answer

exploratory and confirmatory questions about a new phenomenon (Teddlie & Tashakkori, 2009). Another purpose of this design is to guide development of a new instrument, specifically use of qualitative data to inform quantitative instrument development. The exploratory sequential design is a two-phase design, which the researcher begins by collecting and analyzing qualitative data in the first phase (Creswell & Plano Clark, 2011). From the initial exploratory results, the researcher builds to a second phase where quantitative data are collected and analyzed to test or generalize the initial qualitative findings. This design is well suited for exploring a phenomenon (Plano Clark & Creswell, 2008). It is one of the most used approaches when researcher needs to develop an instrument as one is not available (Creswell, 2017). When using the sequential exploratory design, the researcher first qualitatively explores the research topic with a few participants (Creswell & Plano Clark,2011). These qualitative findings will guide the development of items and scales to include in the quantitative survey instrument. In the quantitative data collection stage, the researcher implements and validates the instrument quantitatively. In this design, the qualitative and quantitative data are connected or integrated through the development of the instrument items.

In planning research procedures for a mixed methods study, there are important characteristics that affect the procedures related to the chosen research design. One characteristic includes the sequence of qualitative and quantitative phases (Tashakkori & Teddlie, 1998; Creswell, 2012). The sequence refers to which approach, either qualitative or quantitative, is given more weight and attention during data collection methods and analysis (Morgan, 2014; Creswell, 2003). The priority of data collection and analysis is determined by goals of the study, nature of the research question, type of

study participants, particular design of each phase and intended use of data (Creswell, 2012). Although a few studies have focused on psychometrics of reading impacted by glaucomatous VF loss and others have focused on particular aspects of reading impacted by the visual field loss seen with glaucoma, little has been found on reading changes associated with glaucoma and occupational performance in an older adult population. The QoL studies clearly show that central vision tasks (i.e., reading and detail tasks) are reported as difficult among this population. In this study, priority was given to qualitative data as the data informed the following phase of the study (i.e., results of the qualitative phase will guide the quantitative phase of the study). Qualitative data was connected to the quantitative results and was further used to explain the statistical results in the quantitative phase. The lack of published research identifying the effect of reading changes on occupational performance in older adults with glaucoma supports an argument in favor of using a sequential exploratory design with priority on the qualitative phase. The collection of qualitative data in the first phase is important to understanding the perspective of those who experience the changes in reading as this phenomenon has not been studied previously. According to Creswell (2015), the qualitative research design is used to explore a phenomenon. Once the phenomenon has been explored, the researcher can identify themes, develop an instrument and subsequently test it in the next, quantitative phase of study. Morgan (2008) contends that using preliminary qualitative methods to operationalize the concepts to be measured allow the researcher to be "in touch" with the behaviors and opinions that people associate with your research topic.

Implementation refers to the timing of when the qualitative and quantitative data collection and analysis phases occur in the study. In the exploratory sequential design,

the qualitative data are collected and analyzed (phase one) and followed by quantitative data collection and analysis (phase two).

The exploratory mixed methods approach is a popular design used broadly in health science to develop or adapt an instrument. One example includes the Palcanis and colleagues (2012) exploration of evidence-based dentistry (EBD). This group designed a mixed methods conceptual framework using four phases and eight sequential procedural steps to determine perceptions about curriculum reform based on EBD among faculty, students and alumni of a school of dentistry. Researchers assigned priority to the quantitative data collections, analysis, outcomes and evaluation (Palcanis et al., 2012). Students and faculty responded to survey items developed after a review of the literature and focus group interviews. This group then conducted exploratory factor analysis on the 51 survey items. This analysis yielded a three-factor solution: Factor I – EBD benefits; Factor II – translation of EBD into the clinical environment and curriculum enhancements; and Factor III – EBD barriers (Palcanis et al., 2012). This systematic integrative process to develop a quantitative tool informed by qualitative data collection yielded important information guiding dental curriculum enhancement.

Similar to the exploration of EBD by Palcanis and colleagues (2012), this study sought to use qualitative data to inform items on a quantitative instrument. In this study, qualitative data collection was completed first to identify participants' thoughts and feelings on reading impairment associated with glaucoma and its effects on occupational performance. Quantitative data collection and analysis was completed to better understand the impact on occupational performance that reading changes associated with glaucoma have on older adults as identified in Phase I.

The visual model of this study in Appendix B provides a flowchart of the general step-by-step process involved in planning, constructing, and validating the new instrument. The study involved two phases and were completed in six stages. There were 14 procedures used to develop and pretest the new instrument. These procedures are described in the following sections.

Philosophical Assumptions

While there is a philosophy that underlies each methodological approach, pragmatism serves as one of the philosophical foundations for mixed methods research (Plano Clark & Ivankova, 2016). Pragmatism is oriented toward solving practical problems in the "real world" (Morgan, 2010). Pragmatism is described as being concerned with understanding the relationship between actions and their consequences. Furthermore, knowing this can help us to get more control over our actions, at least more than if we used blind trial and error. The knowing can direct our actions (Biesta, 2010). Cameron (2011) describes pragmatism as "a practical approach to a problem…" (p. 101). Pragmatists believe in the philosophy of using procedures that are the best fit for a research problem being studied. Furthermore, they believe the researcher should use as many methods as needed to understand a research problem (Creswell, 2014). Pragmatism is a real-world, practice-oriented worldview. Pragmatic researchers also are more able to combine empirical precision with descriptive precision (Onwuegbuzie, 2003).

Pragmatists acknowledge that each individual's knowledge is unique because it is based on individual experience. This is important when assessing a relatively unknown phenomenon, such as the effects of reading changes associated with glaucoma on

occupational performance in older adults. Using the individual input, in this case, older adults with glaucoma living in a metropolitan area of a southeastern state, to inform an instrument to assess reading changes related to glaucoma and occupational performance.

In the first phase, the researcher used qualitative methods for discovery and exploration, with the goal to uncover things that are essentially unknown at the beginning of this project. The pragmatic approach combines the inductive logic of qualitative exploration, the deductive reasoning of quantitative confirmation and further the creative problem-solving emphasis of abduction (Johnson & Onwuegbuzie 2004; Morgan, 2014). This is done to generate useful and reliable knowledge for both theoretical and practical application. According to Morgan (2014) one of the key advantages of discovery-oriented designs is to improve the specification of the models that you will test.

Within this and other paradigms, assumptions exist to define further the philosophical lens; these include ontology, epistemology and axiology (Lincoln & Guba, 1985). The ontological assumption relates to beliefs one holds about the nature of existence and reality; specifically, whether reality is subjective with multiple explanations or objective and factual (Lincoln & Guba, 1985). The ontological view of the qualitative researcher conducting this mixed methods study is that "universal, absolute realities are unknowable and the objects of inquiry are individual perspectives or constructions of reality" (Hatch, 2002, p. 15). For this study, the researcher gathered individual perspectives through qualitative, personal interviews. This is done to construct multiple realities of how older adults with glaucoma feel about the impact reading difficulties have on occupational performance. Because individual experiences are bound by diverse contexts, developing a single reality to describe this experience is impossible.

Closely related to the ontological is the epistemological assumption. This assumption describes our view of how knowledge is acquired and the relationship between the researcher and what is being studied (Lincoln & Guba, 1985). The researcher serves as the primary instrument of data collection, resulting in a personal relationship with participants. This is the foundation to build rapport and to develop collaborative relationships that facilitate the investigation of the central phenomenon, i.e., the effect of changes in reading in older adults with glaucoma on occupational performance.

It is nearly impossible to achieve separation between the researcher and participants. A level of autonomy between researcher and participant will be retained while partaking in their individual roles in this study. This will provide the foundation for the axiological assumption that inquiry is value-bound (Lincoln & Guba, 1985). It will be impossible to investigate a topic such as the effect of reading changes and the effect on occupational performance among older adults without consideration of values. The researcher and participant develop values and beliefs about this topic that must be acknowledged. Biases and experiences are listed as the researcher's own "lens."

Phase I, Qualitative

Phase I of this study was a qualitative exploration of the thoughts, beliefs and perceptions of older adults with glaucoma on reading difficulties they experience and how this impacts their occupational performance. This phase included qualitative data collection, followed by analysis to organize the data into themes, sub-themes and categories. The themes, sub-themes and categories were then used to create the items of the scale to be used in data collection in Phase II.

Recruitment and Sampling for Qualitative Phase

Selection of individuals was done purposively to obtain diversity in glaucoma diagnoses and reading experiences. The researcher recruited participants from the University of Alabama at Birmingham School of Optometry (UABSO) and the UAB Center for Low Vision Rehabilitation (UAB CLVR). The UABSO Adult Ocular Disease clinic manages adults with ocular diseases, such as glaucoma, macular degeneration and several others. This low vision clinic sees an average of 15 patients with glaucoma per day, four days per week. The UAB CLVR is a multi-disciplinary center serving central Alabama and surrounding areas with comprehensive low vision serves. The center has patients of all ages and all levels visual impairment. The center provides optometry, occupational therapy and psychology services to their patients. The center treats over 1000 patients with glaucoma each year. Both of these sites were used for recruitment in order to get the perspective of older adults with glaucoma on reading changes, any changes they experience in daily life and the compensatory strategies they employ, if any. Permission to access these recruitment sites was granted by the medical directors of these sites.

Clinicians and researchers employed at both centers identified individuals with a diagnosis of glaucoma (verified by medical record) who can read (by patient self-report) and disseminated the study recruitment letter. The recruitment letter for the study was written to meet readability and visibility standards for the visually impaired. For example, the researcher presented text at the 5th grade reading level and included bolded Arial font that was large print, specifically 20 point. This formatting allowed potential participants with vision loss access to the recruitment letter with or without optical devices. The

recruitment letter carefully explained and provided the study purpose, inclusion criteria, use of and access to data, contact information, an option to decline participation, and a copy of the interview questions (please refer to Appendix B for example of the recruitment letter and the interview questions list). Once the potential participants contacted the researcher via telephone, the research process was explained and the visit to complete the interview was scheduled.

After a medical record review of over 150 records of those identified as potentially meeting the inclusion criteria, the researcher compiled a list of 85 prospective participants. These prospective participants were sent the IRB-approved recruitment letter via mail. The recruitment letter included information describing the purpose, the nature of the data and its uses, time commitment, and who to contact for more information, see Appendix C. Of the 85 potential participants that were sent letters, 12 responded with interest.

Sampling for this study was two-phased, as there are two phases of data collection and data analysis. Qualitative or Phase I sampling included a purposeful sampling strategy, as the research attempted to obtain insights into the individual's experiences (Onwuegbuzie & Leech, 2007). Purposeful sampling in qualitative research is used to intentionally select participants who have experienced the key concept being explored in the study (Creswell & Plano Clark, 2018). The study specifically utilized maximum variation sampling, which is a type of purposeful sampling. Maximum variation sampling is used to document unique or diverse variations that have emerged in adapting to different conditions (Patton, 2002). Maximal variation sampling is a purposeful sampling strategy used by researchers to sample cases or individuals that differ on some

characteristic or trait (Creswell, 2011). For this study, characteristics included equal samples of female and male participants and those residing in communities of varying socio-economic status. Because the prevalence of glaucoma is higher in African American population (National Center for Health Statistics, 2011) than in other populations, it was important to have representation from this population among those interviewed. The researcher strived for equal number of male and female participants; representation from varying socioeconomic statuses; and racial diversity among the participants. Potential participants were screened for cognitive deficits using the Short Portable Mental Status Questionnaire [(SPMSQ), (Pfeifer, 1975)]. This screening tool has been validated and standardized for use with the older adult population. It is used to quickly screen for cognitive deficits and does not include visual tasks. A score of less than two is considered to have normal cognition. Those who scored two or less on the SPMSQ were invited to participate in the research study. Potential participants were also screened for depression and health literacy. The screening tool used to screen for depression was the Geriatric Depression Scale (GDS-SF) (Sheikh and Yesavage, 1986). The GDS-SF consists of fifteen yes or no questions about mood experienced over the past week. The score of 5 or less on the GDS-SF were considered normal. Those scoring in the normal range and those with depression who were receiving treatment for it were invited to participate in the study. The screening tool used to screen for health literacy was the Rapid Estimate of Adult Literacy in Medicine—Short Form (REALM-SF) (Arozullah et al., 2007). REALM-SF) is a 7-item word recognition test to provide clinicians with a valid quick assessment of patient health literacy. A score of 4 to 6 on

the REALM-SF indicates a fourth to sixth grade reading level. The potential participants scoring in this range or higher were invited to participate in the research study.

Potential participants were screened for cognition, literacy level and presence of depression. These screenings included screening tools that have been standardized and validated for the older adult population. The SPMSQ is a 10-item cognitive screening tool that scores based on the number of incorrect answers on the 10 items. Those scoring 0-2 errors are considered to have "normal mental function" and those with 3-4 errors are considered to have "mild cognitive impairment," those with 5-6 errors will be categorized as having "moderate" and lastly "severe cognitive impairment" is noted with 7 or more errors (Pfeiffer, 1975). Those scoring in "normal mental functioning" and "mild cognitive impairment" were included in the study.

Rapid Estimate of Adult Literacy in Medicine (REALM) (Arizullah et al., 2007) will be utilized for literacy assessment. This assessment is a brief, validated instrument that has been standardized for assessing adult literacy. It involves reading a list of words and is scored by the number of words read. Those with a fourth to sixth grade literacy level and higher were included in the study. In addition to the literacy screening, the Geriatric Depression Scale-15 Item [(GDS-15) (Vinkers, Gussekloo & Stek, 2004)], was used to screen for depression. The GDS-15 is a self-report measure of depressive symptoms designed for use in older adults. This measure has been found to be a reliable and valid measure of depression in older adults. Those with no depressive symptoms and those with mild depressive symptoms who self-report treatment for the depression were included in the study.

The qualitative phase inclusion criteria consist of the following: adults 50-years-of-age and older; having self-reported glaucoma (diagnosis confirmed by database of patients with glaucoma diagnoses at recruitment site distributing letters to this cohort); English speaking; intact cognition evidenced by normal or mild cognitive impairment demonstrated on SPMSQ; free of depression as evidence by a score of less than 5 on GDS-15, literate evidenced by score of fourth to sixth grade reading level on REALM-SF and self-report of participation in occupations requiring reading.

The researcher's goal to recruit participants until saturation was achieved. Saturation occurs when the researcher no longer is hearing or seeing new information emerge within the data (Lincoln & Guba, 1985). Therefore, in qualitative methodology, sample sizes may vary depending on the study phenomenon. The researcher's initial goal was to recruit 15 to 20 participants. The researcher chose this sample size as it will likely provide enough data to reach saturation of the thoughts and perspectives of older adults with glaucoma on reading changes and the effects on occupational performance (Strauss & Corbin, 1998). Saturation occurred after twelve interviews.

Development of Interview Protocol

The study began with a qualitative exploration of the perceptions of patients with glaucoma on their reading abilities, reading difficulties, how the reading difficulties affect their daily occupational performance and what strategies they employ to deal with the changes they experience in reading to complete occupational performance. A semi-structured interview protocol was developed by the researcher with the committee providing guidance (See interview protocol in Appendix E). The format of the protocol followed the example provided by Creswell (2012). The protocol had a description of the

project to be read to the interviewees, and then it asked them if they would still like to participate. If they indicated yes, then the interview proceeded. Prior to beginning the interview, participants were given a code that they would use when being referred to in the study. After the code was given, an engagement question was asked initially to introduce participants. Specifically, the first question asked participants to talk about themselves. This question was used to (a) serve as an ice-breaker, (b) increase the comfort level of participants, and (c) gain additional details on the participants for the qualitative phase (Hatch, 2002).

The researcher developed the interview protocol and questions using information gathered from literature about qualitative methodology and the study phenomenon, including what previous research has shown about reading, glaucoma and occupational performance (Lincoln & Guba, 1985; Strauss & Corbin, 1998). Specifically, the researcher reviewed previous research examining older adult engagement in reading and the difficulty encountered with reading for occupational performance. This review of the literature found that those with glaucoma read slower, especially if bilateral field deficits (Ramulu, 2013a and 2013b); fatigued at a quicker rate than age-matched and took longer to recover once fatigued Ramulu, 2013a) and had decreased participation in reading tasks (i.e., newspaper) (Nuygen, 2014). Questions were expanded and modified, clarifying thoughts and beliefs on reading and any challenges faced with occupational performance and individual experiences and coping strategies for the challenges faced when attempting to complete reading tasks for occupations. Pilot-testing with three individuals with glaucoma, resulted in word changes to improve clarity and understanding of the questions.

Qualitative Data Collection

Each of the interviews were scheduled after the potential participant verbally agreed over the phone to participate. Once the participant agreed, the interview was scheduled. Most of the interviews were conducted in the participants' home environment, while three of the interviews were conducted over the phone. The face-to-face interviews were scheduled via telephone, once the participant agreed to the interview. The researcher traveled to the participant's home for the face-to-face interview. The screening procedures were completed and no participants were excluded based on screening data. Once the screen was complete, the researcher read the informed consent document to the participant. The participants were then asked to sign the informed consent, if they had no questions and still desired to volunteer for the interview.

The interviewer kept handwritten notes in addition to recording interviews. The purpose of the written notes was twofold. First, the researcher added notations and highlights to indicate the necessity to probe for clarification and second, the notes provided a backup copy in case of a problem with the recording.

The data was collected via interviews and field notes taken by the interviewer during the interviews. The first ten interviews were completed face-to-face and, in the participant's, natural environment, while the last two interviews were completed via telephone while the client was in their home. The last two interviews were completed via telephone because of the geographical distance to these locations. According to Jacob and Furgeson (2012), the qualitative interview should consist of open-ended questions. The interviewer should use a script to begin and end the interview. The questions should progress from easier to those that may be more difficult to answer. Another

recommendation is to use questions with opening phrase "Tell me about…" in the interview. The phrase "tell me about" is not only an invitation for the interviewee to tell a story, but it also assumes that the interviewee will talk and it subtlety commands the interviewee to begin talking.

With the participants who completed phone interviews, the researcher completed the screening procedures over the telephone. Once screening was completed, the researcher reviewed the consent form with participants and then mailed two copies of the informed consent, with instructions for returning one of the forms in the self-addressed stamped envelope that was also provided. Once the researcher received the signed informed consent, the participant was called and the interview was scheduled. Each of the interviews were recorded with a digital recorder.

The interviews lasted between one and one and a half hours each. Within this environment, the researcher ensured confidentially by securing a private space. The researcher audio-recorded each interview using the interview protocol to guide dialog. This script, sent with the recruitment letter, provided participants with a descriptive introduction to the study, the semi-structured open-ended research questions, and concluding remarks expressing appreciation to the participant. The first ten interviews were recorded using an Olympus VN-7200 digital voice recorder, while the telephone interviews were recorded with a call-recording app from the Apple App Store. All recordings were transcribed verbatim by the researcher. The interviewer's notes from the interviews were added to the transcriptions.

Each transcript was checked against the recordings by the researcher and notes taken for each interview for accuracy. Detailed notes taken during the interview sessions

were used to augment the transcripts of the audio recordings. Each interview recording was then transcribed by the researcher. The written transcription was then reviewed by the researcher for clarity. Two participants were called via telephone to review the transcription and provide corrections and/or clarification to the transcribed interview.

Qualitative Data Analysis

The data collected in the qualitative phase, was analyzed using inductive thematic analysis. The aim of the inductive approach is to reduce the volume of information by systematically organizing the data into categories and themes from specific to general (Creswell, 2014). According to Creswell and Creswell (2018), when using aspects of the qualitative results to inform the quantitative data collection, it is important for the researcher to be identifying useful quotes or sentences, coding segments of information and the grouping of codes to develop themes.

Creswell and Creswell (2018) describes data analysis as best represented as a "data analysis spiral." The researcher moves in analytic circles rather than using a fixed linear approach. The data is the center of the spiral and the facets of the analysis and "loops" of the spiral circle around the data. Some of the steps or "loops" of the spiral are described as follows:

Data management - the first step that began the process. In this study, the researcher organized the interview transcriptions into a computer file, converting the recordings to text in sentence, story form (see Appendix E for transcripts). Field notes from the researcher are included.

Reading and memoing – was the next step in the analysis process. Agar (1980) suggests that the researcher reads the transcripts in their entirety several times and

immerse yourself in the data. During this step, the researcher read the transcript several times and noted the ideas about the emergent themes.

Interpreting data into themes – the next step in the analysis process. Creswell (2014) describes this step of describing, classifying and interpreting the data as the heart of qualitative research. This loop in the spiral involves forming codes to represent the data. Coding involves aggregating the text into small categories and assigning labels to the code. Ivankova (2015) describes coding as a central strategy of inductive qualitative analysis, further describing it as what actually creates the picture of events. In the proposed study, the researcher used the data to develop themes. Themes in qualitative research are broad units of information that consist of several codes aggregated to form a common idea. The themes that were found became scales and subscales to be measured. The individual codes within each theme became the variables and some of the specific quotes from the individuals as specific items or questions on the instrument.

Thematic content analysis was conducted to search for themes across the data set following the approach described by Braun and Clarke (2006). The investigator read each interview transcription carefully and broke the text down to small units. Each unit was organized according to category, thus creating a large mass of data segments and annotations (McLeod, 2001). The process begins with organization and microanalysis of the data (Strauss & Corbin, 1998). Once audio tapes were transcribed, the researcher completed line-by-line analysis comparing records to observation field notes, when applicable, to envision categories, their properties and dimensions. Once transcribed, the researcher read and re-read the transcripts to identify meaning and associations across all 12 interviews. To accomplish this, the researcher completed simultaneous coding through

open and axial procedures. The researcher constantly compared the data during open and axial coding, using decisions to modify and inform the process (Strauss & Corbin, 1998).

Trustworthiness of Qualitative Data

Quality assurance plays an important role in qualitative research, but different strategies are employed than in quantitative research. In quantitative research, the researcher establishes reliability and validity of the data, whereas the qualitative researchers strive for trustworthiness. Trustworthiness of the study provides persuasion that the results are worth considering and contribute to the existing body of knowledge (Lincoln & Guba, 1985). The researcher employed methods to establish credibility, dependability, transferability, and confirmability - ensuring trustworthiness, quality, and authenticity of the study results. These terms are comparable to internal validity, external validity, reliability and objectivity used in quantitative methodology (Lincoln & Guba, 1985). Credibility refers to the extent to which the findings are believable and promote confidence in their "truth." Lincoln and Guba (1985) describe member checking as a critical technique for establishing credibility as this involves the participants in review of the data and findings. This review can help to ensure their perspectives are captured accurately. In the proposed study, the researcher completed member checking by summarizing key points expressed in the interview with study participants immediately following data collection (Lincoln & Guba, 1985). Participants had the opportunity to amend or confirm the summarized information. Also, researcher communicated with each of the participants about clarity of statements made during interviews. This was done in order to clarify items as the themes developed.

Dependability refers to the extent to which the findings are consistent and could be repeated. Lincoln and Guba (1985) suggested that use of a reflective journal addresses all four aspects of trustworthiness. For this study, the researcher kept a reflective journal. This journal contained information such as study procedures, methodological decisions, decision rationale, and personal reflections. This procedure also served as a strategy to ensure confirmability, which refers to the extent to which the findings are shaped by participant's views and not a researcher's bias.

A third procedure to ensure credibility and trustworthiness includes peer debriefing. Peer debriefing is based on the same principle as member checking but involves the researcher's discussing the research process and findings with impartial colleagues who have experience with qualitative methods. In the current study, this was completed by discussing the research process and findings with two optometrists, who specialize in low vision and who each have over 20 years of experience in patient care. Insights was discussed and problems presented as a form of debriefing. Lincoln and Guba (1985) suggest that this is one way to keep the researcher honest and the searching questions may contribute to a deeper analysis by the researcher.

Transferability refers to the extent to which the findings are applicable to other contexts. The strategy Lincoln and Guba (1985) suggest to ensure transferability is to collect detailed descriptive data. The use of thick, rich description will enable possible comparison with other research contexts. The researcher provided detailed accounts of the quantitative data collection and analysis.

Qualitative Analytical Process

According to Holloway and Todres (2003), qualitative analysis approaches are complex and nuanced. Technical rigor in quantitative analysis is a major factor in the credibility of qualitative findings. Analysis does not take place in a linear form as the parts of the process overlaps each other. Through this analysis the researcher captures important meaning from the data in relation to the research questions. (Braun & Clarke, 2006). For example, phrases that are repeated throughout the data were derived. These repeated phrases were found across all twelve interview transcripts. The thematic analysis involved moving back and forth among the twelve interview transcripts during data analysis. While there are multiple methods for thematic analysis, this study utilized the six steps outlined by Braun and Clarke, (2006).

Step 1: Familiarization with the data. Immersion involved 'repeated reading' of the data in an active way (i.e. searching for meanings, repeated phrases, etc.). The note-taking for developing themes began here. The researcher read over the transcripts as they were completed and several times after, highlighting and familiarizing with the data.

Step 2: Generating initial codes. Step two comprised generating an initial list of ideas about what is in the data. The researcher began to see common ideas and repeated phrases among the transcripts.

Step 3: Searching for themes. Step three began after all data was coded. In this step, the common ideas were sorted into potential themes and sub-themes. A table of themes and related topics was created. The table was helpful for sorting the common ideas into different themes. Step three involved relationships between codes, themes, and levels of themes. For instance, data that explored activities given up became the theme

"occupations given up" and activities that coded as difficult, but still completed with assistance became the theme of "occupations completed with difficulty" and also the theme of "methods for coping" emerged as well.

Keywords-in-context analysis identified keywords and surrounding words to determine the overall meaning of the keyword. The investigator used probes to further explore the meaning of keywords. For instance, keywords such as lighting, activities you complete each day, difficulty experienced with these activities and how do you cope with the difficulties experienced indicated the theme "methods for coping" with several sub-themes emerging (i.e., use of magnification devices, have someone do the task for you, lighting).

Narrative analysis treats data as potential stories. This allowed the researcher to consider research participants' personal evaluations. The study revealed several occupations that were difficult as a theme based on narrative analysis of participants' responses to the instructions to tell interviewer a little about themselves. For instance, a participant described themselves as a busy-body who was very healthy overall except she could not see, which caused her to have to stay at home.

Step 4: Reviewing themes. Step four involved two levels of reviewing and refining themes. Level one was a review of all coded data with consideration of whether they formed a coherent pattern. This review was done with the entire data set. This involved coding any additional data within themes that was missed in earlier coding. The table of themes was further developed and grouped by similarity listing the sub-themes.

Step 5: Defining and naming themes. Step five began with a completed thematic map. At this step, each theme had a detailed written analysis. It is also important to

consider how a theme fits into the broader illustration of the entire data set. This step should clearly define what the themes are. In this study, this process consisted of team members (e.g., researcher and a dissertation team member with qualitative research experience made up the research team) independently coding select pieces of text data and comparing the codes and emergent themes to resolve discrepancies.

Step 6: Production of a report. Step six was the final analysis and write-up. The purpose of the write-up was to tell the story of the data in a manner that demonstrates the validity of the analysis. This write-up included illustrative participant quotes to support the themes and sub-themes, as well as tell the story of the data.

Connecting Quantitative and Qualitative Phases

The next step included instrument development from the qualitative findings, moving into the second, quantitative phase. In this study, the qualitative and quantitative phases were connected following qualitative data collection and analysis. The results from the qualitative data analysis informed the instrument items. According to Morgan (2014), in discovery-oriented uses of qualitative input designs, the qualitative phase of the study is largely exploratory. For example, to develop a new questionnaire, start with a qualitative phase where researcher interviews participants and identify phrases, questions, or terms used to help derive the items used.

The researcher then examined the relationship among the items. Integration from the two study phases enhance generation of knowledge about how the reading changes associated with glaucoma affect occupational performance among older adults with glaucoma.

Item Generation and Format

Clarity of items also is a pertinent area for content experts (DeVellis, 1991). An instrument may represent a content domain accurately; however, participants may not respond due to unclear instrument directions, item format, or response options (Ferketich, 1991). To address clarity of the items, content area experts were asked to review the simplicity of item presentation and instructions found in the assessment. As a result of the content review process, items with complex sentence structure or unclear definitions were eliminated.

In this study, the researcher used the findings from the qualitative phase by applying it to the development of a quantitative instrument. At this point in the research project, the first draft of the instrument was constructed. The themes and sub-themes from Phase I were used to develop the items for the quantitative instrument. The instrument was developed based on the qualitative data analysis and a thorough review of the relevant literature. The literature was used for methodological guidance about the principles of the survey instrument development. For example, Ramulu and colleagues (2013) found that when reading continuous text silently, persons with glaucoma had less endurance than those in control group. Also, Nyugen and colleagues (2014) found that those with glaucoma reported less participation in reading tasks. These findings were reflected in the questions on the reading assessment. Instrument development was achieved by using the themes and sub themes – to makeup the items and the scales for the items. The items were fixed-responses (i.e., Likert-scale items) and checklists. The instrument was structured and closed-ended. The number of questions depended on the amount of information obtained in the qualitative interviews regarding the variables of

interest from the research questions. The variables included the following: 1) the changes which the older adult with glaucoma identify in reading that they experience; 2) how the changes affect occupational performance that require reading; and 3) the strategies that they employ to cope with the reading difficulties they experience in occupational performance.

Item Content

Structural Elements in Content Reviews

Items of an instrument are operational definitions; therefore, it is critical that items reflect the sample and measure a domain of content (Slocumb & Cole, 1991). When examining the content validity of an instrument, Berk (1990) suggested use of panel members be asked to judge how representative individual items are of the content domain. As part of the review process, a panel of experts read the *Glaucoma Reading Behaviors Inventory* and were asked to suggest revisions for items that were not consistent with conceptual definitions or were not representative of the content domain (Lynn, 1986). The panel of experts was comprised of two physicians, one optometrist and one ophthalmologist with many years of experience in evaluation and treatment of those with glaucoma; two occupational therapy practitioners who specialize in low vision rehabilitation and provide OT intervention with clients with glaucoma; the final member of the panel was a health science researcher with experience in survey development. The panel of experts was asked to review the instrument items with the following in mind: 1) are the items necessary to this instrument, 2) are the questions worded for optimal clarity and 3) are the answer choices clear. The panel members with sent the instrument and asked to make recommendations and edits on the document and provide any commentary

and recommendations for changes based on the 3 criteria above. Items deemed by the majority of experts to be not be important in measuring occupational performance and reading were excluded from the instrument. The majority of experts was determined as being three of five. If three members recommended changing or excluding an item, the recommendation was followed. There was a small number of items that were removed and there were a few items that were edited for clarity.

Reliability and Validity

Determining the reliability and validity of scales is an important aspect of the instrument development process. Reliability is defined as the ability of an instrument to produce consistent results (Onwuegbuzie et al., 2009). The validation of scales is essential to ensure the inferences drawn from a scale are accurate (Cronbach, 1971). Validity is the degree of accuracy with which an instrument assesses a construct that a researcher is trying to measure. A valid instrument allows for elimination of other possible explanations for the findings (Thorndike, 1997). Reliability and validity of the instrument was assessed as part of the development process.

Survey Pretest

The newly developed instrument for measuring glaucoma reading behaviors and the effects on occupational performance among older adults was pretested with a small sample of the study target population. This testing was done to ensure clarity and comprehensiveness of the items of each scale of the instrument and to develop content validity of the new instrument.

Following the review of the survey instrument, the researcher convened a small group of 10 members of the intended audience to pretest survey instructions and items.

Results of pretesting are described in Phase II survey pretesting. Following pretesting, a sample of 70 older adults with glaucoma pilot tested the survey. At this point, internal consistency reliability was estimated. As stated below, three questions were used to guide the quantitative phase. Questions were extrapolated to estimate the reliability and validity of the newly revised instrument and provided preliminary information about the reading behaviors of older adults with glaucoma and its effects on occupational performance.

Face Validity

Face validity considers how suitable the content of a test seems to be on the surface (Morgan, 2014). While face validity is similar to content validity, face validity is a more informal and subjective assessment. Cognitive interviews will also be used to introduce the survey to the target population to assist in establishing face validity of the instrument. Willis (2005) defines cognitive interviewing as a "process of identifying how participants comprehend, process, and/or detect any problems" (p. 3). This process helps to determine whether the intent for each question is realized (Dillman, Smythe, & Christian, 2009). In this study, the researcher conducted cognitive interviews with five people as recommended by Willis (2005). The individual interviews were conducted in the privacy of the participant's home. The participants were allowed to take the survey to become familiar with the questions and write down any issues or questions they have with the survey. This yielded word and phrasing changes in several questions on the instrument.

Cognitive Interview

Developing and evaluating questions has been a key challenge for survey researchers (Beatty & Willis, 2007). Beatty and Willis (2007) discuss cognitive

interviewing as an emerging and prominent method for identifying and correcting problems with survey questions. The researchers further state that numerous academic survey centers, along with government agencies and commercial research firms have incorporated cognitive interviews into their usual procedures for questionnaire development. Beatty and Willis (2007) discussed two primary paradigms as the basis for cognitive interviewing: the probing and thinking-aloud interviewers. The probing interviewer guides the interaction, generally asking direct questions about the basis for responses.

The cognitive interview method used for this study was the "think-aloud." The think-aloud interviewer conducts the cognitive interview with guiding questions, such as "tell me what you are thinking," and "how did you come up with your answer to this?" After the five selected participants completed the draft instrument, the researcher facilitated discussion of their thought processes. Participants were asked to "think out loud" as much as possible with little intervention from the investigator (Beatty & Willis, 2007). The goal was to generate information that was unseen, which was then used to evaluate how well the survey questions were aligning with the research questions. There was no interview guide used. All of the interviews started with the question "How did you come up with your answer to the question about the reading that you currently do?" The interview then was guided by how the interviewee responded.

Beatty and Willis (2007) also explain the advantages and disadvantages to this approach. The think-aloud procedures are relatively standardized where the data are collected during the response process. Think-aloud procedures are thought to reduce the chances that the interviewer introduces bias into the data collection process. According

to Bolton and Bronkorst, (1996) one advantage of think-aloud cognitive interview technique is that interviewers need not be knowledgeable about questionnaire design or the purpose and utility of specific questions.

Originally, criteria to select pretest participants included:

1. Older adult who was confirmed to have glaucoma of both genders and
2. Read and participate in ADLs and IADLs that involved reading

The investigator recruited from the interview pool from Phase I and persons known personally to have glaucoma. The interview and pretest were done separately for each individual, just as the instrument was designed to be administered. Individuals were administered the instrument and responded to each question. Five completed the draft survey. Two were Caucasian and three were African American. All completed the instrument administration and responses in 35 minutes or less.

Once participants completed the instrument a short, guided discussion using a semi-scripted procedure (Akyol, Garrison, & Ozden, 2009) was conducted. Participants responded to questions such as: Can you tell me any changes you recommend to improve the instructions for this instrument? Was the arrangement of questions clear? Were the questions understandable? Were the response options clear? Can you explain, in your own words what each group of items was asking? The process resulted in suggested edits such as keeping the answer choices as they were ("always, frequently, occasionally and never") because respondents did not always use one method and favored choices over "used and not used" as choices. Other suggestions included adjusting item order within the survey to avoid confusion and re-wording some questions for clarity. The researcher recorded notes from the discussion and asked participants to verify content when

responses were unclear. Following pretesting, the researcher invited two members of the dissertation committee and expert panelists to review the revised instrument for further refining. The committee members were experienced in qualitative data analysis and also working with the individuals with glaucoma. The clarity of questions and general comprehension were assessed, along with the question format and the sequencing of the questions. Once this final committee review was completed, an independent review and discussion was conducted with a doctoral-level trained researcher with a few years of experience in instrument development. Responses from the pretest, committee review, and review from an instrument development expert guided additional modification of the instrument before pilot testing.

Content Validity

The content review process, a critical step in instrument development as it results in the generation of new ideas and addresses concerns and challenges in the developed instrument. The strategy is often used to document content validity of an instrument. This process ensures items have the same meaning to every respondent, are communicated consistently to all respondents, and are scripted to prepare a respondent to answer questions (Fowler, 2009). For this study, content reviewers were needed to identify if: (a) the items and scales measure the effects of reading limitations from glaucomatous visual field loss on occupational performance; (b) the scale is concise and comprehensible; and (c) additional scales or items were needed to measure the phenomenon of interest. For this study, content validity was established during a two-phase process using the methodology described by McKenzie, Neiger, & Thackeray (1999) in which reviewers provided qualitative suggestions initially and later offer quantitative ratings of the

relevance/importance of each item. For both the qualitative and quantitative reviews, the researcher will provide review forms.

The researcher identified experts/content reviewers (N=5) for this study. Specifically, these reviewers were selected based on the criteria of APA in the Standards for Educational and Psychological Testing (APA, 1985). In which the reviewers need to meet two basic criteria, including need to agree to review the instrument, have the timeframe to complete the review and meet two other criteria from list (see Appendix A for complete list). The instrument was disseminated to experts in the field (Optometry and OT) for review for content and accuracy. The experts included professionals who have experience with low vision rehabilitation and assessment of persons with glaucoma. Based on feedback from the expert review, the instrument was revised as needed. This review, described above was completed via email. The experts were asked to engage in a qualitative review of the instrument. The content reviewers provided feedback on each item in terms of wording and whether the item needed to be removed. This review indicated if there were items that need to be added to the survey. The reviewers conducted a quantitative review of the instrument questions after incorporating original reviewer recommendations from the qualitative review. The reviewers rate the items as essential, useful but not essential, and not necessary. See Appendices G and I for initial instrument developed and revised instrument.

Comprehensiveness

The panel of experts evaluated the total instrument for comprehensiveness and understandability (Grant & Davis, 1997). By asking content experts to evaluate the total instrument, the researcher was able to identify items that needed to be added to the

content domain or deleted because they did not represent the content domain. In this study, no items were added to the content domain, nor were any items deleted for content validity.

PHASE II – Quantitative

Phase II of this research was a quantitative exploration of the reliability and validity of the newly revised instrument that was designed to measure the reading abilities and their effect on occupational performance in older adults with glaucoma. The following section describes the quantitative methods used in this study.

Quantitative Research Questions

1. What is the estimated face validity, content validity and internal consistency reliability of items to measure the impact of reading changes from glaucoma on occupational performance?
2. How do the items within the scale correlate to measure reading performance in older adults with glaucoma?

Phase II Recruitment and Sampling

Qualitative results informed the quantitative phase of the study. Once the instrument was developed, pilot-tested for content validity and internal consistency reliability and revised as needed for clarity and content, the instrument was administered to participants. The instrument was administered by the researcher. Participants completed the revised assessment of reading by means of instrument administration in which interviewer read the questions and recorded the participant's responses (this method is commonly used for participants with visual impairment).

For the pilot testing phase of the study, a non-probabilistic sampling was used. The number of participants was 70. The intent of non-probabilistic sampling in quantitative research is to select a large number of individuals who are representative of the population or who represent a segment of the population (Creswell & Plano Clark, 2011). The study sample will consist of subjects recruited from a convenience sample (Creswell, 2012) based on patient data in UAB School of Optometry Adult and Low Vision Module, The UAB Center for Low Vision Rehabilitation in Birmingham, Alabama and Premiere Medical Ophthalmology in Mobile and Daphne, also in Alabama. Using the patients of multiple centers mentioned will allow for a diverse and wide range of possible participants with glaucoma who provide insight on different life experiences.

Inclusion criteria for the quantitative phase included the following: English speaking men and women ages 50-89 years old with diagnosis of primary open angle glaucoma, primary angle closure glaucoma, pseudo-exfoliation glaucoma or pigment dispersion glaucoma, and visual acuity of 20/60 or better in at least one eye. Also, participants should be free of cognitive deficits, evidenced by normal scores on SPMSQ, free of depression as evidence of scores in normal range on the GDS-SF and at least a fourth to fifth grade reading level as evidence by a score of between 4 and 7 on the REALM-SF.

The exclusion criteria include the following: VA worse than 20/60 in the better seeing eye, vision loss secondary to another eye diseases (including macular degeneration, cataracts, diabetic retinopathy). The inclusion/exclusion criteria for quantitative phase is very similar to that used in the SEE projects (Ramulu, 2009) and the

research Ramulu (2013a, b and Nguyen, 2014) completed on sustained, out loud reading and reading engagement.

Data Analysis

Once the instrument administration was completed, the information was entered into a database in Statistical Package for Social Sciences (SPSS) (Version 22.0) with instrument responses and medical history to be stored on secure laptop in a locked storage area. The analysis included internal consistency reliability (Cronbach's alpha), which was used to determine if the item scales demonstrated reliability. A Cronbach's alpha value of 0.7 or higher is the minimum acceptable internal consistency score (Nunnally & Bernstein, 1994). Exploratory factor analysis of the instrument was conducted. Exploratory factor analysis was used strengthen the content validity of the instrument. Additionally, descriptive statistics were calculated for demographics and the instrument scales to answer mixed methods research questions.

The researcher interpreted results from the study within the framework of the discipline of occupational therapy and occupational adaptation. The investigator reported on the determinants that influence reading performance among older adults with glaucoma and occupational performance comparing quantitative results to the qualitative interviews findings. The investigator also returned to related literature and compared data from this study to what was previously known in order to make connections to complementary scholarship and offer new insights. The related literature did not yield any previous instrument that would measure reading effects on occupational performance among older adults with glaucoma. The literature did provide relevant finding on glaucoma and quality of life (Aspinall 2007, Nelson et al., 2013), impact of different

factors on related to glaucoma on reading (Nyugen 2013a;2013b, Ramulu, 2009). For this study, the logic behind triangulation was selecting a combination of methods to yield trustworthy data of value to the researcher and discipline (Johnson & Turner, 2003). It is helpful to understand gaps in the literature and to identify inconsistencies in findings across different kinds of data in clinical research and in choosing interventions for populations of interest.

Statistical Analysis

After the instrument was administered and the data collection completed, the researcher entered all data into an SPSS database, which was used to conduct the descriptive and inferential statistics for this study. Missing data or participants not meeting the study's eligibility requirements was excluded from further analysis.

Computed variables. A mean score was calculated for each of the scales used within the statistical analyses. These scores were calculated in order to standardize the range of the scale scores while sustaining the structure of the scale variables (Hosmer, Lemeshow and Sturdivant, 2014). To calculate a mean score, the responses for each Likert item on a scale was summed for each participant, and then the sum was divided by the number of items for the scale. Once the scale mean was calculated for each participant, the mean score for the group was calculated by summing the mean scores of the participants and then dividing by the number of participants.

Descriptive statistics. Descriptive statistics were computed on the scales that will be developed. The frequency distributions were calculated to show the distribution of the items, the spread of the answer choices and identified that all answer choices were selected by participants. The means and standard deviations were calculated for each

scale. The variables will be tested for univariate normality by calculating the skewness and kurtosis values of each individual variable and composite scale score. Skewness refers to the "degree of symmetry of a distribution about the mean, and it is equal to zero when the distribution is normal." Kurtosis refers to the "degree of peakedness of a distribution", and it is equal to zero when a distribution is normal (Mertler & Vannatta, 2013). This is used to assess floor and ceiling effects so that the scale represents a range of values "not too easy nor too hard."

Internal consistency reliability. Once the instrument was revised based on content and face validity assessments, it was administered to a study sample (N=10) of the study target population for assessment of readability and sampling validity (Onwuegbuzie et al., 2009). Because this was the piloting phase, a convenience sample of ten was used. The instrument items did reflect thoughts conveyed by participants in Phase I of the study. Also, results of the pilot testing included the descriptive statistics and Cronbach's alpha for each scale to estimate internal consistency reliability for each scale (these results are included in chapter four). Once the instrument was deemed easy to read and to understand, validated and adequately capture the perceptions of reading changes form glaucoma and the effect on occupational performance, the revised instrument was ready for the quantitative phase of the research project.

Exploratory factor analysis. Exploratory factor analysis was performed using a Varimax rotation procedure. The analysis will be performed using SPSS (Version 27.0). The key objective in factor analysis is to reduce a larger number of observed items into a smaller number of items. This is a technique of the principal components analysis

(Tabachnick & Fidell, 2007). It is used to interpret each component, computing the correlations between the original data for each variable and each principal component.

Another objective is to account for variability within the items. Thus, as data is run through a factor analysis in SPSS, components or factors will be determined. The items will then be reviewed to determine if they load onto a certain factor and will be analyzed based on their correlation to one another. The number of factors to extract and rotate will be estimated using two measures: Kaiser's Rule of Thumb (eigenvalues greater than 1) and examination of the Scree Plot. The factor loadings were assessed for consideration within each research question. According to Tabachnick and Fidell (2007), at least three to five measured variables representing each common factor should be included to designate a factor. Additionally, items can be retained that load strongly on one component while showing lower but still strong loadings on another. When this situation occurred, the researcher returned to the qualitative themes to identify if the item fit with the underlying construct to be measured. If the qualitative data supported retaining the item, it remained with the factor.

The quantitative phase of the study yielded a new instrument to measure reading behaviors among older adults with glaucoma. Items on the instrument reflected the thoughts and beliefs of the participants in qualitative phase of the study. Results of the pilot test included descriptive statistics of the participants and Cronbach's alpha for each scale to estimate internal consistency reliability.

Quality Assurance for Overall Mixed Methods Study

For quality assurance of the methods, this study applied the legitimation model developed by Onwuegbuzie & Johnson (2006). Legitimation plays an important role in

mixed methods research. The term legitimation has been used by quantitative and qualitative researchers to represent validity in mixed methods research. Legitimation is a process of continuous evaluation throughout mixed methods research to demonstrate the quality of inferences resulting from the quantitative and qualitative phases of a mixed methods study. Legitimation should be examined at the end of each study phase within a mixed methods study (Onwuegbuzie & Johnson, 2006). Onwuegbuzie and Johnson (2006) have created the legitimation model, which consists of nine types of legitimation: sample integration, inside-outside, weakness minimization, sequential, conversion, paradigmatic, commensurability, multiple validities, and political legitimation. Within this sequential study, legitimation will be established during data interpretation of both qualitative and quantitative data and prior to generalization of the data. This study incorporated five types of legitimation, which will be used to ensure the quality of the inferences of the mixed methods study. These five types included sample, sequential, inside-outside, weakness minimization, and multiple validities. Each type is described below along with an explanation on how the procedures relate to this sequential mixed methods design.

Sample legitimation refers to the situations in which a researcher wants to infer statistical generalizations from sample participants to the larger target population. Onwuegbuzie and Johnson (2006) conclude the following: unless exactly the same individuals or groups are involved in both the qualitative and quantitative components of a study, constructing meta-inferences by pulling together the inferences from the qualitative and quantitative phases can be problematic. In the proposed research, inferences to be made from the quantitative data yielded by a larger, convenience

sampling of the population will be integrated (i.e., into a meta-inference) with inferences made from qualitative data arising from a smaller subset of the same sample.

Sequential legitimation refers to the minimization of problems associated with the order of the qualitative and quantitative phases in a mixed methods study (Onwuegbuzie & Johnson, 2006). This study is designed with two phases in a sequential mixed methods design. Qualitative data was collected on the reading changes and how they affect occupational performance in older adults with glaucoma and this data will inform instrument development. The quantitative phase aimed to develop reliability and content validity of the instrument that was designed to assess reading changes and the effects on occupational performance in older adults with glaucoma. The findings from the qualitative phase through the completion of the interviews by participants was used to develop the items and scales of the items on the instrument. Findings from the qualitative and quantitative phases were used to produce the meta-inferences to explain how reading changes associated affect occupational performance in older adults with glaucoma.

Inside-outside legitimation refers to how accurately the researcher presents the insider and observer's view within the description or explanation. The insider's view was represented within the qualitative data, whereas the outsider's view was represented by the quantitative data. It is pertinent that the researcher justifies conclusions and minimizes bias of quantitative and qualitative data interpretation and integration. This can be done via member checking, peer review, and external auditing (Onwuegbuzie & Johnson, 2006). In the present study, the qualitative data consisted of interview data on the thoughts and feelings older adults have about reading changes associated with glaucoma and how these changes affect occupational performance. The quantitative data

was collected from administration of the instrument to older adults with glaucoma to further explore how occupational performance is affected by vision loss associated with glaucoma in older adults from the data collected during the qualitative phase. Within the qualitative phase of this study, it was essential for the researcher to maintain objectivity when interpreting the data. The researcher used peer reviewers and dissertation committee members for the qualitative phase to review the data and interpretations of the research to minimize the threat of bias related to the researcher's own beliefs and values derived from past experience. For the quantitative phase, the researcher solicited others (i.e., peer reviewers and dissertation committee) to review the relationships among the items of the instrument and how they are conceptualized and interpreted.

Weakness minimization legitimation refers to how the weakness of one method (quantitative/qualitative) is strengthened by the other approach (qualitative/quantitative). The weakness of each method is assessed, and the researcher assesses the extent to which the strength of each method can accommodate the weakness of the other to design a study that creates high quality meta-inferences. This information is utilized by the researcher to combine, weigh, and interpret results (Onwuegbuzie & Johnson, 2006). For this sequential mixed methods study, the qualitative phase informed items and scales of items of an instrument examining the reading changes associated with glaucoma and the effects on occupational performance among older adults. However, there is a possibility of recall bias or the reporting of socially desirable answers. The quantitative phase allowed for establishing reliability and content validity of the instrument. After the integration of data, the results of this process provided a richer explanation than either method could provide alone, of the examination of reading changes associated with glaucoma and the

effects on occupational performance among older adults. A better understanding of how these reading changes affect occupational performance can lead to more thorough evaluation of and better treatment options in low vision rehabilitation.

Multiple validities legitimation refers to yielding higher quality meta-inferences via mixing of quantitative, qualitative, and mixed validity types. All three validity types are addressed and maximized (Onwuegbuzie & Johnson, 2006). For this study, in the qualitative phase, minimal bias was essential to produce accurate results by using thick, rich descriptions, disclosure of researcher's beliefs and biases, triangulation, and member checking. In the quantitative phase, older adults with glaucoma were administered the instrument in a private, one-on-one setting in an optometry office. Also, reliability and validity were assessed for the revised instrument. During integration of quantitative and qualitative data, meta-inferences were drawn relevant to the population of interest – older adults with glaucoma.

Data Storage

Data storage is a challenging aspect of mixed methods research, due to the large amounts of data collected (Creswell, 2012). One data storage procedure used for this study included saving backup copies of the quantitative data set and transcribed interviews (i.e., quantitative and qualitative) to the researcher's password protected personal computer, and the surveys, transcribed interviews, recording devices are kept locked in a file cabinet located in the researcher's office (Creswell & Poth, 2018). The survey data was stored in an SPSS file on the researcher's password protected personal computer. All surveys, transcripts, and audio-recordings will be destroyed three years following completion of the study and result dissemination.

Data security for this study included (a) The use of paper-based notes, (b) the use of recording devices for interviews, (c) development of a master list of gathered information, (d) masking the identity of the participants in the data by using a pseudonym, (e) development of a data collection matrix to easily identify and locate the information gathered for the study. Each participant will be assigned a de-identifying code to keep his or her information private. For the qualitative interviews, the researcher used the participant's first, last initial, day, month number and a numerical value assigned for each interview. For example, if the participant is the first person to be interviewed on January 03 and have initials J.W., the code was JW010301.

Ethical Considerations

The research was designed and implemented in compliance with the UAB Institutional Review Board (IRB) guidelines and requirements. The UAB IRB received all necessary materials for this project, including written informed consent through expedited review. Because the proposed study is a sequential mixed methods design, the researcher sought IRB approval for the initial study phase and submitted an additional application for the subsequent phase because its design depended on the results from the preceding phase.

Prior to beginning data collection, the researcher completed the informed consent process and assured participants that all identifying information, screening data, recorded interviews, and observation notes would be held in the strictest confidence. This was assured by the researcher conducting all interviews for first phase within participants' homes. Within this environment, the researcher ensures confidentially by securing a private space. The researcher recorded the interviews on a digital recording device. This

device will be stored in a locked filing cabinet in the researcher's private UAB office. Prior to the interview, the recruitment letter assured that participation was voluntary. Also, the participant were informed of their status as a volunteer for the study and the purpose of the study and interview. Additionally, all other research materials including quantitative survey data was stored there. The researcher stored all transcribed interviews on a password protected, encrypted computer.

Summary

In summary, the purpose of this chapter was to explain the rationale for using sequential exploratory mixed methods approach. This approach was chosen as it is a widely used for developing a new instrument in health science research. The sequential exploratory design was used to develop a new instrument to measure reading behaviors among older adults with glaucoma and to describe the methods used in this study. The qualitative data analysis informed the items of the instrument used for data collection in quantitative phase. The quantitative phase involved a pilot exploration of the psychometric properties of the instrument. The quantitative analysis yielded a new, reliable and initially validated instrument that can be used to measure glaucoma reading behaviors and the effects on occupational performance among older adults.

CHAPTER FOUR

RESULTS

Chapter Four describes the qualitative and quantitative analysis interpreted with reference to the research questions. The chapter is divided into two sections: Phase I (qualitative findings) and Phase 2 (quantitative results). A sequential exploratory mixed methods approach (Creswell, 2010) was applied to explore and describe reading behaviors of older adults with glaucoma. This approach was useful to generate survey items for pretesting and piloting during Phase II of the study (Huberman, Miles & Saldana, 2014).

Presented within Phase I is the results from the qualitative data gathered as a result of conducting semi-structured interviews with a sample of older adults with glaucoma. It begins with an overview of the study setting and contexts and participant characteristics. It then describes in detail the study results emerging from the inductive thematic analysis.

This chapter discusses the results of the interviews and the integration of the data to construct the instrument prior to phase two. In the first phase of the study, the interviews were completed, along with member checking of the initial twelve interviewees. The second part of this chapter contains the results of the second, quantitative phase of the study.

Setting/Context

The geographic area for the dissertation study was central to south Alabama. Alabama is a southern state with hills and broken terrain through south Alabama, with the Gulf of Mexico and the state of Florida as its southern border. Average summer high temperatures are 80 degrees with 5.3 inches of precipitation. Average winter high varies throughout the state from 33 to 44 with 5.1 inches of precipitation. United States 2017 Census data reported a population size of 4,874,747 persons with a median age of 36.1 years. Adults 65 and older comprise 16.1% of the overall population. The ethnic groups that comprise the majority of the population are African-American (26.8%) and European-American (69.3%). Median household income is $44,758. (U.S. Census, 2017).

Participants recruited for this study were all clients evaluated and treated at a university-based low vision center and two non-profit, community-based low vision centers. The university-based, multi-disciplinary center, which opened in 2002, offers comprehensive rehabilitation services to individuals of all ages who have a condition causing visual impairment. In 2017, the center saw 2,043 clients; 1491 were over the age of 50 and 163 were diagnosed with glaucoma (L. Forte, personal communication, April 12, 2018). The center employs professionals with expertise in optometry, ophthalmology, occupational therapy and mental health services.

The non-profit, community-based low vision practice is also a multi-disciplinary center that operates very similar to the university-based center. In this center, clients are referred by their primary eye care specialist undergo a comprehensive vision examination by a low vision physician. If applicable, the low vision physician refers clients to

occupational therapy. Occupational therapy intervention enables the client to maximize residual vision for safe and independent completion of ADLs.

Community Services for Vision Rehabilitation (CSVR), located in Mobile Alabama was another recruit site for this study. This Center employs optometry and occupational therapy services to meet the needs of those with low vision in South Alabama and the Mississippi gulf coast. In 2018, the center saw just over 1000 clients. Over 70 percent of the clients seen at CSVR were adult, over the age of 50 years. Over 150 of these adult clients had a glaucoma diagnosis (C. Glaus, personal communication, April 30, 2019). The non-profit, community-based low vision practice is also a multi-disciplinary center that operates similar to the university-based center. Similar to UAB CLVR, this center sees clients referred by their primary eye care specialist. The clients undergo a comprehensive vision examination by a low vision physician. If applicable, the low vision physician refers clients to occupational therapy. Occupational therapy intervention enables the client to maximize residual vision for safe and independent completion of ADLs.

Phase 1: Qualitative Results

The following sections provide descriptions of the participants and the themes found in the qualitative data analysis. The section concludes with a discussion of how this data was used to develop the survey instrument.

Participants

Each story is unique and reflects the individual characteristics of that participant. Twelve individuals participated in this phase of the study, six males and six females. Ages ranged from 50 to 92 years. Sixty percent of participants were Caucasian and 40

percent were African American. Forty percent of the participants resided in independent living apartments for older adults, while the other 60 percent lived in single-family homes. Further information describing participant characteristics is below in Tables 1- 3.

Table 1

Demographics of Participants

	Gender	Race	Age	Education	Household Income	Employed
CR41701	F	W	89	Bachelor's degree	$30,000 to 39,999	N
VG41702	F	W	92	Some college	$30,000 to 39,999	N
GD41703	F	W	81	Some college	$40,000 to 49,999	N
DMT080904	F	AA	53	Masters or higher		Y
ES081505	F	W	64	High School Diploma	More than $50,000	Y
LL082806	M	AA	64	Some college	$40,000 to 49,999	N
RP091507	M	AA	66	High School Diploma	$20,001 to 29,999	N
RB092408	M	W	60	Masters or higher	Did not answer	Y
PM092509	M	AA	50	Middle school	Less than $20,000	N
RT101210	M	W	68	Some college	More than $50,000	N
TW101311	M	AA	69	Some college	Did not answer	Y
SE121412	F	W	61	High School Diploma	Less than $20,000	Y

Note. W= white, AA= African American, Y= yes, N= no

Table 2 provides a summary of the participant's ocular health. This information was gathered via chart review from the low vision center where participants were recruited. Three visual functions are described in this table, visual acuity, contrast sensitivity function and visual field. The low vision center's optometrists administered all visual function tests during usual care. Several of the participants did not have visual field information available.

The participants were also screened for literacy level, presence of depression and

cognitive deficits. Table 3 provides a summary of scores obtained from the screening, specifically the REALM-SF, SPMSQ and GDS. All participants met the minimum screening measures and qualified to participate, indicating intact cognition and the presence of at least a 6th grade reading level.

Table 2

Visual Acuity, Visual Field and Contrast Sensitivity Function

	VA	VF	CSF (LogMAR)
CR41701	LPO 20/100		1.0
VG41702	20/919 20/70		0.96
GD41703	20/40 20/40		1.0
DMT080904	20/25 20/50	OD: inferior field loss OS: measures 20° central	1.44
ES081505	20/30 20/25		n/a
LL082806	20/60 20/200		0.96
RP091507	HMO 20/80		0.64
RB092408	20/25 20/40	OD: temporo-inferior field loss	1.44
PM092509	NLP 20/30		0.96
RT101210	20/25 20/1000		1.04
TW101311	NLP 20/40	OS: measures 20° central/paracentral	0.96
SE121412	20/250 20/800		1.04

Note. VA= visual acuity, listed OD (Right eye) first and OS (left eye) second

Table 3

Screening Data: REALM-SF, SPMQ-SF and GDS-SF

	REALM-SF	SPMSQ	GDS-SF
CR41701	HS reading level	0	3
VG41702	HS reading level	0	2
GD41703	HS reading level	0	2
DMT080904	HS reading level	0	1

ES081505	HS reading level	1	2
LL082806	7th-8th grade reading level	1	1
RP091507	7th-8th grade reading level	1	1
RB092408	HS reading level	0	1
PM092509	4th-6th grade reading level	1	0
RT101210	HS reading level	0	1
TW101311	7th-8th grade reading level	0	4
SE121412	7th-8th grade reading level	0	1

Note. REALM-SF: HS Reading level is a reading level equivalent to that of someone in high school or beyond
SPMSQ-SF: 0-2 errors indicates normal mental functioning
GDS-SF: A score of 0 to 5 is normal; a score greater than 5 suggests depression

Visual acuity is the ability to see detail at a specified distance and was assessed using the Early Treatment of Diabetic Retinopathy Study Acuity Chart (ETDRS). The ETDRS chart is frequently used clinically to measure visual acuity. Visual acuity scores in this table represent best-corrected visual acuity. The WHO categories of visual impairment were used to describe acuity scores, as it is the most recognized global classification system (Colanbrander & Fletcher, 1995). Specific categories include *near normal* (20/30 - 20/70), *moderate* (20/80 - 20/160), *severe* (20/160 - 20/400) and *profound* (20/400 -20/1000). Visual acuity scores indicated that the participants had varying degrees of impairment however, the majority had moderate to profound loss in one eye with near normal acuity in the other. Individuals with near normal vision in one eye should be able to see visual detail but may experience some difficulty with text smaller than newspaper print.

Contrast sensitivity function is the visible qualities of objects against backgrounds and was assessed using the MARS Perceptrix. The MARS chart is a true contrast sensitivity test that assesses the lowest contrasts the client can perceive. The MARS chart is commonly used in low vision optometry. It provides a picture of the effect of contrast sensitivity on function. Contrast sensitivity function scores obtained from the

MARS Perceptrix are categorized by degree of loss. Specific categories include *profound* (0 – 0.48), *severe* (0.52 – 1.00), *moderate* (1.04 – 1.48), *typical for age 60 and older* (1.52 – 1.76) and *typical for middle age and young adults* (1.72 – 1.92) (Mars perceptrix, 2012). All participants scored within the moderate to profound impairment level indicating deficits in contrast sensitivity function. These deficits may influence safety in environments with low vision contrast features such as unmarked curbs and stairwells.

Visual field is the world that we see when we are looking forward without moving our head or eyes and was assessed using a Humphrey Visual Field Analyzer. The Humphrey Visual Field Analyzer Test screen the central 60 degrees of visual field. This visual field test can screen a larger area and more peripheral, which gives a better representation of the visual field affected by glaucoma. Visual field integrity is described by location and density of scotoma or blind spot (Colanbrander & Fletcher, 1995).

Participant Descriptions

The following section provides a description of each of the participants in Phase I. The participants were all over 50 years of age, included six women and six men and were Caucasian and African American. Below is a brief description of the participants.

Participant CR41701. At the time of the study, CR41701 was an 89-year-old Caucasian female diagnosed with glaucoma over 10 years ago. CR is a retired elementary school teacher. CR lived alone in a 1-story house in Greenville, Alabama. She had been widowed since 1999 when her husband of over 40 years died. CR had children that live nearby, friends and a paid assistance that helps her complete her errands and provide transportation to medical appointments.

CR described her most recent vision change as occurring during a follow-up visit

to her glaucoma physician. She had elected to follow medical advice and have a surgical procedure to reduce intraocular pressure. This procedure involved placement of a shunt with removal of a "stopper." When the physician removed the stopper, post-operatively, CR said her vision was never the same. She had driven to Birmingham that day with her friends and they had dropped her off and went shopping. She called them and told them she could not see very well and they picked her up and drove her back to Greenville. It was at this point she had to make some changes to her daily routine. She now has her daughter and her son-in-law to complete financial management, as it is too difficult to read and manage these affairs each month. She states that she only reads what she has to read now. Previous to her vision changes, she played the organ and piano for her church, reading music and no longer can do this. CR continued to read her devotional materials each morning and also reads her local, weekly newspaper. She had to use her electronic magnifier to read. She stated that she struggles with reading with the "machine" as she needs the print to be dark on a white background, because of her poor contrast sensitivity function, but the bright background cause glare. CR was able to continue to cook, which is a valued activity for her. She cooks for herself each day and states that as long as she knows where everything is located, she does fine with this.

Participant VG41702. At the time of the study participant two VG41702 was a 92-year-old Caucasian female diagnosed with glaucoma over ten years ago. VG lived in an independent living facility, in Bessemer, Alabama, where she has resided for three years. VR described herself as someone who loves to go places and do things. When asked what things she enjoyed doing, she stated that she used to play cards, dominoes and other games but she had to quit playing cards and games because of her visual impairment.

VG stated she keeps the obituaries from the newspaper with her at all times each day. She stated that she was losing family members and friends at an alarming rate. When asked how she read the newspaper, she stated that she uses her 4X illuminated hand held magnifier. She also asked others to help her by reading the names for her. She also participated in bingo in the facility. She had large print bingo cards but her neighbors would assist her if she missed a called number.

She watched a lot of television. VG stated that a neighbor who subscribed to the television (TV) Guide was made her a note that was printed in large, black letters with the television programs that she watched. She was very appreciative of this. It made it easier for her to know the time and channels for the TV programs.

She stated that glaucoma has very much affected her daily life. She no longer drove, which prohibited her from being able to participate in leisure activities. She reported that many of her leisure pursuits are very important to her and she misses being able to go and do things. Also, she requires assistance from others to complete daily tasks, especially reading tasks. VG really wished there was a way to cure glaucoma.

Participant GD41703. At the time of the study participant three GD41703 was an 88-year-old Caucasian female living in an independent living facility in Birmingham, Alabama. She lived in her own apartment alone. She was widowed for over 30 years at time of interview. GD reported that she was very active in the community and was involved in three dance clubs. Since her vision changed in last two years, she reported that she limits her activities to those provided by the facility where she lives and the activities to which the facility will provide transportation.

GD reported that she no longer read for pleasure and used the Talking Books Service available through the National Library of Congress for reading books. She did do some reading daily but it was limited to her financial affairs, mail and the correspondence she received from the Senior Living Facility. She used a desktop electronic magnifier for any reading that she did. She was not able to use the hand held or stand magnifiers.

For medication management, GD used a system where a device that reads a QR label on the prescription bottle. This system allowed her to identify her medications as the device reader read the information about the medication in the bottle. She did note that she had allergies and often had to take over-the-counter medication and these were difficult to identify. The device did not identify over-the-counter medications.

GD also used her computer to manage her financial affairs. An occupational therapist specializing in low vision rehabilitation, had made a home visit. The OT made recommendations for computer modifications to make the screen, the keyboard and the mouse pointer more visible. She did report that she took longer to complete financial management but was able to do this at the time.

GD also had a smart phone at the time of the interview. She had significant difficulty operating the device. She could only answer phone calls and turn the phone on and off. She formerly had been able to text, make phone calls, browse internet and use email. Since her vision had declined secondary to worsening glaucoma, she was unable to use her phone in the manner she used to. GD reports that her vision changes related to glaucoma had significantly changed her life, limited her social engagement and caused her much frustration.

Participant DMT080904. At the time of the interview, the fourth participant was fifty-two years old. She was an African American female with synonym DMT080904. DMT was diagnosed with glaucoma in 2007. At the time, she was a post-doctorate fellow having just finished her doctorate work in Virginia. She recalled when she was diagnosed with glaucoma. She stated that her eyes were hurting and feeling very heavy. Her mentor got her in with a local glaucoma specialist and she had been seeing the doctor since then. She was diagnosed with advanced stage glaucoma.

DMT was employed at time of the interview. She was in administration at a university and she worked remotely. She spent at least 8 hours per day reading on the computer. She used a laptop with a 15-inch screen and recently had switched to an iPhone from another type of smart phone. DMT had significant eye symptoms from reading on her computer all day. She had worked with an OT who had recommended some adaptations to her work station to increase visibility. These adaptations included the following: a laptop with at least 19- inch screen, dictation software and natural spectrum lighting. At the time of the interview, her employer had not provided the items recommended for her.

Participant ES081505. At the time of the study, participant five was sixty-four years old. ES081505 was female, employed as an administrative assistant at a university in Birmingham, Alabama, where she also lived with her husband. She did drive but avoided nighttime driving because of her vision. ES enjoyed spending her weekends and free time with her husband and her grandchildren.

ES reported that she did most of her work on a computer and she had difficulty with reading on the computer screen for more than 15 to 30 minutes at a time. She would

have to take breaks from reading on the computer screen. She had made some changes to her computer screen display to decrease the glare she experienced. ES reported that she did not read much outside of work because of the difficulty she had with reading. She was looking forward to retirement and not having to read a computer screen within two months of completing this interview.

Participant LL082806. At the time of this interview, participant six was sixty-four years old. LL082806 was a retired corrections officer. He had retired three years ago because of his vision. He lived in Mobile, Alabama with his wife and his adult son. LL was a veteran and had completed rehabilitation at the Biloxi Veterans Affairs Blind Rehabilitation program. Through the blind rehabilitation program, LL had received a desktop electronic magnifier, handheld electronic magnifier, light emitting diode (LED) adjustable lamp, computer software for magnification and voice over, dark grey glare shields, medication modification system and taking books. He also received orientation and mobility training (O&M). He used a long white cane when he participated in community mobility.

LL had a routine he followed each morning. He would get up, exercise with weights, do his Bible readings using his electronic magnifier, eat breakfast prepared by his wife and take his medication, also managed by his wife. He enjoyed browsing internet new sites and checking his email. He used computer software that provided screen magnification on his computer. He spent about four or more hours per day on his computer.

A few years previous to this interview, LL had founded a ministry in which he provided programs and counseling to children with incarcerated parents. Because of his

visual impairment, he was not able to participate in this ministry as he would like. He continued to be a "Big" as part of the Big Brothers Big Sisters program.

Participant RP091507. At the time of the interview, participant seven was sixty-six years old. RP091507 was an African American male who resided in a senior living center in Bessemer, Alabama, a suburb of Birmingham. RP stated that he had good days and bad days with his vision. Diagnosed with glaucoma 10 years ago, he had had five surgeries in each eye. During the interview, RD stated that he did read some during the day but that it was extremely difficult. He used his glasses and a magnifier with a light for reading. If that did not work, he would use the older electronic magnifier that had been given to him by a rehabilitation counselor at the Alabama Department of Rehabilitation. He stated that he did not really want everyone knowing his business so he did not like to ask for assistance from others who lived or worked in the facility. He did have a paid caregiver that came in for a couple of hours per week to assist with medication management and she would assist him with reading.

RP was on disability because of his vision. When he did work, he was a cook at several area restaurants. He enjoyed conversations with his neighbors, listening to audio books and trying to read his Bible. RP had taken classes and completed training at the Alabama School for the Blind. These classes included orientation and mobility training, technology and Braille instruction.

Participant RB092408. At the time of this interview, participant eight was a sixty-year old Caucasian male. RB092408 was a preacher at a church in Spanish Fort, Alabama, a small bedroom community on the Eastern Shore of Baldwin County in south Alabama. RB lived in a one-story home with his wife. RB enjoyed reading, exercising and

spending time with his wife. He had run a couple of marathons and had switched to walking and some weight training for his exercise.

RB reported that he read all of the time. His job required him to read for many hours to prepare for sermons and teaching other classes in the church. At the time of this interview, he was spending four to six hours per day reading books and on his computer. He reported no difficulty at that time, with reading and for long periods of time. He also enjoyed reading in his spare time. While he did have visual field changes related to glaucoma, he did not feel that his reading was impacted by the changes.

Participant PM092509. At the time of the interview, participant nine was fifty years old. PM092509 was an African American male who was diagnosed with glaucoma several years previous to this. He had also suffered a stroke that resulted in weakness of his left upper and lower extremities. He walked with use of a cane. He reported that he no longer drove. He lived with his sister and her two children in a manufactured home outside of Demopolis, Alabama. PM had been disabled since his stroke five years previous to this time.

PM was very limited in his ambulation with a cane but enjoyed getting out of the house and riding to town, as he called it, with his family members and friends. His friends would stop, pick him up and take him with them when they had to go grocery shopping or other errands.

PM reported that he did not read much and his reading was limited to his mobile device. He changed the text on his phone to large print. He also used the voice to speech feature on the phone. He read his mail with use of a handheld illuminated magnifier. He only used the magnifier for spot reading. His sister assisted him with financial

management, medication management and health management. She also did the cooking; however, PM used a microwave occasionally.

Participant RT101210. At the time of the interview, participant ten was sixty-eight years old. RT101210 was a Caucasian male, who was retired and lived on a farm, with his wife, outside of Tupelo, Mississippi. He was diagnosed with glaucoma in 1995, but had significant visual changes in the year prior to this interview. RT was a retired minister and a past president of his local chapter of the Kiwanis Lions Club. Prior to his vision loss, RT was an avid hunter and enjoyed working around his property, activities that he had to give up when he experienced the latest vision changes in last year.

Prior to this interview, RT had been evaluated by an OT who specialized in low vision rehabilitation. The OT had made some adaptations to his computer and this allowed him to be able to see his emails and read commentaries on the internet. The OT had also introduced electronic magnification to RT. He was able to read books and the newspaper. He stated that he quickly fatigued and had to limit his reading to about thirty minutes to one-hour sessions.

Participant TW101311. At the time of this interview, participant eleven was sixty-nine years old. TW101311 was an African American male, living in an independent living cottage village for seniors in Bessemer, Alabama. As stated above, Bessemer is a suburb of Birmingham. TW lived alone and he operated an upholstery business out of his home. He had several lamps around his sewing machine and work area. He used a computer to aid in managing his business. His nephew had helped him change the settings on his computer. These changes included increasing contrast of the print and enlarging the print.

Despite severely limited visual fields and impaired visual acuity, TW continued to drive. He said he often was unable to find someone to deliver furniture for him. He stated that he felt comfortable driving but that he had experienced some recent near misses that did worry him. He only drove in daylight hours and within about 20 miles of his home.

*Participant SE121412***.** At the time of the interview, participant twelve was sixty-one years old. SE121412 was a Caucasian female, who lived alone in an apartment in Tupelo, Mississippi. SE had one daughter and she lived nearby. SE was diagnosed with glaucoma in 1989. SE was employed at the Industries for the Blind of Mississippi. She stated that she bagged flatware for eight hours per day, five days per week. The work was monotonous but it was a job.

SE did not drive and used a taxi service for transportation to and from work. This was expensive but she did not have other options. SE did not have any difficulty in performing her job duties. She had learned the locations of the flatware and the locations for the flatware to be placed once bagged.

When asked how she copes with her vision loss and the challenges she faces she stated that she was encouraged to journal her thoughts and feelings. The journal, along with listening to books on tape and socializing with her friends was how she spent her free time. She also mentioned that her daughter was very helpful to her and would help her get her groceries and took her to doctor appointments.

Thematic Analysis

The following section will report the results of analysis of the interviews. Microanalysis of the interview and observation data revealed themes and sub-themes from the interview data. These results are discussed in the following paragraphs.

Once data analysis was completed, the raw data was categorized into themes, sub-themes and categories of the sub-themes. Five major themes emerged from the data analysis. The five themes included: (a) Occupations given up, (b) Occupations performed with difficulty, (c) Reading completed now, (d) Reading problems reported and (e) Methods for coping. The sub-themes included activities of daily living (ADLs), instrumental activities of daily living (IADLs), leisure, community mobility, ocular health and functional vision issues.

Theme 1*: Occupations Given Up*

The first theme to emerge from the data analysis was occupations given up. The sub-themes from this theme include IADLs, leisure activities and community mobility.

Table 4

Sub-themes and Categories of Theme 1: *Occupations Given Up*

Theme	Sub-themes	Categories
Occupations given up	IADLs	Reading for IADLs Financial management Cooking Medication Management
	Leisure Pursuits	Music (reading it) Leisure reading Social activities - playing cards, games
	Community Mobility	Driving

IADLs

The first theme that emerged was *occupations given up*. Throughout the interviews, participants consistently commented about the occupations, specifically IADLs, that they had to give up because of the difficulty they experienced with completing these tasks. Please see Table 4 for a summary of the sub-themes and categories of Theme 1.

Reading for IADLs

The next category that emerged in the sub-theme of IADLs given up was reading for IADLs. Eleven of the participants interviewed reported giving up some, even most of the reading that they did prior to the changes in their vision. Spot reading and leisure reading were both reported as "done with difficulty and also "given up." GD41703 shared how this change affected her, stating, "What I used to like to do when I could see is keep up with the stock market and read and just be involved. I was in a lot of organizations and now I don't read. I am read to." TW101311 noted some of his reading difficulties when he stated, "I try to read the Bible and my Bible materials each day. I tend to let my mail pile up and then it takes me hours to try to read it." RP091507 found that getting help with reading important correspondence works best for him. He stated, "The social worker helps me, especially if I got anything to do with social security or anything I think important." When asked about his daily reading, PM092509 stated, "I don't read at all period. They won't let me read. I can't see it." ES081505 echoed a similar experience with leisure reading while in the bathtub, stating, "I actually I don't read a whole lot. I used to, but I really do not. I used to enjoy taking a leisure, long bath, you know, like on Saturday night or something but I don't do that anymore because the light that I have in my bathroom is not very strong and I can't do it."

Financial Management

The next category in the sub-theme of IADLs given up was financial management. Financial management included reading the bills, writing checks, and reconciling financial records. Three of the 12 participants reported that they no longer were completing these tasks and had a family member completing for them. When asked about completing her financial management, CR41701 states, "Edith, my daughter does my bills." VG41702 echoed a similar experience, stating, "My son-in-law and my daughter is power of attorney and they take care of my bills." She went on to discuss that her mail goes straight to her family members and she does not have to deal with them at all. The third participant that reported giving up financial management tasks reported that he would get the social worker for the facility in which he resides to read his bills and statements. He used the auto draft feature offered through his financial institution to pay the majority of his bills. He would also get assistance from his personal care attendant when he handled cash or used a credit card.

Medication Management

Medication management was the next category that emerged in this sub-theme. Medication management involves obtaining prescription medications, getting refills, administration of the medications and awareness of side effects of the medications. These tasks involve reading prescription labels, considering the time of day to take the medications, phone calls for refills and doctor appointments for refills and bloodwork.

When asked if he could read his medication labels, RP091507 stated, "No, I can't see them. I get somebody to read them for me." He further described his medication routine as the following, "A lot of stuff I do is by touch. I get all the medicine out of the

bottle and if I drop one on the floor, I don't know what it is so I go back to the bottles." When asked if he could identify the medication bottle he said that he could not. The interviewer was able to observe his medication routine. The medication labels were in large print. RP091507 also reported that he had his medications delivered through via the mail. He stated that the mail pharmacy will-call him on the telephone and inquire as to which medications he needs. He had a personal care assistant that assisted him as he could not see the labels. While he wanted to continue management of his medication, his vision no longer allowed him to be independent with these tasks.

Participant LL082806 had such difficulty with his medication management that he gave it up and turned that task over to his spouse. He was even given adapted tools to improve his performance; however, it still took him more time to do this and he did not want to make medication errors. Participant LL082806 states the following regarding his medication management:

> My wife does the medications for me. Although, I did get the talking script through the VA and I have the machine for that but it seems like it is just easier to ask her to do it, but you know if I was by myself I'm sure I would need to refresh myself and learn how to do that because they actually did the medications that I get from the VA and they do the talking script and I have to put the bottle in the machine and it will tell me what it is. I believe that I could probably do with magnifiers and take them myself but since I have help I just say I'm probably hindering myself but I do rely on her to do it.

He further stated, “So what she does is put [the medications] in a pill box for me each week.” He found it easier to allow his spouse to manage his medications and save his energy and use of his vision for other tasks and activities that he wanted to do.

Meal Preparation

Meal preparation involves many visual tasks that can be difficult to complete when visual impairment is present. Reading package directions, nutritional labels, recipes, ingredients and other reading tasks can present difficulties to those with visual impairment. Many meal preparation tasks are low contrast and require task lighting to be able to do and often still are difficult to complete. Other meal preparation tasks that can prove difficult to complete with a visual impairment include identifying canned goods in cabinet/pantry, identifying when meat is done, reading a thermometer, seasoning foods, measuring ingredients for recipes, setting the cooking temperature and cooking time on appliances, among several other tasks.

When asked if he completed meal preparation, participant PM092509 stated, “No, well, just breakfast sometimes. Like maybe an egg or put something in the microwave. I cannot see the numbers so I just turn it on and stand there a minute. They don’t let me do too much stuff like that now.”

Similarly, VG41702 reported she had given up most of her meal preparation. She lived in a senior living facility in her own apartment. She had 2 meals per day provided to her and she would microwave meals brought to her by her family or she would prepare a quick meal, such as a sandwich. GD41703 also lived in a senior residence apartment. She reported that she had extreme difficulty finding items in her refrigerator and her cabinets. When asked to describe her difficulty with identifying items in the refrigerator,

she stated, “Just picking and choosing which is the fruit and which is the other things unless I put it away. If someone else puts it away it’s difficult for me to see and I leave it.” She also received most of her meals from the facility. She reported that she did not like to eat alone and her friends would come by to get her to go to dining room. Her friends would help her read the menu. If her friends were not available, she would bring the menu back to her apartment and use her handheld magnifier to read the menu.

Leisure

The second sub-theme to emerge under *occupations given up* was leisure activities. These activities included music, specifically reading music, leisure reading and other social activities. Over 90 percent of participants reported giving up at least one activity that they enjoyed doing in their spare time.

Reading Music

The first leisure activity reported as given up was reading music. Two of the twelve participants reported having to give up playing musical instruments because they could no longer read music. For example, CR41701 played the organ in her church for over 40 years. When asked why she gave this up, CR410701 stated, “Cause I can’t see. I can’t see the music and I can’t see the notes, so I just had to quit.” The second participant echoed a similar experience, RT101210 stated, “Playing the guitar in the church praise brand was one of my unpaid gigs, but I haven’t been able to do that since January. “

Leisure Reading

The second category to emerge from the sub-theme of leisure occupations given up was leisure reading. Several of the participants reported they had given up reading for leisure. VG41702 reported that she had given up reading novels as she could no longer

read her books. She had neighbors that would read the Bible during the devotion times. These neighbors also read books to the group. RT101210 shared similar experience stating, "Reading is one of my pastimes, but I haven't been able to read since January."

Social Activities

The third category to emerge from the sub-theme of IADLs given up was social activities. Social activities that were reported included playing cards and games, community outings with friends and family, dance classes and attending church services/other church activities. One problem with going out in the community is the difficulty experienced with identifying people from a distance. CR41701 mentioned this in her interview, stating, "I can't tell who people are. Edith and I go to the drugstore, to Wal-Mart, or grocery store and people come speak to me all the time and I'll have to say now tell me who you are because I can't see."

Giving up social activities can lead to social isolation. One participant described having to give up social activities, such as playing cards and dominoes. This led to her no longer attending events where the activities would involve those in which she could no longer participate. This threat of social isolation was one of the factors that led her to leave of home of many years and move to a senior residential facility. She reported the following, "I used to play cards. I used to play dominoes and stuff like that, but then my eyes got bad so I quit trying to play. We played Rook and poker and all kinds of stuff. It was fun, but I don't try to get involved." Participant GD41703 stated the following, "Here we have certain things that we do and I have shortened my activities primarily to things at Brookdale and that Brookdale participates in. I am still in one dance club." She was very involved in her community prior to her vision loss and now limits her

community involvement to Brookdale events, events that transportation is provided via Brookdale and church. Her family would come and get her so that she could attend church services.

Participant RP091507 stated that he did not get out of the house often because of his vision. He stated, "I don't go no more unless I'm riding and I don't like riding because I can't see where I'm going even when I'm riding with somebody. They can take me anywhere." Participant TW101311 also felt that his vision interfered with his social activities, even relationships. He stated, "I feel like [my vision] interferes with my social life also. As far as dating goes, sometimes I don't want to share my vision with people. Because sometimes people look at you differently. At least that is how I look at it." He also reported that he was unable to go out in the church ministry because of his vision loss.

Community Mobility

The third sub-theme to emerge under the theme occupations given up was community mobility. Community mobility involves the modes in which people move about their community, including driving. Over half of the participants interviewed had given up driving.

Driving

Driving was the first category under the sub-theme to emerge in this category of occupations given up. Community mobility is defined as "planning and moving around in the community and using public or private transportation, such as driving, walking, bicycling, or accessing and riding in buses, taxi cabs, or other transportation systems" (AOTA, 2014, p. S19). Community mobility is grounded in independence, spontaneity,

and identity. It begins when we are passengers in a car seat and continues as we learn to drive a car. Although the mode of transportation may change, the meaning remains constant: transport from one location to another enables participation in the things we want and need to do (occupations). Driving is the primary mode of transportation and community mobility in the Southeast. There is a lack of public transportation outside of large city centers (American Public Transit Association, 2013).

Sometimes the decision to quit driving comes gradual for those with low vision, while other times it is sudden. CR41701describes how her vision changed suddenly and how this led to her driving cessation:

> A lot of losing my vision was when he took the stopper out of the shunt. That's when it all went. That day he took the stopper out of the shunt, it affected everything. Yeah, usually one of my younger friends would drive and take my car and they could go to the Brookwood Mall because we would eat lunch there and I'd drive back up to Vestavia to Dr. Mayes's office and that day they just happened to drop me off and leave me and went shopping. I called them when I got through and I said, 'y'all are going to have to come get me, I can't see anything,' so they did.

CR went on to state that she did not drive again after this day as she did not feel comfortable and her vision never improved after this doctor visit.

LL082806 recalled when he quit driving, stating the following:

> When I really noticed that I was having problems was I was still working at the sheriff's department and I was on night shift and I knew I was already driving during the day making adjustments and one night I tried to drive to work and I

had to turn around and come back home and have someone to drive me to work because I literally got afraid that I might hit someone because I actually couldn't see the white line that's on the side of the highway.

He went on to add that he felt like he could still drive during perfect weather conditions (i.e., daylight, close to home, no rain) but that his wife was not in favor of that and he did not want to hurt anyone.

Another participant described the impact that driving cessation had on his daily life as the following:

I have to stay around here now. I used to be very active, very independent, travel, and a lot of things, but now I'm pretty much stuck here at home except my wife bought me a gator for my birthday a couple of weeks ago and we've got some property and I'm able to get my chainsaws out and carry those around and I do ride it around a little bit, some of the back roads, so I get a little independence here in the past few weeks.

While his vision had slightly improved after he quit driving, he was still not legally able to drive and did not drive on the road.

Participant SE121412 described how not being able to drive affected her life in general and her daily routine. Her daughter was granted a license to drive at the age of 15 because of her mother's inability to drive. She described her then current situation as follows:

"I have to arrange transportation. Now, Saturday I've got a friend from work that is picking me up, but if I can't get her then I usually get a cab to some of these functions because I don't want to not do and I don't want to have to depend on

Cindy to take me because she might have something going on that day or night. But, if she doesn't, she says sometimes she would take me but I don't want to cause her to not do what she has to do either. So, I have to figure my budget in there for an extra money for the cab for that night. The going and coming so that is another expense. That's why I don't go as much as I'd like to because I have to figure in another expense and right now I'm paying $100 a week to get back and forth just to work. I also have doctor's visits that I have to go to and it gets to be expensive."

Participant VG41702 discussed how she had adjusted to not being able to drive, among other activities. She reported that she liked to go places and do things but that she pretty much did not go places anymore because she could not see well and did not want to burden her family. She had moved into a retirement center in senior housing and was adjusting well. GD41703 had a similar experience in that she had also moved to a retirement community, in part because of driving cessation secondary to her visual impairment. She gave up most of her organizational participation, stating the following: "I have shortened my activities primarily to things at Brookdale and that Brookdale participates in. I'm still in one dance club outside of the facility and I go to church activities at my church."

Driving cessation limits participant RP091507 activity outside of his retirement facility also. He stated that, "I don't go no more unless I'm riding and I don't like riding because I can't see where I'm going even when I'm riding with somebody. They can take me anywhere and I wouldn't know." PM092509 reported that he spent most of his time at home because he could no longer drive but he did enjoy getting out. He stated,

"The Children will give me a ride and they'll take me up to town and go to the store and stuff like that." He elaborated further that he enjoyed getting out of the house as he often was bored. Prior to his stroke and the vision loss, he did not stay put very long. It was a hard adjustment to make after he had the stroke.

Summary of Theme 1

In summary, the first theme to emerge from qualitative data analysis was occupations that were given up. The interviewees reported on several IADLs they had to give up because of their visual impairments. These included leisure reading, medication management, driving and some social activities. The loss of independence with occupations, specifically IADLs had varying effects on each of the participants.

Theme 2: Occupations Performed with Difficulty

The next theme to emerge was *occupations performed with difficulty*. This theme included sub-themes of ADLs and IADLs that participants reported to continue to do, but with difficulty. Participants also reported difficulty with leisure activities and community mobility. The categories included shaving, seeing faces, watching TV, falls and fear of falling, using a smart phone and computer use. Please see Table 5 for a summary of the sub-themes and categories for Theme 2.

Table 5

Sub-themes and Categories of the Theme 2: *Occupations Performed with Difficulty*

Theme	Sub-themes	Categories
Occupations performed with difficulty	ADLs	Shaving
	IADLs	Seeing faces
		Medication management
		Financial management

		Meal preparation: Identification of food in fridge, using spices, operating knobs on appliances Computer use Using Smart phone
	Leisure	Watching TV Social activity
	Community Mobility	Falls and fear of falling

ADLs

The first sub-theme from *occupations performed with difficulty* was ADLs, with one category, shaving. Over 90 percent of participants reported that they continued their basic ADLs, such as bathing, dressing, grooming and toileting without difficulty.

*Shavin*g

Difficulty with shaving was the first ADL category reported as difficult by one participant. Shaving is a low contrast task, as the human face has no contrast. In clinical practice, often times difficulty with shaving is reported. Also, most of those shaving tend to adapt to the vision loss in shaving by shaving by "feel." RT101210 was relatively early in his learning to adapt to living with vision loss. He reported that shaving was "fairly difficult."

IADLs

The second sub-theme that emerged from the theme *occupations performed with difficulty* was IADLs, with one category, shaving. Over 90 percent of participants reported that they continued performing and participating in IADLs, such as meal preparation, medication management, financial management and using a smart phone for IADLs without difficulty.

Seeing Faces

The first category to emerge in the sub-theme of occupations, specifically IADLs performed with difficulty involves seeing faces and being able to identify a person by their face. CR41701 states, "I can't tell who people are. Edith and I go to the drugstore, to Walmart or a grocery store and people come speak to me all the time. I'll have to say now tell me who you are because I can't see. I've learned to do that. I don't let it bother me." GD41703 also pointed out difficulty with this low contrast situation, stating, "I'm having trouble now seeing down the hall. I can't tell who people are. So far, I'm able to see outlines and at least know where I'm going."

Medication Management

The second category to emerge under the sub-theme of IADLs performed with difficulty was medication management. Medication management also emerged as an occupation that was given up. One participant that gave up medication management reported that he gave it up because it was just easier for his spouse to do it as she did not have any vision problems. Other participants lived alone and did not have the option of someone doing for them on a daily basis.

Participant RP091507 reported that he was not able to read his medication labels. He stated, "I go through Aetna mail delivery and I have it on the computer and they will ask me what I need and I tell them. It comes in at different times of the month that they send me pills." He went on to state that he identified his medications by touch. He stated, "I get all my medicine in my hand and if I drop one on the floor I don't know what it is, so I go back to the bottles." He also had large print labels on his medication bottles and was able to identify them when asked. TW101311 continued to do his medication

management and his system was to keep his medications in one central place and he stated that he did not really have to read the labels.

GD41703 reported that she used a machine to read her medication labels. Her insurance company or pharmacy sent her the device. The medication label contained a QR code and the device read the code and read aloud the medication type, strength and dose that the patient was to take. She did report that when she took over-the-counter medication, she would occasionally have difficulty identifying the medication. RT101210 reported that he could only read his medication labels with his handheld magnifying glass. Conversely, SE121412 used insulin and she had recently switched to the insulin pens because she could not accurately draw up an insulin dose. She stated:

> What I like about the pens for the insulin is they click and I can tell how many clicks to turn it until I get the dose of insulin I need in the morning and one at night. And like the vitamins and stuff, I fix myself but my pharmacy I use they fix if for the morning and they fix it for night in little zip packing, so I know what doses are for what, like a.m. and p.m.

SE121412 also reported that she used a pharmacy that puts her prescription medications in a packet for each day for 30 days. She stated the following: "My doctor's office will usually sends [prescriptions] into the pharmacy and [the pharmacy] will change the dosage and they put the medications in the machine to fill them." She went on to state, "They will call me and say that they need to change the next month's packets." She felt that her pharmacy was a lot of help in managing her medications.

PM092509 stated that he could not read his medication labels but that he only had medication for managing his hypertension and his eye drops for managing his glaucoma.

He did not have any difficulty identifying the medications because one was drops and the other was pills. VG41702 reported that she was able to read her medication labels because her pharmacy used large print labels that she could read with lighting and her magnifier. Similarly, CR41701 used her magnifier to read her medication labels. She also reported that she and her daughter would fill a pill box each week. Her daughter just made sure that CR was accurately placing the medications in the pill box.

Financial Management

Financial management was third category to emerged in the sub-theme of IADLs performed with difficulty. More than half of the interviewees continued to manage their personal finances and two participants were managing a business account. One of the assumptions of the Occupational Adaptation Framework is as follows: Because of the desire for mastery, the person intends to produce a response to the occupational challenge that will be adaptive and therefore will lead to mastery (Schkade and Schultz, 1992). This subprocess of the framework is evident in the desire to continue to manage this occupation. RT101210 stated the following:

> I still have an ongoing ministry and finances and things like that that I have to prepare a monthly report for my accountant. I was able to do that this month. In the past it has been very difficult and very frustrating to try to read bank statements and balance checkbooks and do things but with the new glasses I'm able to see enough to do that.

He went on to say that while it took him longer to prepare the financial statements, he was unable to do it for past few months prior to getting prism glasses and adding task lighting.

SE121412 had her daughter to help with some of the financial management she did. She did bank draft for her utilities. She was telling interviewer about a letter that was left on her door recently that stated the water bill was going up $800 when actually it was only going up $10 because she was signing a year lease at her apartment complex. She got "all worked up" and it was really unwarranted but because she could not read all of the form she was misinformed. She also stated that she could read her check stub because she knew where the important numbers where on the stub.

GD41703 reported that she had a helper that came in a half day each week to assist her with bill paying. TW101311 stated that he tended to let his mail pile up but that most of his bills were bank draft. He called the bank about once per week to get his balance and to find out what had posted to his account. He still ran a small upholstery business.

Among the other participants, two had never been the one to manage the family finances. Two gave up the IADL and let their children complete for them because it was too difficult. The other participants did not mention financial management.

Meal Preparation

The components of meal preparation was fourth sub-theme to emerge under this theme. The components of meal preparation that were reported as difficult were reading recipes, accurately measuring ingredients, operating the appliance knobs and dials and identifying when food was fully cooked. LL082806 stated the following: "I use just regular handheld magnifier to read the labels and sometimes with the bifocals if I position them just right I can generally see the seasoning. But, I, that is what I usually need those devices for is when I'm seasoning the food." He also mentioned that he had bump dots

on his microwave and stove to identify settings for those appliances. He also used a magnifier to set the knobs.

DMT080904 stated that she used her slow cooker for a lot of meals because it was easy to just put the ingredients in the cooker and cook for four to six hours. As already mentioned, she did occasionally use YouTube to get new recipes. Conversely, RP091507 did not use recipes and stated that he was a cook for 35 years. He reported he only prepared meals that he had prepared several times previously. He did have difficulty with identifying seasonings. He stated, "I know what I buy and I still put it in my hand. If I put it in my hand I will know how much I got." He added that he cannot see the appliance knobs and dials but goes by feel. He had not burned anything yet.

TW101311 did all of the cooking for himself. He stated that as long as he had enough light, he really did fine in the kitchen. He used a magnifier and the stove light to read labels and directions. GD41703 reported that she had difficulty looking in the refrigerator and identifying what she needed. She stated that she only prepared very simple meals in her apartment. She did not use the oven. She only used the microwave and the occasionally she used the stove top. She lived in a senior residential facility and had one meal per day in the dining room with other residents.

SE121412 only cooked microwave meals that her daughter would bring to her. She would get the same few microwave meals and SE knew how long to cook them as they were familiar to her. PM092509 also only used the microwave for simple meal preparation. He reported that he had a difficult time with identifying foods. He had a system for using the microwave. He would put food in and then push the 1. This would

start cook time going for one minute. He would stay with the food and then stop microwave when he thought food was ready.

VG41702 also only used her microwave for warming up microwave meals or meals that her daughter brought to her. She used her handheld magnifier to read the labels for cooking time, if she could not read it. She also lived in a retirement facility and ate two meals per day with the other residents of the facility. In contrast, CR41701, who lived alone at time of the interview, stated the following, "I like to cook. I make cheese straws and everybody loves my cheese straws. I cook for myself every day. As long as I know where everything is I don't have any problems." She did report difficulty operating microwave if she did not have the light just right.

Computer Use

The fifth category to emerge in this sub-theme was computer use. Several of those interviewed used a computer for various tasks and with varying degree of difficulty. Participant TW101311 described his computer use as the following: "On the computer, well, I read a lot of my ministry activities. I read on a website. And it is updated sometimes on a daily basis. But there is so much I will never get around to reading it all. I don't read it every day, maybe 3 to 4 days per week." When asked why he did not read on the website every day, he stated, "It gets to be too much. Like if my eyes are tired or I have other things that I need to do during the day I may not read that day because I have to like drive somewhere or work some."

RP091507 reported that he only used a computer when he attended technology course at the Alabama Institute for Deaf and Blind. The courses were designed to educate and train consumers, low vision and blind individuals, on assistive technology to

improve their use of technology and increase their independence with daily tasks requiring reading.

In contrast, LL082806 starts his day by checking his email and "just pretty much surf the internet" as he gets up. He spent a lot of his day using the computer. He also used adaptations such as computer software to increase size of images and text on the computer screen, inversion of the colors and text to speech features. He stated the following:

> Most helpful is the inversion of the colors, but one of the astonishing things that has happened lately is that I was not able to see just the regular white background screen. Now, there are certain times and this is just recently within the past months or few weeks, I'm able to see most internet sites without the inverted colors, so I typically change back and forth if it gives me that luxury if I do run into something I can, but probably if I try the built-in magnification that Windows has I probably would need the inverted colors, but I do, so that's what I use.

He went on to state that he sat very close to the computer. He spent on average three to four hours at a time on the computer. He also built a computer to which he was adding the accessibility software.

RT101210 was an avid technology user also. He was only about six months in to his vision impairment and was learning to live with the vision he has. He was also receiving occupational therapy from an OT with expertise in low vision rehabilitation. He stated the following:

> Cheri came today and she fixed my iPad, it is 15 inches I believe and I've got a MacBook Pro which is the large one as well. Cheri fixed the writing, print, text

> whatever on it to make it bigger. I just hadn't been able to use my MacBook Pro for several months. Well, I hadn't used it this year. She fixed it so that the pointer is large enough I can see it and its almost the size of a dime, it looks like now, she made everything bold. She has really helped fix some things.

He went on to say he loves to read Bible commentary and type up his sermon notes and had not been able to do that in last few months. He was working on his first sermon since his vision changed and was extremely grateful for that.

Participant GD41703 was also struggling with computer use. She reported that she was in finance prior to retirement and was used to reading spreadsheets and other financial materials. She had significant difficulty with that at time of interview. She also reported that she used the bank website for bill paying and tried to read her emails. She had also had low vision OT and one of the areas addressed was computer use. Her OT had demonstrated adaptations to increase the size of the mouse pointer on the screen, increase the size of the font of the text, change the font type to that of a sans serif font and increase the contrast of the print on the screen. She also had purchased a large print keyboard and a mouse that had magnification capabilities. Even with all of the adaptations GD41703 had in place she still reported the following, "I do have a helper a half a day each week that comes in and helps me with paying my bills as the computer is not as easy for me to use as it once was."

There were three participants that used the computer extensively for work. RB092408 stated, "I'm on the computer almost all morning, sometimes all afternoon." He went on to add that he had made the font on the computer larger and that it made it easier to read on the computer. Conversely, ES081505 reported significant difficulty

with computer use. She stated, "When I first get to work and start working on the computer, it may be 45 minutes or so before I have to take a break and usually what I do is get up and walk." She went on to add, "When I am not at work, I try to stay away from the computer as much as possible."

Participant DMT080904 was remotely employed in an administrative role at a university. She reported that she spent eight or more hours per day reading and most of that on a computer screen. She went into detail about one of the administrative tasks that she would have to complete on the computer. These tasks often took a lot of time to complete and caused significant eye strain and fatigue that would lead to eye pain and headaches. She stated the following:

"I'll give you an example to tell you about that. I'm on the leadership team … I'm a program coordinator and you have other program directors, like two of them. So, I report directly to the Dean, so she may have state petition or an appeal and what that particularly means is if a student is petitioning for a grade reviewing. I have to investigate that. That means I will have to self-enroll into previous terms and look for that student based on their student ID which is a long ID and I have to input that information and search. The system will populate for all of those student's courses and it just say summer 2017, they are specific codes so it may say for example, 9000052017, its different codes, you know what I mean that we have, so I have to look for the code and then once I find the particular quarter or semester that the student was in, then I have to look for the course, and it can be a lot of different lines… So, I could have a day where I may have five of things to do and it depends on the complexity. One may take me two to three days to investigate, whereas one may take me an hour or so."

When asked about the time she spends reading and how long she could read before requiring a break, she stated the following:

> If I'm just glancing at different things where I can make quick decisions that a longer period of time. I'll say maybe two to three hours. If I'm reading something for content in terms of editing and looking at it depth after about a good hour, my eyes are just tired because of the number of screens that I have to manipulate through and then the coloring of the links and I have to take my hand to the computer screen and I take my index finger and slide down and that's how I find arrow with my mouse. I get up close and sliding down looking to see the link that I need, because just looking at I just can't look at how you look at a computer and you scroll down with our mouse or pointer. I have to hold my finger or take a ruler and slide down the screen and find where I need to go.

DMT went on to describe her computer set up, describing her computer screen as tiny and felt that she would have done better with two screens. DMT had been seen by an OT that had made some recommendations for modifying her workspace to improve the visibility of that space. She had forwarded the recommendations to her employer but had yet to see any change, at the time of the interview.

Using a Smart Phone

Use of a smart phone was sixth task that was reported as difficult but participants continued to do. An advantage of smartphones is the accessibility features that allow the user to increase contrast, brightness of screen and size of the text on the screen. Another feature is voice to text for texting or browsing the internet for information such as the weather, ball game scores or other information. Participant PM092509 reported that his

android device was not difficult to use once he increased the brightness on the screen. He did text and made calls on his phone. SE121412 used her Apple device frequently. By using a little lamp near her chair and increasing the brightness of the screen, she was able to play games (Candy Crush and Sugar Smash) on her device. She used her mobile device solely for communication, as she no longer had a LAN line. She used her device frequently for email, texting, making phones, answering calls, playing games and browsing the internet for information.

DMT080904 reported that she had recently switched from an Android device to the iPhone because of the accessibility features and the large screen. She used the mobile device for work-related calls, personal calls, texting, games and watching YouTube videos. She used YouTube for videos on recipes. She would "mentally look at YouTube" and find recipes to write down and try later.

Participant RB092408 reported using an iPhone for calls, texts and checking email when away from his computer. While he did use some accessibility features on the device, he reported no difficulty using the iPhone. In contrast, GD41703 used an iPhone but had significant difficulty operating the device. She reported that she could not read the numbers when she received calls. She could not read texts and had difficulty send them. She also reported that she could not access her voice mail when someone left her a message. Her family or friends would usually help her with use of her device when they would come by.

Participant VG41702 was also an iPhone user. A member of her family had set up the accessibility features by increasing the size of the font, increase the contrast and demonstrated the voice feature. She stated that she does not text on the phone. She

further stated, “I talk on it. Mainly I keep up with the time and then if the weather is bad it will come up with the weather telling you. Now it says missed call. What’s that number? Can you read it? It looks like 4 something.” She had significant difficulty reading the numbers, even with them larger.

Participant LL082806 was an avid iPhone used. He had recently switched to the iPhone Plus with the larger screen. He also used his readers to read information on the device. He had also incorporated some accessibility features, such as larger text and high contrast settings. He also complained about some glare on the screen and stated that he really had a difficult time using the phone outdoors. TW101311 reported significant issues with glare, but also mentioned fatigued. He was only able to read on his phone for approximately 3-5 minutes and he had to stop looking at it because it got “fuzzy” and “real quick.” He stated it was “really frustrating.”

Participant CR41701 mentioned phone use but her issue was reading the caller ID device associated with her LAN line. The other participants did not mention smart phone use when asked at length about reading.

Leisure

The third sub-theme to emerge from the theme *occupations performed with difficulty* was leisure activities. All participants reported leisure activities that they participated, usually with difficulty. These leisure activities included watching television and several social activities, such as card playing groups, bingo and social outings.

Watching Television

Watching TV is the first category to emerge from the sub-theme of leisure. This activity can include operating the remote, actually viewing the details on the screen and

reading on the screen. CR41701 stated that her morning routine included "listening to jeopardy" because she could not read the answers, even when she was close to the television.

Watching television was a big part of participant VG41702 day and evening. She spent a lot of time watching television. She reported that she watched several programs on television, including Dancing with the Stars, Antique Roadshow, The Voice, Late Night with Jimmy Fallon and The Late Show with Jimmy Kimmel, among others. She also reported that she had difficulty with reading the TV Guide magazine. One of her neighbors would tell her what shows were airing and when they were airing. She would also write out the guide on a piece of paper in large print for her. She seemed to enjoy her television shows and would was able to operate her remote without difficulty. In contrast, LL082806 reported the following, "Now the problem I have with the TV is the remote. I cannot see the numbers. I have memorized them but we have the thing that you can talk to and it will do it. I keep asking Teresa to program it. I need her to set it up so I can tell it to turn the TV on." He also reported that he could not see the colors on the television and that the colors are not as bright as they were prior to his vision loss. He also reported glare issues when trying to see the television.

RP091507 stated that he had received some television glasses but that even with the glasses that magnify the screen approximately 2 – 2.5X, he is still unable to see the television. He just listens to the television. Two other participants reported that they do not really have difficulty watching television and still get pleasure from watching television as one of their past times.

Social Activities

The second category under the sub-theme of IADLs that were difficult was participation in social activities. From the first interview to the last, eleven of the twelve interviewed reported some activity that they had given up, usually more than one and often times the activity was social in nature. LL082806 had given up his ministry because he could not drive and had difficulty reading. C41701 had to give up playing the organ at her church because she could not see the music. She also had been involved in church activities and gave that up as well. She still went out to lunch each Sunday after church but had experienced a fall shortly before the interview that left her with a "horror of falling."

VG41702 liked to go places and do things. She stated, "I used to play cards. I used to play dominoes and stuff like that, but then my eyes got bad so I quit trying to play. We played Rook and poker and all that kind of stuff. It was fun, but I don't try to get involved." She also reported that she did not want to be a burden on her family so she rarely asked to go out.

DMT080904 reported that she still drove in daylight hours so she would get out of the house some. She was harassed by a driver after she parked in handicap parking area. She stated that this was one of the reasons she did not get out and go very often. She tried to avoid crowds because her peripheral vision was impaired and she would bump into people and occasionally had tripped over obstacle in public.

When asked how he was coping with his vision loss and the difficulties that he had doing things, RP091507 stated, "I don't do too much. I just eat and catch the bus." He was going to computer and technology courses. He also reported that he enjoyed

sitting on the porch and socializing with other residents at the senior residential facility. Also, he enjoyed listening to books on tape, since he could no longer read for pleasure.

TW101311 was very open about his private and social life, stating that his vision loss affected both. He attributed his vision loss and the resulting loss of independence to helping to end his marriage. He also stated that it interferes with his social life. He stated, "As far as dating goes, sometimes I don't want to share my vision issue with people. Because sometimes people look at you differently at least that is how I look at it."

GR41703 changed her living situation and her involvement when her vision changed. She stated, "What I used to like to do when I could see was keep up with the stock market and read and just be involved. I was in a lot of organizations and now I don't read. I am read to from the stated Department of the Blind." She further stated, "I have shortened my activities primarily to things at Brookdale and that Brookdale participates in." She later reported that she was still in one dance club outside of her senior living center and she still went to church. Her family would come and get her for church activities.

RT101210 stated that he grew up hunting, fishing and riding horses. He also loved to travel and had visited many places round the world. He stated the following:

> I used to be very active, very independent, travel and a lot of things. But, now I'm pretty much stuck here at home except my wife bought me a Gator for my birthday a couple of weeks ago. We've for some property and I'm able to get my chainsaws and carry those around. I do ride it around a little bit, some on the back roads. So, I got a little independence here in the past few weeks.

He was very much still adapting to living with his vision loss at the time of the interview.

SE121412 belonged to a birthday club that met and went out each month for someone's birthday. She enjoyed this because it got her out of the house. She did not want to burden her daughter with transportation and sometimes could not afford the taxi fare, so if someone could not take her, she would not go. She did have friends that would pick her up for events. She also did not feel comfortable in unfamiliar places at night because her of her visual impairment.

Community Mobility

The fourth subtheme to emerge from the theme occupations performed with difficulty was community mobility. This sub-theme included falls and fear of falling. Of the participants in this phase, over 90 percent reported falls and/or having a fear of falling.

Falls and Fear of Falling

Falls and the resulting fear of falling was the first category to emerge from the sub-theme of community mobility. Several of the participants interviewed had experienced a fall, accident and the resulting fear of falling that limited their activity. Participant RP091507 stated, "I can only see straight ahead, so I had to quit driving. I bought me a bike and ran into a car trying to focus on where the car was and the car was there. I couldn't focus on both of them, so I ran into the back of a man's car." CR41701 describes a fall she had due to vision loss. CR states, "We went out to dinner one day at the country club after church and I had on some little heels and I was coming down the steps and I was holding on the bannister and my friend was holding me on this side. All of the sudden, something happened and I lost my balance and I fell over on that bannister

and broke two ribs." She further states, "Now I have a horror of falling. None of the other participants described falling or a fear of falling.

Two other participants described near falling moments and two others described the difficulty with mobility at night that could lead to falls. Participant DMT080904 lacked peripheral vision and described her experiences with community mobility. She would bump into people in public spaces and trip over obstacles and hazards.

Summary of Theme 2

Each participant discussed ADLs, IADLs, leisure activities and community mobility tasks they continued to complete. These occupations differed for each individual based on their needs and assistance they had available. All except one participant interviewed reported difficulty with at least one occupation (i.e., ADLs, IADLs, leisure activities, community mobility).

Theme 3: *Reading Completed Now*

The third theme that emerged was the *reading completed now*. The participants were asked specific questions regarding the reading that they completed during daily activities. These questions included the following: Tell me about the reading that you do during the day; also, do you only reading what you have to read or do you read for pleasure?

The sub-themes that emerged under this theme included continuous text and spot reading. Continuous text reading included reading such as religious materials, newspaper, social media and computer screen reading. Table 6 below provides a summary of the sub-themes and categories from Theme 3.

Table 6

Sub-themes and Categories from Theme 3: *Reading Completed Now*

Theme	Sub-theme	Categories
Reading Completed Now	Continuous Text Reading	Religious Materials (included Bible) Screen Reading
	Spot Reading	Telephone Labels Appliance Knobs Mail

Continuous Text Reading

Continuous text emerged as the first sub-theme from *reading completed now*. This reading is generally reading for a period of time, reading items such as newspaper and books. In contrast, spot reading is reading for a brief period of time, such as a medication label, cooking instructions, mail and financial forms. The participants also reported that smart phones were accessed to make it easier to read on their phone. Some of the participants discussed using accessibility features available to increase the visibility of the text on the screen. The continuous text reading completed by the participants is described below.

As reported in the previous section, RT101210 was a retired minister. He had been an avid reader prior to his fairly recent vision change. He stated that reading was one of his favorite past times. He was adjusting to life with moderately impaired vision. At the time of the interview he had recently began to complete financial reports for his accountant. He was able to read bank statements and balance his checkbooks. He reported that he was able to read the microwave number pad to prepare his breakfast each morning. He also reported that he was able to read on his iPad and his MacBook Pro

after his OT adapted the devices by utilizing the accessibility features. He read some online platforms, such as social media, new websites and his email.

Another participant that wanted to keep reading her financial documents was GD41703. She completed her financial management on the computer. She had a large print keyboard, magnifying mouse and other accessibility features are on her computer. She did report that handwriting was difficult to read. She also struggled with dates, amounts and account numbers.

TW101311 continued to read his mail, his large-print Bible and he used his computer to read his ministry website. He admitted that he let his mail pile up because it was difficult to read. He did read in the kitchen but reported it was difficult to see knobs and read labels and directions. RP091507 also reported that he cannot read do the reading he needs to do in the kitchen. He had previously worked as a cook and knew his way around the kitchen, but now he cannot read recipes, labels and cooking directions. He reported that he seasons his foods by pouring seasoning in his hand and then puts in food. He reported that he listens to books on tape and to the Bible on tape. He did have an electronic magnifier and would use briefly as his endurance was a factor affecting his reading.

Participant CR41701 reported that she read her daily devotional each morning. She also read her local, small town newspaper that was delivered weekly. She used her electronic magnifier to read those printed materials. She also used the electronic magnifier to look up telephone numbers. She managed her own medications and read medicine labels and labels in her kitchen with an illuminated handheld magnifier.

RB092408 reported that he read for as many as 3 to 4 hours at a time. He was employed as a lead pastor of a church in south Alabama. He read for work, everyday life and pleasure. He read mainly his Bible and religious commentary. He also read sermons, correspondence for work and social media. He reported that most of his reading was on screen. He read on his computer and smart phone for most of his reading.

ES081505 was an avid reader prior to her vision changes. She reported that she would read novels for pleasure but did not do anymore reading than she had to for work. She read on her computer at work and reported glare issues and fatigue after about thirty to forty five minutes of reading. She used her reading glasses, several lamps and adaptations to her computer to make it easier to read. Similarly, DMT080904 did most of her reading for work. DMT080904 reported reading for several hours at a time for different tasks that were associated with her administrative role. She did most of her reading on a laptop computer screen. She also used a smart phone for communication associated with her employment.

Participant LL082806 reported that he enjoyed reading and spent several hours of his on the computer reading news websites he was interested in. He further elaborated that he read his email and "just pretty much surfed the internet." He used computer software that enlarged the print, magnified the print, enhanced the mouse pointer and enhanced the contrast on the screen. He also used a large print keyboard. He was able to read about 30 to 45 minutes before his eyes would need a break from reading. He used a smart phone for texting and some email. He enlarged the text on his phone to make it readable. He had recently received an iPad from the Veterans Affairs Blind Rehab program and was learning to use it.

Spot Reading

Spot reading was the second sub-theme to emerge from the theme reading completed now. Spot reading includes reading labels, appliance knobs, mail and telephone/caller id display.

Several of the participants reported that the only reading they were able to do, at time of the interview, was spot reading. This was usually because their vision deficits would not allow for easy reading. VG41702 reported that she did very little reading during her day. She used a handheld illuminated magnifier when she read. She mainly read her medication labels, cooking directions, hand-written TV guide a friend wrote out for her and communication at her senior living facility. Her family handled her financial affairs and her mail was delivered to them.

When asked if he read during the day, PM092509 stated, "Nope. I don't read at all period. They won't let me read. I can't see it." He later went on to report that he did try to use a handheld magnifier to read the mail that he received. He also read his phone and even did some texting on his phone.

SE121412 reported that she only read minimally. Her daughter did most of her financial management. Her daughter was the one that picked up the mail and she would read the mail for her mother. If she did need to do spot reading of a notice she received in her door from rental office, she would use an electronic magnifier to read it. She also reported that she read her phone and had no difficulty with it. She had a smart phone and used the accessibility features including enlarging the print, increasing the brightness and the magnifier feature.

Summary of Theme 3

The sub-themes and categories of this theme that emerged include continuous text and spot reading. Each participant reported their individual reading. These behaviors differed among them based on reading needs, reading abilities and reading endurance. They reported reading printed materials and on screen and any difficulty they had with glare and decreased endurance.

Theme 4: Reading Problems Reported

The fourth theme that emerged was *reading problems reported.* The participants were asked questions about any difficulty they experienced with reading. Some of these questions include the following: Do you have any difficulty with daily activities that require you to read; Do you have any difficulty with reading medicine labels; Tell me about reading your bills; Tell me about the reading you do in the kitchen; and Tell me about what makes it hard for you to engage in reading activities. The sub-themes and categories that emerged from this theme are listed in table 7 below.

Table 7

Sub-themes and Categories from Theme 4: *Reading Problems Reported*

Theme	Sub-theme	Category
Reading Problems Reported	Ocular Health Issues	Burning eyes Eye pain Dry eyes Cloudiness of vision
	Visual Function Issues	Decreased endurance Glare (TV, ambient lighting, outdoors) Blurriness of print Night blindness

Ocular Health

Ocular health issues was the first sub-theme to emerge in theme reading problems reported. Issues within the ocular system and manifest as physical symptoms (i.e., burning eyes, pain in and around the eyes). The participants reported extensively on the ocular health.

Participant ES081505 reported that she sat in front of a computer at work most of her workday and that it was "horrible" for her eyes. She would have to stop working on the computer anywhere from 45 minutes to an hour before she drove home in order to allow her eyes to acclimate to not wearing glasses. Her eyes were always felt tired. She had quit reading for pleasure a few years ago. Her eye fatigue led to her quit reading for pleasure.

Participant DMT reported on pain and eye strain while she was working and doing a lot of reading on her computer. She referred to this pain as a phenomenon that happened quite often. When asked to tell about her eye pain, she stated the following, "The pain is more like a headache inside the eyes. It feels hollow-ish." She would use cold packs, rest and sometimes narcotic pain medicine to alleviate the pain. She also reported that if she strained her eyes for a large part of the day before, she would not be able to work for long periods of time the next day as the pain would become so intense.

Visual Function Issues

Visual function issues was the second sub-theme to emerge from the theme reading problems reported. The issues with visual function occur when the individual is attempting to complete visual tasks. These issues interfere with visual function needed to

complete tasks such as reading. The participants reported on the visual function issues they experienced in some detail.

CR41701 stated the following about using her electronic magnifier to read, "I enjoy that machine I have but my eyes get tired so fast, so I can't read too much." She also complained of burning eyes when they did get tired. She reported extremely dry eyes and that caused the print to be blurry, which made it more difficult to read. RP091507 also complained of watery eyes. He reported that his eyes watered within minutes of trying to read. He also stated that the print would immediately become blurry when reading and it did not seem to matter if he was using the electronic magnifier of the handheld magnifier. His reading endurance was very limited.

TW101311 reported that he got frustrated when he tried to read. He reported the frustration came from his inability to differentiate letters and read because the print is blurry within three to five minutes into his attempt to read. He reported that he can read approximately three to five minutes on his phone or his computer and "it gets fuzzy real quick and I have to stop because it is fuzzy."

Decreased endurance was commonly reported among participants. GD41703 reported that she had decreased endurance and fatigued easily when she read. She also reported that she used drops for dry eyes. RT101210 reported that he experienced eyestrain very quickly when he read. He also tried to keep his eyes "lubricated" with eye drops. PM092509 reported cloudiness of his vision with reading for a short period of time.

Seeing at night was also reported as difficult. PM092509 reported that the cloudiness he experienced was worse at night. Adding task lighting improved his

performance minimally. The addition of task lighting also caused glare. SE121412 reported that she "could hardly see at night." She was using a cane for mobility at night. She also reported that she had more difficulty when she read at night. LL082806 also reported his eyes "getting tired and blurring" when he read for over an hour on his computer. DMT080904 stated repeatedly that her eyes would feel heavy and literally hurt when she would spend hours reading on her laptop. This really affected her work productivity.

Another sub theme to emerge in reading problems reported was glare sensitivity. Participants reported glare issues from the TV, reading on screens, when using the electronic magnifier and from adding task lighting. LL082806 attributed glare as the reason he could not read on the TV. CR41701 felt like she was constantly adjusting the brightness and contrast on the electronic magnifier screen to reduce glare. PM092509 reported that he could not add task lighting when he read because of the glare created on his phone screen.

DMT080904 also reported on her glare sensitivity. She reported that she had to have the maintenance personnel at the complex in which she resided change out the light bulbs in her apartment. She stated the following, "[Light] hurts my eyes. I keep some lights on in my apartment, it's enough for me to see. The low light provides just enough light and then I try to keep my blinds turned down where I don't have all of this brightness." She also referred to the light from the sun, when she is outdoors as "piercing."

Summary for Theme 4

In summary, the participants reported a wide range of problems they experienced with reading. These problems ranged from minor annoyances to significant difficulty even inability to read without adaptations or methods for coping. These significant difficulties and inability to read that were reported led to significant struggles with IADLs, such as financial management and leisure reading.

Theme 5: Methods for Coping

The next theme to emerge was *methods of coping*. Methods for coping are the ways in which individuals experiencing difficulty with occupational performance cope with that difficulty. Methods for coping included use of adaptive strategies and devices, with several categories, including lighting, assistance from others, cognitive strategies and several other methods. Other sub-themes that emerged under methods for coping included magnification and assistive technology; along with support and resources. The sub-themes and categories from this theme are in Table 8. The methods that emerged in the interviews are described below.

Table 8

Sub-themes and Categories from Theme 5: *Methods for Coping*

Theme	Sub-themes	Categories
Methods for Coping	Adaptive Strategies and Devices	Task lighting, lighted phone, large button phone, large print playing cards Assistance from others (i.e., for bills, driving, grocery shopping) Cognition (memory) Computer software with magnification, color inversion and screen reading features – also larger screen, large print keyboard, increase font, etc. Talking devices: medication identification, talking books Large smart phone

	Magnification and Assistive Technology	Angular magnification with light, Relative distance magnification, OTC HHM (non-illuminated) Electronic magnification
	Support and Resources	LVR, AIDB/MIDB, Support groups, VA Blind Rehab Medication management – pharmacy making bubble packs for medications Insulin pens (use the clicks to draw up insulin dose) Social clubs and support organizations

Adaptive Strategies and Devices

Adapted strategies and devices was the first sub-theme to emerge from the theme of *methods for coping*. These strategies and devices included ways to improve occupational performance and use of devices for improving occupational performance related to reading.

Lighting (overhead and task lighting)

The use of task lighting to improve visibility of ADL and IADL tasks, especially those involving reading was the first category to emerge from the sub-theme adaptive strategies and devices. These types of lighting include LED, Stella™ and full spectrum/natural daylight lighting. Each participant reported that task lighting was helpful in completing ADL and IADLs. These tasks included seeing the food on their plate, medication management tasks, reading labels, measuring ingredients, managing finances, among others. When asked about the type of bulb the participants used, not all participants were able to describe the bulb. Four of the participants used full spectrum gooseneck lamps. The other participants used a form of LED, including one participant who had a Stella® lamp.

Addition of task lighting and use of overhead or room lighting was mentioned as a coping method by most participants. Task lighting emerged as a theme and will be discussed in later section.

Participant CR41701 used overhead lighting and task lighting. VG41702 went outside to use sunlight to read but also used a gooseneck lamp to read large print. GD41703 used light "all of the time" because she could not see without light. She also had a night light at night. DMT080904 used overhead lighting while she could tolerate it. She reported glare issues with addition of light.

RT101210 reported that his occupational therapist had made recommendations for room lighting and task lighting. He stated, "She brought a whole suitcase. It had a lamp in it with some lights and she made several recommendations for room lighting that helped." At the time of the interview, he had not yet been able to implement the suggestions she made on lighting. Conversely, ES081505 discussed the lighting in her office. She stated: "I do not use the overhead lighting, which is fluorescent. It is just because it's not pleasant to work under the fluorescent light. They flicker. They flash." She went on to state, "one of my lamps sits in the windowsill. I have a window in my office and as long as the sun is not glaring through the window onto my computer screen, my blinds are open because the natural light is good for me." She used other lamps in her office also.

Participant LL082806 also reported on the importance of his lighting for completing daily tasks. He was building a computer and added task lighting to install a component to the tower. Conversely, RB092408 only needed overhead lighting to complete task requiring reading. TW101311 used room lighting and task lighting in his

home. He stated, "I have to have the light to read anything." He had a torchiere style lamp in living room, incandescent overhead lights and the light above his stove.

Lastly, participant SE121412 reported that she used overhead lighting and two lamps most all of the time. She reported that her daughter had recently replaced the fluorescent bulbs in her fixtures to LED bulbs. She felt that it was brighter in her apartment after that change. She also had a lamp that she said "pretty much stays on all of the time." She would go to the lamp with anything she wanted to see the details on.

Large and Lighted Phone

The second category that emerged from adapted strategies and devices was use of large displays and lighted phones. Several participants reported upgrading their mobile devices to devices with larger displays and also devices that were back lit. Participant CR41701 had a large and backlit button cordless phone with a backlit and large number caller ID display. However, even with the large number display, she continued to experience difficulty reading the caller ID display. With increased effort, she was able to eventually "make out" the name of caller. She was unable to read her caller ID display prior to getting a large, backlit one.

Participant SE121412 used large print measuring cups. She also had two sets of measuring cups. One of the sets was dark in color and the other set was white. This was so that whatever she is measuring can be measured in a contrasting colored measuring cup.

Participant VG41702 reported that she loved playing card games prior to her vision loss. One way she was able to continue playing card games after her vision loss was to use large print playing cards. Similarly, GD41703 was an avid Bridge player.

She was able to continue playing Bridge when the group agreed to play using large print cards.

Assistance from others (i.e., for bills, driving, grocery shopping)

Getting assistance from others for reading mail, managing finances, grocery shopping, transportation and medication management among other ADL and IADL tasks was the third category to emerge from this sub-theme. Several of those interviewed reported giving up IADL tasks because of the visual demand of those tasks. Participant CR41701 had quit managing her finances and had gotten assistance from her daughter for this. She also had given up driving and would have to ask for assistance for transportation. She had friends, her children and also paid a driver to drive her to appointments, to get groceries, to church and other social events. Participant VG41702 reported that she had given power of attorney to her daughter and that she and her son-in-law managed her finances. They also provided transportation for appointments and for grocery shopping. Participant GD41703 reported similar experiences with transportation issues since she was no longer able to drive. Because of inability to drive, she had moved to a senior living center. She reported that she had limited her "goings" to those events and places where the senior living facility provided transportation and to church. Her family came to get her for church.

Participant RP091507 had to depend on assistance from others for reading his mail, ensured accuracy with medication management and transportation. When asked about reading his mail, he stated, "Yeah, I go to Mrs. Cannon. She is the social worker here. She helps me with important stuff like my bills and Medicare papers." He also depended on facility provided transportation for his transportation needs.

Participant LL082806 reported that his wife did his medication management for him. She also did the driving. Similarly, participant RT101210 depended on his wife for transportation and had to have others complete some of his financial management tasks.

Cognition (memory)

The use of cognitive strategies for coping with issues related to vision loss was the fourth category that emerged from this sub-theme. Participant LL082806 reported the following, "I told everyone when I put something somewhere do not move it." He uses memory and routine to reduce the visual demands of locating objects he used on a daily basis.

Two other participants reported that they had their family get them a small variety of microwaveable meals each week because they knew how long to cook those meals. They also both reported that they had memorized the buttons on their microwaves. Participant CR41701 also reported she "just knew where the settings were on her appliances." Similarly, participant TW101311did all of his own cooking and while he did use the lights in his kitchen, he reported that he did not have difficulty with meal preparation as he usually cooked the same foods and knew his appliances well.

Participant SE121412 used several cognitive strategies to reduce visual demand of tasks. The one she reported was using speed dial on her phone. She reported that she had her daughter's number, the cab company number, her brother's number, her pharmacy and all of her doctor numbers on speed dial. She only had to remember one digit to get in touch with her frequently called numbers.

Computer software with magnification, color inversion and screen reading features (also larger screen, large print keyboard and increase font)

Computer software was the fourth category to emerge under sub-theme of adaptive strategies and devices. This was reported by one participant. LL082806 spent a considerable amount of time on his computer. He had a computer software that would invert colors, magnify what was on the screen, had text-to-voice output and enlarged pointer. He also reported he used a large print keyboard and had purchased a 27-inch television to use for his computer monitor. Similarly, participant GD41703 used a large print keyboard and a computer mouse with magnification capabilities. She also had utilized the accessibility features that came with her computer. These accessibility features included increasing the font size, increasing the contrast, enlarging the mouse pointer and slowing down the cursor on the screen.

Talking Books

The fifth category that emerged from this sub-theme was talking books. Talking books was reported as a way to cope with inability to read, especially for leisure reading was utilizing talking books. RT101210 started his day by listening to devotionals on his iPhone. DMT080904 stated, "Sometimes I listen to the Bible because I'm tired of reading." GD41703 was an avid listener of talking books. SE121412 was also one to listen to the talking books frequently.

Large Smart Phone and Use of Accessibility Features on the Smart Phone

Large smart phone and use of accessibility features was the sixth category to emerge from this sub-theme. Eight of the twelve participants reported use of a smart phone. VG41702 and GD41703 both reported significant difficulty using the iPhone. In both instances, their families had purchased the device for the participant. VG41702 used her iPhone to check the weather and for keeping up with the time of day. GD41703

had used her phone more independently prior to her vision loss. She was unable to check messages and could not read text messages. She did use the voice to speech and magnification feature on the device.

DMT080904 had switched to an iPhone from a Blackberry just prior to the interview. She really liked the iPhone and stated that it was much easier to use and she could see and read better on it because the screen was larger. ES081505 also used an iPhone and she did not report any difficulty with the device. She did report that she did not use the phone much as she did not enjoy looking at screens and reading from screens. She would use her phone to text and view photos of her grandchildren.

LL082806 had received an iPhone plus with the largest screen on a smart phone. He reported no difficulty with use of his phone. He did use the accessibility features, including increasing contrast, increasing size of the font and occasionally the magnifier feature. RB was also an iPhone user. While he reported no difficulty with using the device, he did report that he did increase the size of his text messages to make them easier to read.

RT101210 used an iPhone and reported that he used his phone a lot. He had a ministry and was the president of a local Lions Club and his mobile phone was his main mode of communication for these organizations. Similarly, SE121412 used her mobile phone for communication. She also reported that she played several games on her mobile device.

Magnification and Assistive Technology

Use of magnification devices was the seventh category to emerge under this sub-theme. These devices are used to make images the user is viewing appear larger.

Magnification comes in many different forms. Several forms of magnification were mentioned as methods for coping with reading difficulties by participants. The participants' experiences with devices and assistive technology are discussed in the paragraphs below.

Electronic Magnification. Electronic magnification involved the use of a closed-captioned television (CCTV) that uses a camera system to portray the text or images on which the camera is focused onto a screen. The image or text can then be magnified, contrast and brightness can be adjusted and colors can be inverted.

Participant CR41701 was first to report use of electronic magnification for reading. She reported using her CCTV for reading recipes, labels, cooking directions and for looking up telephone numbers in the telephone book. She also read her daily devotional and the local newspaper using her electronic magnifier.

Participant SE121412 had recently acquired a portable electronic magnifier through low vision aids. She reported that she was now able to read her mail, notices that her apartment complex would leave in her door, her medication labels and also checked her accuracy with her insulin doses when using the insulin pens. These devices had made reading easier and allowed her some more independence within her daily life. Similarly, RP091507 had acquired a desktop CCTV from Alabama School for the Deaf and Blind (AIDB). He reported that he was not able to read for more than a few minutes because his eyes watered and the print blurred. He stated, "I go on the machine and I can read some lines but my eyes start running water."

Participant LL082806 also received an electronic magnifier (CCTV) from the VA Blind program. He reported that he did use the "video magnifier" when he had to read

small print. He gave the example of using the video magnifier to read his mail, especially when he knew it was a bill. Conversely, GD41703 spent a lot of time completing her financial management tasks using her desktop electronic magnifier. She did report some frustration with having to use the desktop device, stating: "It is frustrating not to be able to see everything and sometimes the reader reads straight down like this and you might have columns and it is difficult to go across." She demonstrated moving the CCTV tray that the sheet was on toward her (going down the page), instead of moving side-to-side as one would do to read across the page. She also used other devices to magnify the materials she read.

Angular Magnification with Light. The next magnification device that was used by participants was angular magnification with light. The angular magnification devices included hand held illuminated devices of different strengths. These were prescribed by optometrists, usually those specializing in low vision. Ten of the twelve participants reported having a hand-held magnifier, usually prescribed but some used over-the-counter magnifiers with or without illumination.

Participant CR41701, VG41702, GD41703 all reported that they used a handheld, illuminated magnifier for spot reading. Spot reading included reading medication labels, cooking directions on a food container and other quick reads. PM092509 had a handheld illuminated magnifier that he received from AIDB and he reported that he would try to use this device to read his mail. SE121412 reported that she did not use her handheld magnifier as much since she had gotten the electronic magnifier. She did occasionally grab it if it was close by for reading cooking directions, instead of having to turn on the electronic magnifier. RP091507 had a handheld magnifier that he still would try to use

but he reported that he could not really see well enough with it to do reading unless the print was large. LL082806 preferred his video magnifier to his handheld magnifier but would use the handheld magnifier occasionally for a piece of mail.

RT101210, who had had recent vision changes, had only had a handheld, illuminated magnifier for a few weeks prior to the interview. He was getting used to using the magnifier to do some his reading. TW101311 was using his handheld magnifier in the kitchen, where he completed his meal preparation and his medication management. He also used this magnifier for reading his mail, although he admitted that he often would let his mail pile up for a week or so.

Relative Distance Magnification. The next magnification technique to emerge was relative distance magnification. This technique involved decreasing distance from the reading surface. Participant moves closer to what they were trying to see or read (i.e., television, medication label, etc.) or move the object they are trying to identify closer to their eyes. Three participants reported using this method for either television viewing or trying to read labels. Participant CR41701 reported that with more light and moving closer to what she is viewing made things more visible. When she watched television, she would sit next to the television. Similarly, participant VG41702 spent a good portion of her day watching television. She had moved one of her dining room tables right by her television.

Over-The-Counter Handheld Magnifier (non-illuminated). The over-the-counter handheld magnifier (OTC HHM) was the next coping method to emerge. The OTC HHM was mentioned by one participant. Participant DMT080904 used an OTC HHM to read small print in the kitchen and with her mail.

Support and Resources

Another sub-theme for coping methods included support and resources. These support and resources included services like low vision rehabilitation, Veterans Affairs Blind Rehabilitation program, state level department of rehabilitation services for employees and older adults, social clubs and several others. Eleven of the twelve participants had sought support services and local or state resources to help them cope with their vision loss and learn about resources available to them. Three of the participants had received rehab services in both medical clinics and the federally funded programs available through their state department of rehabilitation services.

Low Vision Rehabilitation

Low vision rehabilitation services included optometry or ophthalmology examination most often followed by referral to occupational therapy services. Ten of the twelve participants had been recruited through three low vision rehabilitation programs in Alabama and Mississippi. Seven of the participants had received some level of occupational therapy services with an OT who specialized in low vision rehabilitation. Participant RT101210 was receiving OT services at the time of the interview. He reported that with OT training on devices available and training on use of the devices, he was able to read when he was not able to for months prior. He was also able to complete a monthly financial report when he had not been able to do so months before. He also reported that the training on lighting options were helpful and he could see how the task lamps and changing the type of light bulbs he used would improve visibility of his environment when he had the chance to make the changes. The OT also provided training on accessibility features on devices he already owned. He also was shown glare

shields that cut the glare and he felt improved the sharpness when he viewed through those lenses.

Participant GD41703 had received low vision OT in recent past. She reported that she really wanted to continue using her computer and managing her finances. The OT recommended adaptations to her computer to increase visibility on screen. The OT also recommended a magnifying mouse and large print keyboard. Task lighting was also recommended. She had a tabletop full spectrum lamp and a standing, gooseneck full spectrum task lamp. She stated that she always had these lamps on and they helped her "immensely." She also used her handheld magnifier more effectively after training from OT on proper use. She also had purchased a desktop CCTV and the OT also trained her on use of the electronic magnifier. She also received training on task and environmental modification in OT. Besides her adding light to all tasks she completed, another example of this is modifications for legibility of handwriting. GD41703 was trained on how to improve visibility of this task by addition of task lighting and enhancing contrast so that she can see the line where she is writing and follow her pen tip. After this training, she was able to read what she had written. She felt that she had benefitted from OT services and main benefit for her was continued use of her computer and managing her finances.

Other participants had received low vision OT months to a year prior to interviews. Most of the participants who had received OT services were trying to continue to participate in their ADLs and IADLs. Participant DMT had sought low vision OT because of the exhaustive nature of her work. As stated previously, DMT 080904 was a PhD-trained administrator for a university in the northeast area of the US. At the time of the interview she was telecommuting, which required eight to ten hours

daily reading on the computer. She went to OT seeking recommendations for improving the visibility of her work station, computer and home office environment. The OT completed an interview of her, assessed her needs, assessed her home work space and made recommendations based on the findings. The recommendations made included larger screens for her computers, changing her communication device to an iPhone, task lighting, room lighting changes and task modification to improve visibility and reduce visual demand to decrease her fatigue with computer use and reading. Her employer was slow to provide these accommodations for her.

Alabama Institute for the Deaf and Blind

The Alabama Institute for the Deaf and Blind (AIDB) offered technology courses and daily living courses for adults with low vision and blindness. They also offered Braille reading courses. Two participants had been involved in the technology course. RP091507 reported that he went to AIDB often and he participated in the technology classes and went to the support group that met monthly. He also reported that he had recently begun Braille courses. He stated that one of the reasons he went to AIDB was to be around other people. Conversely, PM092509 had gone to a couple of classes at AIDB and he basically did not feel that he gained a lot of knowledge nor insight from the classes.

State-level Rehabilitation Services

The Alabama Department of Rehabilitation Services (ADRS) offered rehabilitation services and employment support for teens to adults in Alabama. ADRS also had a service for older adults of Alabama that included rehabilitation counseling, rehabilitation teaching and orientation and mobility services. There was one participant

that briefly discussed her participation in this service. GD41703 stated that the rehab teacher with ADRS spent a lot of time at her senior living center. The rehab teacher marked appliance knobs in her kitchen, gave her a talking Bible and got her started with Talking Books program available through the National Library of Congress.

The Mississippi Department of Rehabilitation Services (MDRS) also offers employment support and rehabilitative services to residents of Mississippi. The programs in each state offer similar services. One participant had received employment support through the MDRS. She reported that she worked at the Industries for the Blind. She also had recently been referred back to the older adult division of MDRS and they had provided her with some devices to make her daily life easier. She had received a handheld electronic magnifier, talking clock and other devices for use in the kitchen.

*Veterans Affairs Blind Rehab*ilitation

Participant LL082806 had participated in the Veterans Affairs Blind Rehabilitation program associated with the VA Hospitals. This was a residential inpatient program that provided comprehensive adjustment to blindness training and served as a resource to a catchment area usually comprised of multiple states. Blind Rehab Centers (BRC) offered a variety of skill courses designed to help blinded veterans achieve a realistic level of independence. These skill areas include orientation and mobility, communication skills, activities of daily living, manual skills, visual skills, computer access training and social/recreational activities. The veteran was also assisted in making an emotional and behavioral adjustment to blindness through individual counseling sessions and group therapy meetings (www.rehab.va.gov, 2016). He was admitted to the inpatient rehabilitation program Sunday through Friday for six weeks. As

part of the program, LL082806 received several devices to assist him in maintaining independence in his daily life. The VA had provided him with a Stella lamp, iPhone Plus, desktop CCTV, handheld CCTV, large button remote control, computer accessibility software, long cane for mobility, Talking Script for medication management, handheld magnifier, glare shields and other devices. He reported that he did use most all of the devices in his daily life. The lamp he felt was invaluable. He read small print with the electronic magnifiers. He did not use the long cane for mobility as he reported he needed some additional training on the use of the cane for mobility. He spoke highly of the program and also reported that he has spoken at other low vision support groups and always encouraged veterans to look into the Blind Rehab program.

Support Groups

Two participants reported that they attended low vision support group meetings. Participant PM092509 reported that he went to support group meetings that were held at the AIDB Regional Center where he attended technology courses. He enjoyed the interaction with other people. Similarly, participant LL082806 reported that he attended and led support group meetings at the ADRS office in Mobile, Alabama. He was connected to the support group leader by the local low vision rehabilitation center.

Social Clubs

Another coping method that was reported by one participant was participation in social clubs. Participant SE121412 reported that she was part of a birthday club and took part in a club associated with the National Federation for the Blind (NFB). She reported that the birthday club members would go to dinner once per month and celebrate the members of the group whose birthday was that month. She stated the following, “I don’t

go as much as I would like to go but I try to go as often as I can. I have to arrange transportation."

GD041703 also participated in a social or dance club. Prior to losing her vision and moving to the senior living facility, she was a member of several dance clubs and spent a lot of time dancing. Once she moved and gave up driving, she reduced to only one dance club. She also continued her involvement in her church for social support. Several participants continued to be involved in church activities. Some of them had to change churches to continue their involvement, usually this was because of changes in their living situation.

Summary for Theme 5

In summary, the participants reported a wide range of methods they employed to cope with reading difficulties and the resulting occupational performance issues. These methods ranged from having others complete all or parts of their occupations to spending time with friends, journaling and also seeking state or federal resources. These methods were employed in attempts to reduce the need to read or improve the ability to read to reduce the significant struggles with IADLs, such as financial management, meal preparation and leisure reading.

Summary of Qualitative Findings

Five major themes emerged from the analysis of the interview data, 1) occupations given up, 2) occupations performed with difficulty, 3) reading completed now, 4) reading problems reported and 5) methods for coping. Across all twelve interviews, participants indicated ADLs and IADLs that they had given up due to vision loss. They also shared their experiences with ADLs and IADLs that they continued to

do, including the eye and general symptoms they have with reading. Some reported minimal difficulty with the ADLs and IADLs they continued to do, while others reported significant difficulty and often would give up and ask for help from others. Most demonstrated a desire to remain independent with ADLs and IADLs for as long as they were able to continue to do so. The ability to read as it pertains to completing ADL and IADL tasks was demonstrated to effect participants' independence, including employment. Some were still working and one had a screen reading-intense job.

The participants also shared the methods for coping they used to compensate for vision loss in completing these tasks and occupations, especially those requiring reading. These methods for coping and compensation for their vision loss demonstrated their desire and demand for mastery. These methods included varying forms of magnification, task modifications, cognitive strategies, social groups and many others.

Integrating the Qualitative and Quantitative Phases

The themes, sub-themes and categories were used to develop the survey items. The researcher went back to the literature to draw from what is already known about glaucoma and reading. This included the QoL literature (Nelson et al., 2003), reading fatigue studies (Nyugen et al., 2014; Ramulu et al., 2013a & 2013b) and effects of low vision on ADLs (DeVries et al., 2012; Finger et al., 2011). The researcher reviewed the language and item structure in the Berman study (2017) and the Allen study (2012).

Five main themes and the related sub-themes were used to guide instrument development. The five themes and related sub-themes were further organized into seven subsets, which later became the general reading section and the six scales of the instrument. One example from the theme Methods for Coping, two scales with nine

items each were developed. The scales were methods for print reading and methods for screen reading. Both of these scales included the sub-themes and categories from the theme. The items included methods such as use of reading lamp, large print materials, large print on a screen, having someone else read for the participant, using a line guide to keep place on line, use talking books and use of computer magnification software. These items were rated on a four-point Likert scale.

Another example includes the use of lighting. Every participant reported on using lighting for reading and to identify objects and people. Lighting items were included in four of the six scales of the instrument.

The item development was also guided by the constructs of the OA Framework (Schkade & Shcultz, 1992). These constructs include the desire for mastery, demand for mastery, the occupational challenge, occupational response and occupational environment. Table 9 shows the alignment of OA constructs with themes that emerged from Phase I and survey items from Phase II. For example, the demand for mastery construct guided the development of the theme of *occupations completed with difficulty*. Participants reported that they continued to complete ADL and IADL task with difficulty because they had to continue to do some of these tasks and wanted to remain independent for as long as they could. In phase II the demand for mastery was theoretical basis for the scales related to methods for print reading, methods for computer/screen reading and methods for coping with reading difficulties.

Table 9

Alignment of Theoretical Constructs, Themes and Items

OA Constructs with Definition Occupational adaptation theory postulates that personal adaptation is a human phenomenon that is constantly in a process characterized by disorder, order and reorganization. The desire, demand and press for mastery are constantly present within an occupational environment. (Schultz, 2009)	**Phase I Qualitative Themes**	**Phase II Instrument Items (by Scale and Section)**
Desire for Mastery: The person is made up of systems that are unique to the individual and these are: sensorimotor, cognitive and psychosocial systems. All occupations involve all the person systems and the contribution of each system shifts depending on the circumstances surrounding the specific occupation.	•Occupations Completed with Difficulty	•General Reading •Print Reading Methods •Computer/Screen Reading
Demand for Mastery: Demands to perform occur naturally as part of person-occupational environment interactions hen demand for performance exceeds person's ability to adapt, dysfunction occurs	•Occupations Completed with Difficulty •Mechanisms for Coping	•Print Reading Methods •Computer/Screen Reading •Everyday Life Impact •Lighting •Glare with Reading
Occupational Challenge: The constant factor of press for mastery yields the occupational challenge. This press for mastery is created by demand and desire for mastery.	•Occupations Given Up •Reading Completed Now •Reading Problems Reported	•Everyday Life Impact •Glare with Reading •Fatigue with Reading
Occupational Response: an observable outcome of the adaptive response, which refers to an action and behavior carried out in response to an occupational challenge.	•Occupations completed with difficulty •Mechanisms for Coping	•Print Reading •Computer/Screen Reading Methods
Occupational Environment: focuses on the external factors of the occupational adaptation process that affect the person. The process in the occupational environment begins with a constant demand for mastery. Any circumstance in the occupational environment presents a demand for mastery. The occupational environment is the dynamic and experiential context within which the person engages in occupations and occupational roles.	•Methods for Coping	•Lighting •Glare with Reading

Phase II: Quantitative Results

The following sections provide a basic description of the survey instrument, demographics for the quantitative sample, results of the reliability factor for each scale, exploratory factor analysis and correlation statistics for each scale that were used in establishing validity in the qualitative data analysis. The section discussion is organized by the quantitative research questions.

Sample Characteristics

The majority of participants were female (61.4%), with mean age of 70.7 years. Just over 97 percent of the participants had a diagnosis of glaucoma (97.1) with the glaucoma severity ranging from mild (34.1%) to severe (28.6%). Two of the 70 participants (2.9%) had diagnosis of glaucoma suspect. On follow-up, one participant had been followed by the physician for many years with mild glaucoma, but had recently been taken off of glaucoma medication due to decreased intraocular pressures. Conversely, the second glaucoma suspect diagnosis was changed to mild glaucoma by the physician on the day of the participant's participation in this study. Most of the participants wore corrective lenses (72.9%) and reading glasses (94.3%). Level of education widely varied, with participants with a high school diploma (25.7%), some college (30%) and Bachelor's degree (24.3%) rounding out the top 3 of the category. Most participants were not employed (70%). The table below provides descriptions of the demographic variables (Table 10).

Table 10

Description of Demographic Variables

Demographics	Number of Participants	% of Total	Mean (SD)
Age			70.7 (11.6)
Race			
African American	29	41.4%	
Caucasian	41	58.6%	
Other		0 %	
Gender			
Female	43	61.4%	
Male	27	38.6%	
Total		100%	
Ocular History			
Glaucoma	68	97.1%	
Glaucoma suspect	2	2.9%	
Glaucoma Severity			
Mild	22	31.4%	
Moderate	22	31.4%	
Severe	20	28.6%	
Unknown	6	8.6%	
Wear glasses			
Yes	19	27.1%	
No	51	72.9%	
Reading glasses			
Yes	66	94.3%	
No	4	5.7%	
Level of education			
Some High School	3	4.3%	
HS Diploma	18	25.7%	
Some College	21	30.0%	
Associate's Degree	3	4.3%	
Bachelor's Degree	17	24.3%	
Graduate Degree	8	11.4%	
Employed			
Yes	21	30%	
No	49	70%	

Results of Quantitative Analysis

The revised instrument included one demographic question, eight general reading questions, two check lists for print and screen reading and six sets of items comprising scales of the instrument. A total of 70 items were in the survey. Items on scales ranged between seven and 12 parts. Item responses were on a four-point Likert scale. In total, 70 instruments were administered during this piloting phase. Results presented separately for each of the three quantitative research questions. All 70 respondents completed the entire instrument and therefore, all 70 were used in the quantitative analysis. Results of this first study of reading behaviors of older adults with glaucoma and the effect on occupational performance must be interpreted with caution due to small sample size.

Research Question 1

What is the estimated face validity, content validity and internal consistency reliability of items to measure the impact of reading changes from glaucoma on occupational performance?

For statistical analysis, the survey instrument was divided into six scales with seven question pertaining to general reading assessment that were not included in the factor analysis. The six scales included the following: 1) Print/paper reading assistance/methods of modification; 2) Screen reading assistance/methods of modification; 3) Everyday life impact of reading difficulties; 4) Lighting for Reading; 5) Glare with Reading and 6) Fatigue with Reading and Symptoms of Fatigue.

Statistical Analysis of the Six Scales of the Instrument

The statistical analysis of each scale is described below. There is a description of the statistics results, frequency table and factor analysis table for each of the six scales.

Reliability coefficient and factor analysis are reported with specific rules for each statistic. Cronbach's alpha was used for each scale of the instrument to estimate internal consistency reliability. Exploratory factor analysis was performed using a Direct Oblimin rotation procedure. The analysis was performed using SPSS (v26.0). The number of factors to extract and rotate was estimated using two measures: Kaiser's Rule of Thumb (eigenvalues $\geq$1) and examination of the scree plot. Factor loadings $\geq$.30 were considered acceptable (Tabachnick & Fidell, 2007). The results for each scale are discussed in the following paragraphs.

Scale One

Scale one asked respondents to rate, on a four-point scale, their use of varying methods to aid in reading printed materials. Table 11 contains the frequencies and percentages for each response choice of each item. At least 60% always or frequently used a reading/desk lamp when they were reading printed materials (i.e., newspaper, magazines, mail, etc.). Around 50% reported they frequently or occasionally used large print reading materials, also used a ruler or line guide to keep their place or find next line when reading. Fewer agreed on the other methods listed, except use of reading glasses, which almost 85% reported always or frequent use of reading glasses for print reading.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.65. The two rules of factor analysis suggested extracting and rotating two factors. Table 12 contains a summary of factor analysis for *Scale One*. The two factors accounted for 38% of the variance. However, when a two-factor solution was run, the second factor had only three items loaded on it. When a three and four factor solution were analyzed similar outcomes occurred. Therefore, the data suggested that the most

conservative solution was a single factor solution. All of these items of this scale were identified in the qualitative analysis as important methods for reading print materials. The Cronbach's alpha for this scale does approach the threshold of .70. It is possible the smaller number of items in the set may have contributed to a slightly lower alpha coefficient.

Table 11

Frequency Table for Scale One

Do you use any of the following to read printed materials?	Response Choices			
Item	Always	Frequently	Occasionally	Never
Reading/desk lamp	31.4% (22)	37.1% (26)	18.5% (13)	13% (9)
Large print materials	7% (5)	20% (14)	34.2% (24)	38.8%(27)
Ruler or line guide to keep place or finger used to keep place on line	2.8% (2)	24.3% (17)	34.4% (24)	38.5%(27)
Prescribed magnifier lens	4.2% (3)	11.4% (8)	7.1% (5)	77.3%(54)
Electronic magnifier	0% (0)	4.3% (3)	2.9% (2)	92.8%(65)
Magnifier purchased in a store	1.4% (1)	10% (7)	12.9% (9)	75.7%(53)
Reading glasses	71.4% (50)	12.9% (9)	8.6% (6)	7.1% (5)
Get assistance from others (have them read)	0% (0)	8.6% (6)	25.7% (18)	65.7%(46)
Talking books or audio books	2.9% (2)	1.4% (1)	21.4% (15)	74.3%(52)

Table 12

Summary Table of Factor Analysis for Scale 1

Do you use any of the following to read printed materials?	Factor 1	2
Reading desk/lamp	.263	**.590**
Large-print materials	**.331**	.012
Ruler or line guide to keep place on line	**.729**	**.293**
Prescribed magnifier lens	**.678**	-.056
Electronic magnifier	**.538**	-.197
Magnifier purchased OTC	**.309**	-.006
Reading glasses	.278	**.339**
Get assistance from others	**.600**	-.294
Talking/audio books	**.390**	-.293

Note: Factor loading ≥ .30 are in boldface.

Scale Two

Scale two, similar to scale one was examining participant use of methods for screen reading. This scale asked respondents to rate, on a four-point scale, their use of the varying methods. Table 13 contains the frequencies and percentages for each response choice of each item. At least 60% always or frequently used their reading glasses when they were reading on a screen (i.e., computer screen, e-reader, tablet, mobile device). Around 50% reported they always or frequently kept on a room light when reading on a screen. Nearly 45% reported they increased the size of the letters/words when reading on a screen. Very few reported any use of large-print keyboards or screen magnification for screen reading.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.65. The two rules of factor factor analysis suggested extracting and rotating three factors. Table 14 shows the factor analysis results for scale two. The three factors accounted for 43% of the variance. However, when a three-factor solution was run, the third factor had only three items loaded on it. Running a two and four factor solution achieved the same outcomes. Again, the data suggest that the most conservative solution was a single factor. All of the items within the scale were identified in Phase I as important methods for screen reading, except use of computer and reading glasses. For this reason, the item related to "use of computer glasses" was removed. Similar to *Scale One*, the Cronbach's alpha for *Scale Two* approached the threshold of .70. The smaller number of items in the set likely contributed to a lower alpha coefficient.

Table 13

Frequency Table for Scale 2

Do you use any of the following to read on a screen?	Response Choices			
Item	Always	Frequently	Occasionally	Never
Add reading/desk lamp	20% (14)	8.6% (6)	17.1% (12)	54.3% (38)
Keep on a room light	35.7% (25)	15.7% (11)	20% (14)	28.6% (20)
Increase the size of print on screen	17.1% (12)	27.1% (19)	27.1% (19)	28.7% (20)
Change contrast on the screen	1.4% (1)	18.6% (13)	11.4% (8)	68.6% (48)
Large-print keyboard	1.4% (1)	4.3% (3)	0% (0)	94.3% (66)
Computer software (OCR, magnification, etc.)	0% (0)	1.5% (2)	1.5% (2)	97% (60)
Computer glasses	1.4% (1)	0% (0)	1.4% (1)	97.2% (68)

Reading glasses	51.4% (36)	10% (7)	5.7% (4)	32.9% (23)
Have someone read for you	0% (0)	2.9% (2)	15.7% (11)	81.4% (57)

Table 14

Summary Table of Factor Analysis for Scale 2

Do you use any of the following to read on a screen?	Factor 1	2	3
Add reading lamp	**.566**	.032	-.349
Keep room light on	**.473**	.160	-.277
Increase size of print on screen	**.615**	**.383**	.041
Change contrast on screen	**.567**	-.130	-.007
Large-print keyboard	**.693**	-.499	**.352**
Computer software (OCR)	**.405**	-.352	.125
Reading glasses	**.473**	**.389**	-.002
Have someone read for you	.046	**.451**	**.646**

Note: Factor loading ≥ .30 are in boldface.

Scale Three

Scale three asked respondents to gauge the impact of reading difficulties they may experience on everyday life. The respondents were asked to gauge this impact on a four-point scale. Table 15 shows the frequency of the responses. Over 40% of respondents reported that reading for pleasure was greatly or moderately impacted by their reading difficulties. This was the only everyday life event that was reported by the overwhelming majority of respondents to be strongly impacted by reading difficulties. All of these areas

were reported as areas of difficulty in Phase I. One possible explanation of the low impact is the respondents to the survey had varying levels of mild to severe glaucoma, whereas the Phase I respondents were mostly severe glaucoma.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.94. The rules for factor analysis suggested extracting and rotating two factors. Table 16 shows the factor analysis results for scale three. The two factors accounted for 63% of the variance. All items in this scale loaded on one factor, while less than three loaded on the second factor. This suggests that the scale should be a one factor scale. All of these items within the scale were identified in Phase I as everyday life impacted by reading difficulties, so all items were kept.

Table 15

Frequency Table for Scale 3

For each of the following statements, choose the response that best describes how much your everyday life has been impacted/ challenged by your reading difficulties.	Response Choices			
Effects of reading difficulties on everyday life Item	Greatly	Moderately	Slightly	Not at all
Reading for pleasure	30% (21)	14.3% (10)	23% (16)	32.8% (23)
Dressing, grooming and bathing activities	5.7% (4)	5.7% (4)	13% (9)	75.6% (53)
Work or job duties	10% (7)	5.7% (4)	5.7% (4)	78.6% (55)
Social communication	3% (2)	7% (5)	14.3%(10)	75.7% (53)
Participation in community activities	8.6% (6)	8.6% (6)	15.7%(11)	67.1% (47)

Social interactions (limited because of vision?)	8.6% (6)	5.7% (4)	18.6% (13)	67.1% (47)
Medication tasks	3% (2)	8.6% (6)	34.2% (24)	54.2% (38)
Financial Tasks	4.3% (3)	11.4% (8)	25.7% (18)	58.6% (41)
Preparing meals	4.3% (3)	4.3% (3)	20% (14)	71.4% (50)
	8.6% (6)	5.4% (4)	13% (9)	73% (51)
Getting around in community				
Writing tasks	7% (5)	7% (5)	21.6 (15)	64.4% (45)
Electronic devices	10% (7)	5.7% (4)	18.6% (13)	65.7% (46)

Table 16

Summary Table of Factor Analysis for the Final One-Factor Solution for Scale 3

Choose the response that best describes how much your everyday life has been impacted/ challenged by your reading difficulties.	Factor 1
Reading for pleasure	**.528**
Dressing, grooming, bathing activities	**.684**
Work or job duties	**.518**
Social communication	**.724**
Participation in communication activities	**.861**
Social interaction	**.851**
Medication tasks	**.835**
Financial tasks	**.818**
Preparing meals	**.752**
Getting around in the community	**.842**
Writing tasks	**.883**
Electronic devices	**.816**

Note: Factor loading ≥ .30 are in boldface.

Scale Four

Scale four measured use of lighting for reading. This section asked respondents to respond on a four-point scale to situations in which they used lighting when reading. The respondents overwhelmingly use direct light (lamp) when reading print (75%) and do not use direct light or a lamp when reading on a screen (64%). Nearly 75% reported they always or frequently keep on the room light when reading print while just over 50% keep on a room light when reading on a screen. Over 70% reported that direct lighting makes it easier to read, while 65% reported that overhead lighting makes it easier to read. Table 17 contains the frequencies and percentages for each response choice of each item for scale 4.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.82 for items of scale four. The two rules for factor analysis suggested extracting and rotating two factors for this scale. Those factors accounted for 63% of the variance. All of the items for this scale were retained. Table 15 contains the summary of factor analysis for scale four.

Table 17

Frequency Table for Scale 4

How often do the following situations occur?	Response Choices			
Item	Always	Frequently	Occasionally	Never
Use direct lighting when read print	38.6%(27)	37.1% (26)	15.7% (11)	8.6%(6)
Use direct lighting when read on screen	17.1%(12)	18.6% (13)	32.9% (23)	31.4% (22)
Direct lighting makes it easier to read	44.3%(31)	30% (21)	15.7% (11)	10% (7)

I use room/overhead lighting when I read print	34.3%(24)	40% (28)	17.1% (12)	8.6% (6)
I use room/overhead lighting when I read on a screen	22.9%(16)	31.3% (22)	22.9% (16)	22.9%(16)
Room/overhead lighting makes it easier to read	27.1%(19)	38.6% (27)	28.6% (20)	5.7% (4)

Table 18

Summary Table of Factor Analysis for Scale 4

How often does the following situations occur?	Factor 1	2
Use direct lighting when reading print	**.559**	**.622**
Use direct lighting when reading on a screen	**.572**	.185
Direct lighting makes it easier to read	**.654**	**.498**
I use room/overhead lighting when I read print	**.798**	-.370
I use room/overhead lighting when I read on a screen	**.798**	-.346
Room/overhead lighting makes it easier to read	**.681**	-.304

Note: Factor loading ≥ .30 are in boldface.

Scale Five

Scale five asked respondents to rate, on a four-point scale, their glare issues when reading. Table 19 contains the frequencies and percentages for each response choice of each item. At least 70% occasionally or never experienced difficulty with glare when reading. Less than 20% experienced glare when they added a task lamp for reading. Over 90 % reported that they do not avoid direct lighting. These items were all strongly associated with reading issues reported in Phase 1.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.88. The two rules for factor analysis suggested extracting one factor. This

factor accounted for 64% of the variance. However, when a two-factor solution was run, the second factor had less than three items loaded on it. Similar to results found *in Scale One* and *Scale Two*, the data suggest that the most conservative solution is a single factor solution. The summary of factor analysis for this scale is listed in Table 20.

Table 19

Frequency Table for Scale 5

How often do the following situations occur?	Response Choices			
Item	Always	Frequently	Occasionally	Never
Glare causes difficulty with reading	14.3%(10)	14.3%(10)	38.6% (27)	32.8%(23)
I have problems with glare with printed materials	10% (7)	14.3%(10)	31.4% (22)	44.3%(31)
I have problems with glare when I add task lighting with reading print	3% (2)	15.7%(11)	32.8% (23)	48.5%(34)
I have problems with glare with screen reading	5.7% (4)	24.3%(17)	30% (21)	40% (28)
What do you do to minimize glare?				
glare shields	0% (0)	7% (5)	10% (7)	83% (58)
adjust lighting source to try to reduce glare	5.6% (4)	23% (16)	31.4%(22)	40% (28)
Do you avoid direct lighting because of glare?	0% (0)	8.6% (6)	24.3% (17)	67.1%(47)

Table 20

Summary Table of Factor Analysis for Scale 5

How often do the following situations occur?	Factor 1
Glare cause difficulty with reading	**.864**
I have problems with glare when reading printed materials	**.873**
I have difficulty with glare when I add task lighting with reading print	**.827**

I have a problem with glare when I read on a screen	**.790**
What do you do to minimize glare?	
Use glare shields	**.398**
Adjust lighting source to try to reduce glare	**.631**
Do you avoid direct lighting because of glare?	**.626**

Note: Factor loading ≥ .30 are in boldface.

Scale Six

Scale six asked the participants, on a four-point scale from always to never, their experience with fatigue and reading and also fatigue symptoms. Table 19 contains the frequencies and percentages for each response choice of each item. Nearly 50% of respondents reported always and frequently experiencing fatigue with reading. Less than 40% reported having to stop reading either on a screen or print because of fatigue. With fatigue symptoms, respondents reported always or frequently experiencing burning eyes (34.3%), dry eyes (40%), watery eyes (42.8%), and blurriness of print (54%). Less than 20% reported pain in/around eyes and night blindness.

Cronbach's alpha coefficient revealed an internal consistency reliability coefficient of 0.90. The two rules used in factor analysis suggested extracting and rotating two factors. Table 22 shows the summary of factor analysis for scale five. The two factors accounted for 65% of the variance.

Table 21

Frequency Table for Scale 6

	Response Choices			
Item	Always	Frequently	Occasionally	Never
I experience fatigue with reading	18.6%(13)	30%(21)	30%(21)	21.4%(15)

I have to stop reading because of the fatigue	17.2%(12)	20%(14)	37.1%(26)	25.7%(18)
Do you have fatigue with the following?				
Printed materials	17.2%(12)	28.6%(20)	31.4%(22)	22.8%(16)
Screen reading	8.6% (6)	25.8%(18)	32.8 (23)	32.8%(23)
Symptoms:				
Burning eyes	8.6% (6)	25.7%(18)	27.1%(19)	38.6%(27)
Pain in/around eyes	4.3% (3)	11.5% (8)	21.4%(15)	62.8%(44)
Dryness of eyes	15.7%(11)	34.3%(24)	25.7%(18)	24.3%(17)
Watery eyes	7% (5)	35.8% (25)	24.4%(17)	32.8%(23)
Blurriness of print	20% (14)	34% (24)	23% (16)	23% (16)
Night blindness/problems with bright lights at night	15.7% (11)	15.7% (11)	23% (16)	45.6% (32)

Table 22

Summary Table of Factor Analysis for Scale 6

Fatigue	Factor	
	1	2
I experience fatigue with reading	**.849**	-.348
I have to stop reading because of the fatigue	**.933**	-.195
Do you have fatigue with the following?		
Reading printed materials	**.846**	-.240
Reading on a screen	**.658**	-.002
Fatigue Symptoms		
Burning eyes	**.797**	**.334**
Pain in/around eyes	**.609**	**.480**
Dryness of eyes	**.540**	.226
Watery eyes	**.563**	.081
Blurriness of print	**.729**	-.141
Night blindness/problems with bright lights at night	**.502**	.117

Note: Factor loading ≥ .30 are in boldface.

For the six scales the evidence of content validity and reliability was derived through literature reviews, qualitative interviews, and expert panel feedback. Each of these methods guided construction of the survey instrument. Each of these methods were used to provide evidence of content reliability and validity for assessing reading behaviors of those with glaucoma. Construct validity was estimated through exploratory factor analysis as reported for research question one. Factor analysis results as reported for research question one provided evidence of identifiable factors for each scale. Factor analysis results should be interpreted with caution due to the small sample size. Cronbach's alpha was calculated for each set of items on survey scales to provide evidence of internal consistency reliability. Cronbach's alpha coefficients ranging between 0.65 and 0.94. Table 23 contains alpha coefficients and number of factors for each scale for research question two.

Table 23

Results for Reliability and Construct Validity

Scale	Number of Items	Alpha Coefficient	Number of Factors
Scale 1	9	.65	1
Scale 2	8	.66	3
Scale 3	12	.94	1
Scale 4	6	.82	2
Scale 5	7	.88	1
Scale 6	10	.90	2

Research Questions 2

How do the items within the scale correlate to measure reading performance in older adults with glaucoma?

The correlational relationships between the items suggest there is a relationship among the items of the six scales. For scale one, there were two items "use of a reading/desk lamp" and "use of reading glasses" that did not load on the single factor. The correlations show a similar relationship as the factor analysis. Scale two correlations were similar to those of scale one.

Strong correlations among the items were noted in scales three, four, five and six. The correlation among the items of these scales were found to be consistent with the factor analysis findings. For example, items measuring everyday life impact in scale 3, which revealed a single factor, all correlated with one another ($p < .0001$). Very similar patterns were found for the items in scales four, five and six. Appendix J contains item correlations tables for scales one through six.

Summary of Quantitative Findings

The systematic approach including using mixed methods played a critical role in informing the factor structure of each scale. The reliability factor suggests moderate to strong reliability among the items of the scales of the instrument. Factor analysis and use of the two rules for factor analysis indicated each survey item likely measures certain constructs of reading behaviors of older adults with glaucoma and the impact on occupational performance. In summary, the quantitative phase of this study yielded a new instrument, with initial reliability and validity established to measure glaucoma reading behaviors among the intended audience.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

Chapter Five provides a discussion of the integration of Phase I and II of the study and presents a comprehensive overview of the relationship between changes in reading associated with vision loss from glaucoma and occupational performance in older adults with glaucoma living in a metropolitan area in a SE state.

This discussion of the study results by specifically addressing all of the qualitative, quantitative and the mixed methods research questions. This chapter also provided a discussion of the findings, limitations of the study, implications for clinical practice and recommendations for future research.

Major Findings

The discussion of major findings is organized by phases and the research questions considered in each phase. The qualitative research questions will be discussed first, followed by the quantitative questions and lastly the mixed methods questions.

Phase I

Qualitative Research Question 1

What beliefs do older adults with glaucoma living in a SE metropolitan area have about the changes in reading they experience?

The first qualitative research question addressed the beliefs older adults with glaucoma living in a SE metropolitan area have about the changes in reading they

experience. Results revealed that older adults with glaucoma have strong beliefs about how the visual changes associated with glaucoma affect reading and how these reading difficulties effect their daily life. The participants of Phase I shared their experiences of trying to continue participation in their daily life with moderate to severe vision loss from glaucoma.

However, the participants also shared their struggles with continued participation in everyday life and how they struggled with having to depend on others and some with not having others to depend on or simply not wanting to depend on others. More than one participant changed their living arrangements to from living in their own home to a retirement center, often in order to have transportation options, people to socialize with and people to help them with IADLs. These IADLs included financial management, managing the mail, medication management and meal preparation. While some of the participants continued to struggle with these activities, other participants reported they had given up or asked for help from family or paid for assistance. The impact on ADL, IADLs, reading for pleasure, community mobility and social interactions were themes emerging from Phase I and survey data from Phase II indicated that the majority of respondents were experiencing difficulty in one or more of the listed areas.

With regards to community mobility, only three participants of the twelve interviewed in Phase I reported continued driving, two of those did so while not meeting the vision requirements for legal driving in the state. The sequelae of effects that can occur with driving cessation are plentiful and will not be discussed in this paper. However, many negative consequences can accompany driving cessation. In the Southeastern portion of the United States public transit systems are limited and there are

many rural areas with no access to public transportation. Driving cessation severely limits community mobility and requires these individuals to depend on their families and friends or pay for transportation services (Aspinall et al., 2008).

Driving, and more so community mobility informed the assessment in its inclusion of an item in Scale 3: *Everyday Life Impact*. The item seeks to quantify the impact the person's reading difficulties have had on everyday life with regards to getting around out in the community. Because community mobility emerged often within the qualitative data analysis, it was important to reflect this in the items of this instrument.

In scales one and two the items were comprised of the methods for coping with reading difficulties that emerged from the data analysis. Several of the items were direct sub-themes and categories of the theme: *Methods for Coping*. While factor analysis suggested *reading glass* and *reading/desk lamp* did not belong with scale one, the items were kept with this scale because of the repeated use of these categories in the qualitative analysis.

Scale four is comprised of items related to lighting used for reading. Lighting used to for reading was a category from the sub-theme of adaptive strategies and devices that emerged from theme five, *methods for coping*. Lighting, specifically room or overhead lighting and task or direct lighting were mentioned by all participants. Because of its importance when reading, items related to lighting are found in several scales, including scales, one, two, four and five.

Scale five items are related to glare with reading. Several of the participants reported glare with reading, especially if extra light was added. Glare with watching TV was also mentioned by approximately 25% of participants. The items in scale five also

include those related to reducing glare. These items were based on reported methods for reducing glare from the data analysis. These items included use of glare shields, adjusting light source or removing light source.

The theme *reading problems reported* informed the items of scale six. The reading problems reported were related to fatigue with reading and included ocular health and visual function related items.

While the participants shared their struggles with continued participation in everyday life and how they struggled with having to depend on others, they also shared their methods for coping and how they deal with their occupational performance difficulties. The information reported in the interviews led to many of the items of the instrument.

Qualitative Research Question 2

What strategies do older adults with glaucoma employ to compensate for and cope with reading deficits experienced during occupational performance?

While the research has demonstrated the difficulties that older adults with glaucoma face with reading (Nguyen et al., 2013b; 2013a; Ramulu, 2013; Burton et al., 2012; Ramulu, 2009), very little was found on strategies used to overcome these difficulties with reading in this population. The research has also demonstrated that adults with glaucoma report reduced QoL when compared to age-matched controls (Sherwood, et al., 1998) and their vision-related problems and priorities include central vision issues (Aspinall et al., 2008; Nelson et al., 2003; Lee & Martin, 2000). The qualitative phase of this dissertation study sought to answer the question: *What strategies do older adults with*

glaucoma employ to compensate for and cope with reading deficits experienced during occupational performance?

The participants reported methods in which they cope with their vision loss and the difficulties experienced with reading affecting everyday life activities. The interplay of demand for mastery and desire for mastery can impose a facillitory or inhibitory behavior when it comes to methods to choose adaptation methods. Data obtained from the participants regarding use of methods to improve performance with reading to improve participation in ADL and IADL activities revealed several different methods. The majority of respondents used magnifiers of varying types to read their mail, medication labels, directions for cooking in the microwave and so on.

The information gathered from qualitative data analysis regarding mechanisms for coping with reading deficits experienced during occupational performance was used to inform the assessment by adding items related to methods for coping for several scales of the assessment. When assessing reading performance, it is imperative to try to understand the methods that are employed to improve performance. In the scale related to print reading, the items related to coping methods included the following: use of magnification, addition of room lighting, addition of direct lighting and having someone else read. Similarly, the methods for coping for screen reading included several options. Some of those options were screen magnification software, addition of lighting, enlarging print and having someone else read. Each of the methods used to build the scale items were methods that emerged in the qualitative data analysis.

According to the OA Framework (Schkade and Schultz, 1992) the demand for mastery, which occurs when the demand for performance exceeds the person's ability to

adapt, dysfunction occurs. The greater the level of dysfunction, the greater the demand for change in adaptive process. Sufficient mastery and ability to adapt result in success in occupational performance. The theoretical concept of *desiring mastery* from the OA Framework (Schkade and Schultz, 1992) can explain the individual desire to continue to do the task and their ability to adapt to the demands of the occupation. This construct offers a theoretical basis for use of methods for coping. Older adults with glaucoma reported they want and need to continue to complete their occupations (demand for mastery and desire for mastery) and they reported several different methods they use (occupational challenge) to maintain their participation in those occupations, community mobility and daily life (occupational environment).

Phase II

Quantitative Research Question 1

What is the estimated face validity, content validity and internal consistency reliability of items to measure the impact of reading changes from glaucoma on occupational performance?

When developing a new assessment or survey for measure of a new phenomenon, one primary consideration is estimation of validity and reliability. As previously described, validity refers to the extent an instrument measures what it intends to measure, while reliability determines whether the instrument produces consistent results across administration.

Ramulu (2014) called for more vigorous research of reading among older adults with glaucoma due to a lack of validated instruments that address reading in older adults with glaucoma. More rigorous studies using a model such as the one explored in this

study are needed as rehabilitation disciplines try to better understand the impact of glaucoma-related visual impairment on reading and the impact this has on occupational performance; a better understanding of how those affected cope and methods they employ for coping with these changes; and how we must modify and develop new and more appropriate types of interventions that consumers will use and find helpful as they face the difficulties associated with continuing ADLs and IADLs that require reading when can be so difficult. The use of a systematic exploratory sequential mixed methods design addressed this gap in the professional literature.

For this dissertation study, a new instrument was developed that was designed to understand the reading difficulties experienced by older adults with glaucoma and how these difficulties impact occupational performance. The instrument was informed by the themes and sub-themes that emerged from the qualitative data. The quantitative phase was used to determine if this instrument was psychometrically sound.

Based on the results of the reliability analysis and exploratory factor analysis the instrument does have demonstrate reliability and content validity. The results from the cognitive interviews completed after initial instrument development revealed the instrument demonstrated face validity. The quantitative phase of this study yielded a psychometrically sound instrument to examine the effects of reading difficulties on occupational performance experienced by older adults with glaucoma.

Quantitative Research Question 2

How do the items within the scales correlate to measure reading performance in older adults with glaucoma?

Results of the correlational statistics revealed fair to moderate correlations among items in the first two scales of the instrument, while moderate to strong correlations were found in scales three, four and five. Scale six was shown to have strong correlations. These results were consistent with the finding in the factor analysis.

Mixed Method Question 1

What do the qualitative and quantitative data together reveal about the relationship between changes in reading associated with vision loss from glaucoma and occupational performance in older adults with glaucoma living in a metropolitan area in a SE state?

In an effort to better understand reading changes and coping related to glaucomatous vision-loss, a two-phase sequential exploratory design was employed. First, qualitative interviews with older adults with glaucoma were conducted. This qualitative data collection phase allowed exploration of a variety of life experiences, including participation in ADLs and IADLs that require reading and how these are affected by glaucoma-related vision changes. The sequential exploratory design permits the interpretation of qualitative results to inform quantitative instrument development.

The dissertation study used face-to-face qualitative interviews with semi-structured questions guided by relevant literature and clinical experience to explore how the knowledge, beliefs, attitudes and coping methods related to reading difficulties related to vison loss from glaucoma and how this affects occupational performance in older adults in metropolitan SE. By way of the sequential exploratory approach, the alignment of theoretical framework, sequence, priority and the integration of findings were all criteria imposed to strengthen the mixed methods study and its implications on future research and ultimately clinical practice.

The complexity of reading difficulties experienced by those with varying levels of glaucoma highlights the increasing need to clearly understand the underlying cause of, interventions for and effects on occupational performance and everyday life. This sequential mixed methods study used the Occupational Adaptation framework to guide the instrument development. This instrument was designed to examine meaningful and interpretable factors of reading behaviors in older adults with glaucoma. Themes that emerged from the qualitative phase of study aided in validation of item retention or removal in the quantitative analysis. The qualitative phase of data analysis provided insights into perceptions that older adults with glaucoma had regarding the impact of their reading difficulties on their everyday life. The qualitative data revealed that the simple and straightforward results produced by the quantitative phase gave limited insight into difficulties that older adults with glaucoma experience with reading difficulties and how this may impact their occupational performance.

Mixed Method Question 2

What do the qualitative and quantitative data together reveal about the relationship between changes in reading associated with vision loss from glaucoma and occupational performance in older adults with glaucoma living in a metropolitan area in a SE state?

Based on the findings of the study, the qualitative and quantitative data together revealed that older adults with glaucoma continue to participate in some occupations, while discontinuing other occupations. The qualitative data analysis revealed several different reasons for giving up some occupations, while continuing others. The quantitative data analysis revealed the impact that reading difficulty caused on everyday living for older adults with glaucoma. This is problematic as reading is an important

communication skill for maintaining connections to the social world, carrying out essential everyday activities and for overall QoL (Ryan, Anas, Beamer and Bajorek, 2003). Nguyen and colleagues (2014) examined reading ability and reading engagement among participants with glaucoma and age-matched controls. They used several reading items (bills, financial statements, books, etc.) from the AI to examine reading completed by those with glaucoma. This group found that having glaucoma makes reading more difficult across a broad range of reading tasks. Similarly, Ramulu and colleagues (2013a, 2013b; 2014) found that those with glaucoma read slower and fatigue earlier than their age-matched controls on sustained reading tests. These findings are consistent with Ramulu and colleagues research findings in previous reading research (Ramulu, 2009).

Participants also reported varying methods for coping with the difficulty associated with reading changes and the effects of glaucoma on occupational performance. As it relates to print reading, several methods were identified as useful for coping with reading difficulties. Some of these include use of lamps, use of magnifier, reading glasses, using a finger or line guide to keep place on line and even have another person read for them. Some of the methods reported used for screen reading included keeping on a room light, enlarging print and enhancing contrast. A common definition of successful aging is the ability of older adults to maintain their independence (Garfein & Herzog, 1995; Roos & Havens, 1991). Finding tools and mechanisms for improving their ability to participate in ADLs, IADLs, leisure activities can improve their independence and therefore, successful aging.

Additionally, participants in both phases reported impact on everyday life ADLs, IADLs, social participation and reading for pleasure. While glare sensitivity has been

reported as an issue for persons with glaucoma and also was noted by participants in the qualitative phase of the study, there was little correlation with glare and reading difficulty in quantitative phase of the study. Reading was reported as a cause of fatigue in qualitative phase of the study and this also was demonstrated as significant impact on reading in quantitative phase of the study.

In summary, many of the items within questions had strong correlations, while other items showed moderate correlations. Additionally, Cronbach alpha coefficients ranging between 0.65 and 0.94 demonstrate reliability. The item and question structures are the result of the stepwise approach used to identify, extract factors and rotate factors in order to obtain the simplest solution. With regards to the decision-making process for retaining or discarding items, Phase I data, review of pertinent literature and the estimated reliability of items were critical. Statisticians caution against the use of rigid guidelines to determine the number of factors to extract and consideration for items and factors for retention (Nunnally and Bernstein, 1994). The researcher could identify items that make sense theoretically. Additionally, the research used this information to guide interpretation of the factor structure to get the most conservative solution.

Study Limitations

A limitation of the current study is that the participants represented a cross-sectional convenience sample of older adults with glaucoma living in a metropolitan area in the SE. The sample was not random, and findings may not be representative of other older adults with glaucoma in other US cities or elsewhere. While this instrument was developed with a sample from a metropolitan area in the SE, future research on

instrument development will include administration of the instrument to older adults with glaucoma in other area of the US.

Furthermore, because only older adults with glaucoma were included in the study, it is not known if these results would be similar or different for same aged older adults who do not have glaucoma. Future studies will focus on a comparison of age-matched older adults who do not have glaucoma. This dissertation study was an initial exploration of this phenomenon that yielded an instrument with validity and reliability. This instrument was developed to have a tool that attempts to define the problems that older adults have with reading and how this impacts their occupational performance. According to the literature, there was no instrument of this type. This tool, while further research needs to be completed, will aid in understanding the impact on occupational performance and possibly lead to interventions to address reading issues experience by older adults with glaucoma.

The quantitative phase of the study included a limited sample size for validating and reporting on reliability for this newly developed instrument to examine the effects of reading difficulties on occupational performance in older adults with glaucoma. Future research will include opening enrollment to participants across the entire US.

Recommendations for Future Research

Based on the findings of this study, the recommendations for future research are as follows:

1. Conduct further research enrolling a larger number of participants across the entire US to explore the effects of reading difficulties on occupational performance in older adults with glaucoma.

2. Pilot test the instrument with older adults without vision loss to examine if the results of this current study demonstrate the effects on occupational performance and reading are actually related to glaucoma (i.e., age-matched control).

3. Continue to identify items that may strengthen the factor structure of the revised instrument.

4. Utilize research data to inform rehabilitation professionals working with older adults with glaucoma to potentially enhance assessment and intervention for ADLs and IADLs requiring reading.

5. Use this mixed methods model to explore reading issues related to other common visual diagnoses and their impact on occupational performance among older adults.

Dissemination of Research

The findings of this study will be shared with rehabilitation and other health professionals that work with older adults with glaucoma, specifically those that have an interest in understanding how reading and occupational performance are affected by glaucoma. Additionally, a plan for publication will include the following: submission of research methodology and study results to peer-reviewed publications to inform glaucoma and low vision rehabilitation researchers and clinical practitioners; presentation at a national low vision rehabilitation research and clinical practice conference and reports of findings provided to the clinical practices involved in data collection and other stakeholders. One goal for publication of this work is to enhance the scientific foundation of instruments with acceptable reliability and validity. The researcher plans to explore relationships between older adults with glaucoma and the impact of reading

changes associated with glaucoma on occupational performance in future studies, along with continuing the work on strengthening this instrument.

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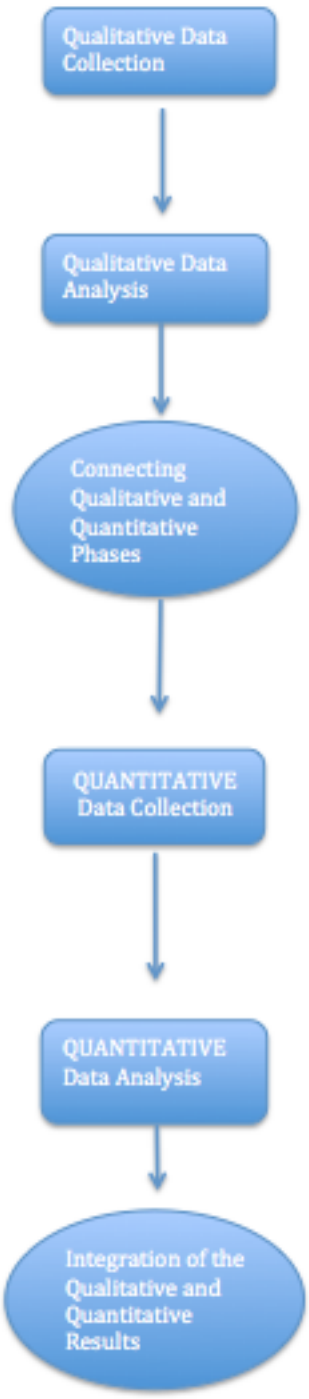
APPENDIX A: VISUAL MODEL FOR MIXED METHODS FOR SEQUENTIAL EXPLANATORY DESIGN PROCEDURES

Visual Model for Mixed-Methods Sequential Explanatory Design Procedures



PROCEDURE	PRODUCT
• Individual in-depth, in-person interview in clinical setting (n=10)	• Text data (interview transcripts)
• Coding and thematic analysis • Cognitive interview of participants to verify accuracy of statements in interviews	• Codes and themes • Similar and different themes
• Using themes from the interviews in qual phase to inform the items/ scales of the new reading assessment • Distribute the new instrument to field experts for review – content analysis	• New Quantitative Instrument to Assess Patient Perceptions on Reading changes associated with glaucoma and the affects on occupational performance
• Revise the instrument • Pre-test the instrument • Revise the instrument • Content Validity • Revise the instrument • In-person administration of the instrument (n=100)	• Numeric data
• Descriptive statistics • Psychometric properties assessment of the instrument: Reliability and Validity • Exploratory factor analysis • SPSS v22 • Rasch Analysis – Winsteps 3.81.0	• Descriptive statistics • Valid and reliable instrument for assessing reading with glaucoma
• Interpretation and explanation of the qualitative and quantitative results	• Discussion • Implications • Future research

Adapted from:
(Ivankova, Creswell, & Sticks, 2006)

APPENDIX B: RECRUITMENT FLYER

UAB SCHOOL OF OPTOMETRY

Call for Participants for Research on Glaucoma and Reading

Do you have a diagnosis of glaucoma?
Do you participate in daily activities that require reading?
Do you experience any difficulty with reading in your daily activities?

If the answer to these questions is yes, we invite you to take part in a voluntary on reading and how that effects daily activities. If you are interested in taking part in this research or finding out more about the project, please contact Robin Deacy at 205-478-1188; email at rdeacy@uab.edu

What you will do?

You will be asked to take part in one interview, lasting about 1 hour. The interview will be face-to-face, confidential and scheduled at your convenience. You will be asked about your perceptions and experiences with the reading that you do in your everyday life.

Why is this research important?

As you know, reading is an integral part of activities that people do every day. Despite what is known about the importance of reading in everyday life, to date, no published research is available describing the effect that reading difficulties caused by glaucomatous vision changes can have on the everyday tasks that are important to people.

What's in it for me?

The confidential information gathered will be used to recommend potential treatment options to improve reading for those with glaucoma

What should I do if I am interested in participating?

Contact Robin Deacy at 205-478-1188; email at rdeacy@uab.edu

APPENDIX C: RECRUITMENT LETTER AND INTERVIEW QUESTION LIST

March 7, 2017

Dear Prospective Participant:

You are invited to participate in a research study because you have glaucoma and you are able to read. The purpose of this study is to examine the thoughts and beliefs of older adults with glaucoma on the effects of changes in reading on occupational performance. Occupational performance is defined as doing the tasks and activities that are important and meaningful to you. Examples include completing financial management, medication management, and leisure reading. Older adult is defined as anyone 50 years of age or older.

To become a part of this study, you need to engage in reading activities. Participants will be interviewed. For your convenience, a copy of the interview questions is attached. The interview will last approximately one and a half and will be conducted at your home at a time that is convenient for you. The interview will be audiotape recorded. The

audiotapes will only be used for data collection and analysis. Your responses will remain confidential. To protect your confidentiality, you will be assigned a "code name" for use in describing and reporting the results. Please be assured that your name will not appear in any of the data, audiotapes, or transcripts and all potentially identifying information will be omitted or changed. You may also be asked to participate in a second interview to clarify responses from the first interview. The second interview may be conducted in person or by phone.

I thank you in advance for your participation in the study. Please feel free to contact me by phone if you are interested in participating in this study or have any questions.

Sincerely,

Robin Deacy

205-478-1188

INTERVIEW QUESTIONS

What do you like to do in your free time?

What does a typical day look like for you?

Do you read during the day? Do you read only what you have to read or do you read for pleasure?

Do you have any difficulty with daily activities that require you to read?

Do you have trouble with reading you medicine labels? Reading your bills? Reading in the kitchen (i.e., recipes, labels, appliance knobs and dials)?

Do you feel like your vision loss is the cause of these difficulties?

Can you describe a time when you first noticed your vision loss affecting daily activities?

How do you cope with or deal with these difficulties? Do you have eye symptoms when you experience the difficulties with reading?

What are the most important activities that you enjoy doing daily?

Can you tell me how your vision loss has affected these activities? How do you deal with or cope with any difficulties you experience while doing these daily activities that are important to you?

Tell me about a time when you were frustrated when you were trying to complete a reading task that is important to you.

Why was it frustrating? Does this happen often?

Tell me about what makes it hard for you to engage in reading activity.

Tell me about any devices that you use to help with reading? Some examples include magnifier, computer, table or ereader, electronic magnifier or task lamp.

Tell me why you use this device?

With regards to lighting, what kind of light do you use? How does it help you with reading?

Tell me your thoughts about your vision loss? How does it affect your daily life?

Is there anything else you would like to add?

APPPENIX D: PHASE I DEMOGRAPHICS DATA SHEET

PARTICIPANT DATA AND DEMOGRAPHIC FORMS

PARTICIPANT DATA FORM

Date: _____ Participant pseudonym: _____ Gender: M F

Age: _____ Ethnicity: _____

Ocular History:

Ocular conditions (list):

1.

2.

Best corrected visual Acuity: OD (right) _____ OS (left) _____

OU (both) _____

Contrast Sensitivity Function: _____

Visual Field: (get a copy of report, if possible)

- Test administered _____
- Results _____
  _____

DEMOGRAPHICS

What is your highest level of education?

☐Elementary school	☐High school diploma	☐Bachelor's Degree
☐Middle school school	☐Some College	☐Some graduate
☐Some high school	☐Associate's Degree	☐Masters or higher

Are you employed? YES NO

If employed, what type of work do you do?

Which of the following best describes your total yearly family income?

☐Less than $20,000 ☐$40,000 to $49,999

☐$20,001 to $29,999 ☐More than $50,000

☐$30,000 to $39,999 ☐Decline to answer

Number of adults in household?

How many adults contribute to the total yearly income?

APPENDIX E: PHASE I SCREENING TOOLS

Short Portable Mental Status Questionnaire

Instructions: Ask questions 1-10 in this list and record all answers. Ask question 4A only if patient does not have a telephone. Record total number of errors based on ten questions.

+	-

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

Total Number of Errors (0-2 is WNL) _____

To Be Completed by Interviewer

Patient's Name: _____ Date: _____

Sex: 1. Male 2. Female

Race: 1. White 3. Other 2. Black

Years of Education _____ 1. Grade School 2. High School 3. Beyond High School

Reproduced from: ***Short Portable Mental Status Questionnaire (SPMQ)*** in: Palmer RM, Meldon SW. Acute Care. In: Principles of Geriatric Medicine and Gerontology, 5th edition, 2003. Eds. Hazzard WR et al. McGraw-Hill Pub. pp 157-168. Geriatrics Review Syllabus: A Core Curriculum in Geriatric Medicine, 5th Edition. Malden, MA: Backwell Publishing for the American Geriatric Society; 2002. pp 403-411.

REALM-SF Form

Patient name _____ Date of birth_____ Reading level_____

Date _____ Examiner _____ Grade completed _____

Menopause	☐
Antibiotics	☐
Exercise	☐
Jaundice	☐
Rectal	☐
Anemia	☐
Behavior	☐

Instructions for Administering the REALM-SF

1. Give the patient a laminated copy of the REALM-SF form and score answers on an unlaminated copy that is attached to a clipboard. Hold the clipboard at an angle so that the patient is not distracted by your scoring. Say:

   "I want to hear you read as many words as you can from this list. Begin with the first work and read aloud. When you come to a word you cannot read, do the best you can or say, 'blank' and go on to the next word."

2. If the patient takes more than 5 seconds on a word, say 'blank' and point to the next word, if necessary, to move the patient along. If the patient begins to miss every word, have him or her pronounce only known words.

Scores and Grade Equivalents for the REALM-SF

Score	Grade Range
0	Third grade and below; will not be able to read most low-literacy materials; will need repeated oral instructions, materials composed primarily of illustrations, or audio or video tapes
1-3	Fourth to sixth grade; will need low-literacy materials, may not be able to read prescription labels
4-6	Seventh to eighth grade; will struggle with most patient education materials; will not be offended by low-literacy materials
7	High school; will be able to read most patient education materials

Geriatric Depression Scale (Short Form)

Patient's Name: _____ Date: _____

Instructions: Choose the best answer for how you felt over the past week. Note: when asking the patient to complete the form, provide the self-rated form (included on the following page).

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

(Sheikh & Yesavage, 1986)

Scoring:

Answers indicating depression are in bold and italicized; score one point for each one selected. A score of 0 to 5 is normal. A score greater than 5 suggests depression.

Sources:

- Sheikh JI, Yesavage JA. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clin Gerontol.* 1986 June;5(1/2):165-173.
- Yesavage JA. Geriatric Depression Scale. *Psychopharmacol Bull*. 1988;24(4):709-711.
- Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res.* 1982-83;17(1):37-49.

APPENDIX F: INTERVIEW PROTOCOL

INTERVIEW PROTOCOL

Interview Protocol: Developing an Assessment of Reading Impairment and Its Impact on Occupational Performance in Older Adults with Glaucoma in a Metropolitan Area of a Southeastern State: A Mixed Methods Approach

Time of Interview: _____

Date: _____

Place: _____

Interviewer: _____

Participant Number: _____

Position of Interviewee: _____

Interviewee Gender: _____

Interviewee Age: _____

When diagnosed with glaucoma:

_____

Introduction:

(Participant name), I want to thank you for taking the time to talk with me today. As stated in my letter to you, I am conducting a study for a research class project at U.A.B. The purpose of my study is to better understand how changes in reading associated with glaucoma affect occupational performance in older adults. Occupational performance is defined as doing the tasks and activities that are important and meaningful to you. Examples include completing financial management, medication management, and leisure reading. Older adult is defined as anyone 50 years of age or older. May I have your permission to audio tape and take notes during our conversation? Audiotapes will be transcribed in their entirety for review by the researchers involved in this study. At the conclusion of this interview, I will provide you with a pseudonym that I will use to protect your confidentiality when referencing you in the study.

Questions:

1. Icebreaker #1: Start by telling me a little bit about yourself.

   Prompts: What do you like to do in your free time?

2. Icebreaker #2: What does a typical day look life for you?

   Prompts: Do you read during the day? Do you read only what you have to read or do you read for pleasure?

3. Tell me what happens when you read.

   Prompts: Do you have trouble with reading you medicine labels? Reading your bills? Reading in the kitchen (i.e., recipes, labels, appliance knobs and dials)?

4. Tell me about any difficulty that you have with daily activities that require you to read?

5. Tell me about your vision loss and any difficulties that you have because of it?

   Prompts: Can you describe a time when you first noticed your vision loss affecting daily activities?

   Prompts: How do you cope with or deal with these difficulties? Tell me about any eye symptoms you have when you experience the difficulties with reading?

6. What are the most important activities that you enjoy doing daily?

   Prompts: Can you tell me how your vision loss has affected these activities? How do you deal with or cope with any difficulties you experience while doing these daily activities that are important to you?

7. Tell me about a time when you were frustrated when you were trying to complete a reading task that is important to you.

   Prompts: Why was it frustrating? Does this happen often?

8. Tell me about what makes it hard for you to engage in reading activity.

9. Tell me about any devices that you use to help with reading? Some examples include magnifier, computer, table or ereader, electronic magnifier or task lamp.

   Prompt: Tell me why you use this device?
   Prompt: With regards to lighting, what kind of light do you use? How does it help you with reading?
10. Tell me your thoughts about your vision loss? How does it affect your daily life?

    Is there anything else you would like to add?

Thank you for your time. May I meet you again in the next couple of weeks if I need to clarify anything? Please be assured that confidentiality will be maintained throughout the study and the reporting process. As this time, what name would you like me to use when I reference you the study?

_____

APPENDIX G: INITIAL INSTRUMENT DEVELOPED: GLAUCOMA READING BEHAVIORS INVENTORY

Glaucoma Reading Behavior Inventory

How would you describe the reading that you currently do?

□ **I do not read** (If you do not read, please explain why.)

□ **Occasional**

□ **Informational**

□ **Avid**

Does this differ from the reading you did prior to glaucoma diagnosis?

□□**Yes** □□**No**

Do you read the following: **(check <u>all</u> that apply)**

□ **Mainly paper reading materials**

□ **Computer or electronic generated reading (on screen of some sort)**

□ **Both equally**

Does this differ from the reading you did prior to glaucoma diagnosis?

□□**Yes** □□**No**

If it is different since your diagnosis, please explain difference.

_____

_____

If you have given up **<u>any</u>** of the reading that you did previous to diagnosis, was this because of the glaucoma?

□□Yes □□No □ N/A

If you answered **<u>NO</u>** to the above question, why did you give up reading tasks?

From the following list, which best describes how much time you used to spend reading over an average day **<u>prior to glaucoma diagnosis</u>?**

□ **I used to read less than 15 minutes**

□ **I used to read between 30 and 60 minutes**

□ **I used to read for one to two hours per day**

□ **I used to read for more than two hours per day**

Compared with your ability to read prior to glaucoma diagnosis, how would you rate your current ability to read in general?

□ **Much worse**

□ **Somewhat worse**

□ **About the same**

How long are you able to read continuously during one sitting before you are tired and have to stop reading?

□ **I used to read less than 15 minutes**

□ **I used to read between 30 and 60 minutes**

□ **I used to read for one to two hours per day**

□ **I used to read for more than two hours per day**

Does this differ from the reading you did prior to glaucoma diagnosis?

□□**Yes** □□**No**

Are you satisfied with your current ability to read continuously?

□□**Yes** □ **No**

Do you experience fatigue with reading and have to stop reading?

□□**Yes** □ **No**

If you experience fatigue with reading, what symptoms do you have?

☐ Burning eyes ☐ Pain in or around eyes ☐ Dryness of your eyes

☐ Blurriness ☐ Cloudiness ☐ Night blindness

☐ Other: _____

If you experience fatigue, do you experience more fatigue with:

□ **PRINTED materials** □ **ELECTRONIC reading**

□ **I experience the same amount of fatigue with both**

Continuous Reading: The INFORMATIONAL AND AVID READERS (OCCASIONAL READERS can skip this section)

Are you able to read more than 15 min at one sitting?

On Electronic Media? □ Yes □ No

On Printed Materials? □ Yes □ No

Has your ability to read continuously for several minutes at a time decreased since your diagnosis of glaucoma?

□ Yes □ No

Do you experience fatigue when reading continuously (more than 15 minutes at a time)?

□ Yes □ No

What difficulties do you experience when reading continuously?

_____

_____

You can have an open end question about the symptoms and ask specifically under what conditions (print or computer) the symptoms occur.

How do these difficulties interfere with your life? Look at the interview transcripts and include the information about working vs not-working)

□ **Interfere with my work**

□ **Interfere with my social communication**

□ **No longer enjoy reading**

□ **Do not interfere with my life**

Has your ability to retain the information you read changed since diagnosis of glaucoma?

□ Yes □ No

What, if any, compensatory strategies do you use when reading continuously?

_____

_____

Does glare cause difficulty with reading?

□ Yes □ No

If yes, do you experience glare issues when reading print?

□ Yes□ No

Adding task lighting with reading print?

□ Yes□ No

Electronic (screen) reading?

□ Yes□ No

Do you use compensatory strategies do you use to control glare?

□ Yes□ No

List the strategies you use:

_____

DO you use glare shields?

□ Yes□ No

Do you adjust lighting source?

□ Yes□ No

Does this aid in glare control? □ Yes□ No

If you read mainly print material, complete Section One. If you read mainly computer material, skip Section One and complete Section Two. If you read BOTH print and computer materials, complete BOTH Sections One and Two.

PAPER/PRINT READING

PAPER/PRINT READING: What materials do you currently read during a typical week? (check all that apply)

□ **letters**□ □ **bills** □ **magazines**□ □ **newspapers**□ □ **medicine labels**

□ **recipes** □ **novels**□ □ **package directions**□ □ **Bible**□ □ **job-related materials** □ **other (list)**

From the following list, which best describes how much time you spend reading paper materials over an average day?

□ **I used to read less than 15 minutes**

□ **I used to read between 30 and 60 minutes**

□ **I used to read for one to two hours per day**

□ **I used to read for more than two hours per day**

From the following list, which best describes how much time you spend reading paper material in one sitting?

□ **I used to read less than 15 minutes**

□ **I used to read between 30 and 60 minutes**

□ **I used to read for one to two hours per day**

□ **I used to read for more than two hours per day**

Do you use any of the following adaptations to read print materials?

□ **Use a reading or task lamp**

☐ **Use large-print materials**

☐ **Ruler or some type of line guide for keeping place on line and/or finding next line**

☐ **Use a prescribed magnifier lens**

☐ Use electronic magnifier

☐ **Use a magnifier purchased in a store**

☐ **Use reading glasses**

☐ Get assistance from others – have them read for you

☐ Other: (list all)

On the following 3-point scale, how difficult do you find it to read **paper materials**?

1 Reading is very difficult

2 Reading is difficult

3 Reading is not difficult at all

On the following 4-point scale please describe how satisfied you are with your current ability to read paper materials?

□ **Very dissatisfied**

□ **Dissatisfied**

□ **Satisfied**

□ **Very satisfied**

COMPUTER AND ELECTRONIC READING

COMPUTER AND ELECTRONIC READING: What materials do you currently read on the computer, e-reader, tablet etc during a typical week?

□□**Email** □ **news websites** □ **social media** □ **e-books** □ **e-magazines**

□ **Financial management** □ **Searching internet for information**

□ **Internet shopping** □ **Other (list)**

From the following list, which best describes how much time you spend reading on the device over an average day?

□ **I read less than 15 minutes**

□ **I read between 30 and 60 minutes**

□ **I read for one to two hours per day**

□ **I read for more than two hours per day**

From the following list, which best describes how much time you spend reading on the device in one sitting?

□ **I read less than 15 minutes**

□ **I read between 30 and 60 minutes**

□ **I read for one to two hours per day**

□ **I read for more than two hours per day**

Do you make any adaptations for reading on a screen?

□ **Add reading/task lamp**

□ **Increase the size of print? Change font type on the screen**

□ **Change the contrast (reverse or bright white) on the screen**

□ **Large-print keyboard**

□ **Computer software with magnification, color inversion and screen reading features**

☐ **Computer glasses**

 Reading glasses

□ **Other: _____**

On the following 3-point scale, how difficult do you find it to read on a computer or other electronic devices?

1 Reading is very difficult

2 Reading is difficult

3 Reading is not difficult at all

On the following 4-point scale please describe how satisfied you are with your current ability to read on a computer screen?

1 Very dissatisfied

2 Dissatisfied

3 Satisfied

4 Very satisfied

APPENDIX H: THE REVISED INSTRUMENT: GLAUCOMA READING BEHAVIORS INVENTORY

GLAUCOMA READING BEHAVIOR INVENTORY

When were you diagnosed with glaucoma? _____
Do you wear glasses when you read? ☐ **Yes** ☐ **No**

General Reading	
How would you describe the reading that you currently do?	☐ I do not read (If you do not read, please explain): _____ ☐ Occasional (mail, bills, labels, etc.) ☐ Informational (above plus newspaper, Bible, etc.) ☐ Avid (books, reading for pleasure)
Which of the following best describes how much time you spend reading over an average day?	☐ I read less than 15 minutes ☐ I read between 30 and 60 minutes ☐ I read for 1-2 hours per day ☐ I read for more than 2 hours per day
Which of the following best describes how long you are able to read continuously during one sitting (i.e., before you are tired and have to stop reading)?	☐ I read less than 15 minutes at a time ☐ I read between 30 and 60 minutes at a time ☐ I read for 1-2 hours at a time ☐ I read for more than 2 hours at a time
How satisfied are you with your current ability to read?	☐ Very satisfied ☐ Satisfied ☐ Minimally satisfied ☐ Unsatisfied
How difficult do you find it to read?	☐ Reading is very difficult ☐ Reading is difficult ☐ Reading is minimally difficult ☐ Reading is not difficult at all
Which of the following do you read: (check all that apply)?	☐ Paper reading materials ☐ Computer or electronic reading (on screen of some type) ☐ Both
Which of the following do you find is the *easiest* material to read?	☐ Paper reading materials ☐ Computer or electronic reading (on screen of some sort) ☐ Neither
Which of the following do you find is the *most difficult* material to read?	☐ Paper reading materials ☐ Computer or electronic reading (on screen of some sort) ☐ Neither

PAPER/PRINT READING: What materials do you currently read during a typical week? (check all that apply)	
☐ Mail: letters, bills, advertisement flyers	☐ Magazines
☐ Newspapers	☐ Novels or other books
☐ Bible	☐ Medicine labels
☐ Recipes	☐ Package directions
☐ Job-related materials	☐ Handwriting (i.e., letter, check, etc.)
☐ Menus	☐ Other (list) : _____
Do you use any of the following to make it easier to read printed materials?	
Reading or desk lamp	__Always __frequently __occasionally__never
Large-print materials	__Always __frequently __occasionally__never
Ruler or line guide for keeping place on line and/or finding next line AND/OR use your finger or something to keep place on line?	__Always __frequently __occasionally__never
Prescribed magnifier lens *Do you know the strength/power?	__Always __frequently __occasionally__never
Electronic magnifier	__Always __frequently __occasionally__never
Magnifier purchased in a store *Do you know the strength/power?	__Always __frequently __occasionally__never
Reading glasses: Prescribed? Store purchased? Strength? _____	__Always __frequently __occasionally__never
Get assistance from others – have them read for you	__Always __frequently __occasionally__never
Talking books or audio books	__Always __frequently __occasionally__never
Other: (list all)	__Always __frequently __occasionally__never
COMPUTER AND ELECTRONIC READING: What materials do you currently read on the computer, e-reader, tablet or smart phone during a typical week?	
☐ Email	☐ Financial management
☐ News websites	☐ e-magazines
☐ social media (Facebook, Instagram, twitter, etc.)	☐ Internet shopping
☐ e-books (i.e., books downloaded on Kindle device)	☐ Browsing internet for information
☐ Other (list): _____	
Do you do any of the following to make it easier to read on a screen?	
Add reading/desk lamp	__Always __frequently __occasionally__never
Keep on a room light	__Always __frequently __occasionally__never
Increase the size of print on screen	__Always __frequently __occasionally__never
Change the contrast (reverse or bright white) on the screen Comment:_____ _____	__Always __frequently __occasionally__never
Large-print keyboard	__Always __frequently __occasionally__never
Computer software with magnification, color reverse and/or screen reading features	__Always __frequently __occasionally__never
Computer glasses	__Always __frequently __occasionally__never
Reading glasses	__Always __frequently __occasionally__never
Have someone read for you	__Always __frequently __occasionally__never
Other: (list all)	__Always __frequently __occasionally__never
For each of the following statements, choose the response that best describes how much your everyday life has been impacted/challenged by your reading difficulties.	
Reading for pleasure	__Greatly __Moderately __Slightly __Not at all

Dressing, grooming, and bathing activities	__Greatly __Moderately __Slightly __Not at all
Work or job duties and responsibilities	__Greatly __Moderately __Slightly __Not at all
Social communication (social media)	__Greatly __Moderately __Slightly __Not at all
Participation in community activities (e.g. church or volunteer activities)	__Greatly __Moderately __Slightly __Not at all
Social interactions (playing cards, games) Are these activities limited due to visual concerns.	__Greatly __Moderately __Slightly __Not at all
Medication tasks	__Greatly __Moderately __Slightly __Not at all
Financial tasks	__Greatly __Moderately __Slightly __Not at all
Preparing meals (i.e., identify food in fridge, read recipes)	__Greatly __Moderately __Slightly __Not at all
Getting around out in the community (i.e., public transportation)	__Greatly __Moderately __Slightly __Not at all
Writing tasks (i.e., signing checks, filling out forms)	__Greatly __Moderately __Slightly __Not at all
Electronic devices (i.e., cell phone, computer, tablet)	__Greatly __Moderately __Slightly __Not at all

LIGHTING FOR READING

How often do the following situations occur? Use the following to answer: "always," "frequently," "occasionally" or "never."

I use direct lighting (e.g. chair or desk lamp) when I read printed materials	__Always __frequently __occasionally __never
I use direct lighting (e.g. chair or desk lamp) when I do electronic or screen reading	__Always __frequently __occasionally __never
Direct (or task) lighting makes it easier to read	__Always __frequently __occasionally __never
I use room or overhead lighting when I read printed materials	__Always __frequently __occasionally __never
I use room or overhead lighting when I do electronic/screen reading	__Always __frequently __occasionally __never
Room or overhead lighting makes it easier to read	__Always __frequently __occasionally __never

Do you know the type of lighting you use for reading? (i.e., fluorescent, LED, halogen) If so, please list:

GLARE WITH READING

How often do the following situations occur? Use the following to answer: "always," "frequently," "occasionally" or "never."

Glare causes difficulty with reading?	__Always __frequently __occasionally __never
I have problems/difficulty with glare when reading printed material?	__Always __frequently __occasionally __never
I have problems/difficulty with glare when I add task lighting with reading print?	__Always __frequently __occasionally __never
I have problems/difficulty with glare when reading on an electronic screen?	__Always __frequently __occasionally __never
What do you do to help minimize glare when reading?	
Use glare shields (i.e., glasses with colored lenses)	__Always __frequently __occasionally __never
Adjust lighting source to try to reduce glare?	__Always __frequently __occasionally __never
Other (please list):	__Always __frequently __occasionally __never

Do you avoid using direct (i.e., task lamp) lighting because of glare?	__Always __frequently __occasionally __never
FATIGUE WITH READING	
I experience fatigue when reading?	__Always __frequently __occasionally __never
I have to stop reading because of the fatigue I experience with reading?	__Always __frequently __occasionally __never
Do you experience fatigue with any of the following? PRINTED materials: ELECTRONIC reading:	 __Always __frequently __occasionally __never __Always __frequently __occasionally __never
How often do you experience the following symptoms of eye fatigue when reading for a period of time?	
Burning eyes	__Always __frequently __occasionally __never
Pain in and/or around eyes	__Always __frequently __occasionally __never
Dryness of your eyes	__Always __frequently __occasionally __never
Watery eyes	__Always __frequently __occasionally __never
Blurriness of print	__Always __frequently __occasionally __never
Night blindness / problems with bright lights at night	__Always __frequently __occasionally __never
Other: (please list)	__Always __frequently __occasionally __never

Comments:

APPENDIX I: CORRELATION TABLES FOR THE SIX SCALES

Correlations for Scale 1 – Methods for Print Reading

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Q1	---	.085	.331**	.161	.037	-.042	.315**	-.068	-.033
Q2		---	.180	.187	.202	.101	.198	.145	.270*
Q3			---	.451**	.234	.355**	.256*	.337**	.137
Q4				---	.396**	.154	.136	.528**	.223
Q5					---	.042	.111	.363**	.356**
Q6						---	.078	.166	.168
Q7							---	.078	-.048
Q8								---	.288*
Q9									---

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Correlations for Scale 2 – Methods for Screen Reading

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Q1	---	.364**	.368**	.310**	.298*	.106	-.138	.258*	-.196
Q2		---	.327**	.256*	.181	.070	-.210	.265*	-.081
Q3			---	.333**	.217	.112	-.050	.467**	.230
Q4				---	.426**	.312**	-.009	.198	-.039
Q5					---	.511**	.113	.128	.066
Q6						---	-.040	.095	-.095
Q7							---	-.194	-.070
Q8								---	.178
Q9									---

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Correlations for Scale 3 – Everyday Life Impact

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12
Q1	---	.45**	.263*	.298*	.323**	.483**	.433**	.480**	.513**	.367**	.510**	.386**
Q2		---	.203	.458**	.525**	.615**	.586**	.595**	.690**	.533**	.572**	.446**
Q3			---	.546**	.492**	.363**	.448**	.332**	.284*	.528**	.356**	.547**
Q4				---	.775**	.544**	.564**	.510**	.498**	.663**	.580**	.589**
Q5					---	.754**	.667**	.684**	.492**	.782**	.734**	.750**
Q6						---	.717**	.746**	.603**	.712**	.759**	.710**
Q7							---	.779**	.694**	.705**	.722**	.597**
Q8								---	.625**	.632**	.719**	.637**
Q9									---	.465**	.766**	.528**
Q10										---	.738**	.758**
Q11											---	.772**
Q12												---

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Correlations for Scale 4 – Lighting for Reading

	Q1	Q2	Q3	Q4	Q5	Q6
Q1	---	.436**	.676**	.270*	.214	.144
Q2		---	.462**	.308**	.463**	.347**
Q3			---	.322**	.328**	.339**
Q4				---	.776**	.681**
Q5					---	.610**
Q6						---

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Correlations for Scale 5 – Glare with Reading

	Q1	Q2	Q3	Q4	Q5	Q6	Q7
Q1	---	.865**	.642**	.716**	.345**	.527**	.456**
Q2		---	.701**	.656**	.273*	.584**	.477**
Q3			---	.662**	.372**	.544**	.586**
Q4				---	.278*	.494**	.510**
Q5					---	.184	.412**
Q6						---	.392**
Q7							---

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Correlations for Scale 6 – Fatigue with Reading and Fatigue Symptoms

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Q1	---	.855**	.805**	.571**	.569**	.370**	.381**	.446**	.690**	.307**
Q2		---	.846**	.613**	.664**	.465**	.464**	.528**	.682**	.483**
Q3			---	.588**	.614**	.398**	.370**	.405**	.621**	.438**
Q4				---	.478**	.454**	.322**	.386**	.443**	.339**
Q5					---	.666**	.541**	.358**	.587**	.470**
Q6						---	.385**	.449**	.313**	.320**
Q7							---	.382**	.365**	.316**
Q8								---	.482**	.247*
Q9									---	.356**
Q10										---

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

APPENDIX J: UAB IRB LETTERS OF APPROVAL FOR BOTH PHASE I AND II

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 | irb@uab.edu

APPROVAL LETTER

TO: Deacy, Robin M.

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance Number FWA00005960

DATE: 18-Jul-2017

RE: IRB-161214004
Developing an Assessment of Reading Impairment and Its Impact on Occupational Performance in Older Adults with Glaucoma in a Metropolitan Area of a Southern State: A Mixed Methods Approach

---

The IRB reviewed and approved the Revision/Amendment submitted on 27-Jun-2017 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review: Expedited (Category 7)
Determination: Approved
Approval Date: 18-Jul-2017
Expiration Date: 20-Feb-2018

The following apply to this project related to informed consent and/or assent:

- Waiver (Partial) of HIPAA

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

470 Administration Building
701 20th Street South
Birmingham, AL 35294-0104
205.934.3789 | Fax 205.934.1301 | irb@uab.edu

APPROVAL LETTER

TO: Deacy, Robin M.

FROM: University of Alabama at Birmingham Institutional Review Board
Federalwide Assurance # FWA00005960
IORG Registration # IRB00000196 (IRB 01)
IORG Registration # IRB00000726 (IRB 02)

DATE: 10-May-2018

RE: IRB-161214004
Developing an Assessment of Reading Impairment and Its Impact on Occupational Performance in Older Adults with Glaucoma in a Metropolitan Area of a Southern State: A Mixed Methods Approach

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The IRB reviewed and approved the Continuing Review submitted on 09-May-2018 for the above referenced project. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services.

Type of Review:	Expedited
Expedited Categories:	7
Determination:	Approved
Approval Date:	10-May-2018
Approval Period:	One Year
Expiration Date:	09-May-2019

The following apply to this project related to informed consent and/or assent:

- Waiver (Partial) of HIPAA

Documents Included in Review:

- IPR