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Exploring Functional Health Literacy in Older Adults with Age-Related Macular Degeneration

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EXPLORING FUNCTIONAL HEALTH LITERACY IN OLDER ADULTS
WITH AGE-RELATED MACULAR DEGENERATION

by

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This three-paper dissertation explores functional health literacy (i.e., the ability to access, process and understand health information) in older adults with vision loss caused by age-related macular degeneration (AMD). This research builds scholarship that explores the unique patient education needs of older adults with AMD. The specific aims of this research are to: (1) explore associations between functional health literacy and severity of visual impairment; (2) determine the general readability, suitability and comprehensibility of online patient education materials (PEMs) designed for older adults with AMD; and, (3) assess the overall quality of one PEM that has been simplified based on recommended guidelines for patients with low health literacy and low vision. Lack of existing research evidence on these topics creates a great need for additional studies to explore the unique health information needs of this population.

This research aims to inform clinical practice about factors that may influence functional health literacy in older adults with AMD. Low health literacy is a significant problem in the United States. In general, there is a disconnect between the readability (i.e., grade level) of PEMs and the average reading ability of American adults. The gap is even wider for older adults and people with visual impairment. Evidence-based guidelines and strategies are readily available to assist with modifying PEMs for patients with low health literacy and low vision (NIH, 2014; NIH 2018; Kitchel, 2011). Health care providers can apply these guidelines to develop appropriate

PEMs for specific patient populations. Providing PEMs patients can access, process and understand is essential for promoting health literacy in older adults with AMD.

The findings gleaned from these studies have important implications for clinical practice. In general, visual impairment may be an underrecognized barrier to both health literacy and the self-management of chronic health conditions. Learning to self-manage AMD is essential for achieving health outcomes, including slowing the progression of vision loss. Older adults with AMD have unique educational needs. In general, readily available PEMs designed for older adults with AMD have suboptimal readability and suitability. Health care providers should apply the evidence-based guidelines for developing PEMs. Providing PEMs that are easy to access, process and understand is essential for patients with low health literacy and low vision may promote health literacy and improve patient outcomes. Additional research is needed to ensure health condition-specific PEMs become the standard of care in the future. Several audiences including researchers, policymakers and health care providers (i.e., occupational therapists, optometrists and ophthalmologists) will benefit from the information gleaned from these studies. Most importantly, older adults with AMD will benefit from health care providers who understand their challenges and educational needs.

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CHAPTER I

INTRODUCTION

Background

Age-related macular degeneration (AMD) is a chronic health condition that causes permanent vision loss in the central visual field. In the United States (U.S.), AMD is the leading cause of vision loss for Americans over age 65 (Centers for Disease Control and Prevention [CDC], 2018). Due to rapid growth in the aging population, prevalence of AMD is expected to more than double from 2.07 million to 5.44 million by 2050 (National Eye Institute [NEI], 2019). AMD is not correctable; however, it is manageable. Learning to self-manage a chronic health condition is an effective means for improving health outcomes (Brody, Rock-Levecq, Gamst, Maclean, Kaplan & Brown, 2002). Self-management is described as achieving the highest degree of function and the lowest level of symptoms (Clark, 2003). For older adults with AMD, slowing the progression of vision loss is an important health outcome. This population is challenged with managing vision loss in addition to other chronic health conditions. Vision loss creates an independent risk factor for poor self-management of health (Press, Shapiro, Mayo, Meltzer, & Arora, 2013). Health care providers can promote self-management in older adults with AMD by providing patient education materials (PEMs) that are accessible and easy to understand (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman & Rudd, 2005; Sadowski, 2011). Functional health literacy is a key component of the self-management process (Warren, 2013).

Health Literacy

The Institute of Medicine (IOM) defines health literacy as the degree to which individuals have the capacity to obtain, process and understand the basic health information and services needed to make appropriate health-related decisions (IOM, 2004). Health literacy is assessed by measuring skills in basic literacy as they are applied when reading and understanding health information. Many health care providers assess basic literacy based on self-report of the highest grade level completed in school. Research has shown this is an unreliable method (Safeer & Keenan, 2005). Reading comprehension is generally two or more grade levels below the highest grade level completed, and sometimes lower under stressful circumstances (Centers for Disease Control and Prevention [CDC], 2009).

The 2003 National Assessment of Adult Literacy (NAAL) survey is the most current assessment of English literacy of adults in the United States (Kutner, Greenberg & Jin, 2006). The NAAL was designed to measure skills in basic literacy and health literacy in America's adults. Results were reported by grouping adults with similar scores into four categories of literacy performance: Below Basic, Basic, Intermediate and Proficient. According to Kutner, Greenberg and Jin (2006), health tasks at the Below Basic literacy range required locating easily identifiable information in short simple documents, and performing simple quantitative operations (e.g., addition). Health tasks at the Basic literacy range required reading and understanding information in short prose and simple documents, and solving one-step arithmetic operations. Health tasks at the Intermediate level require the ability to interpret or apply information from complex graphs, tables or other health-related texts; and, to locate and use quantitative information to solve problems. Health tasks at the Proficient level require drawing abstract inferences, comparing and contrasting and applying complicated information from health-related texts; and, to locate and use quantitative information to solve multi-step problems.

Low health literacy is a significant problem in the U.S. (Doak & Doak, 2008). Based on the results of the NAAL survey (Kutner, Greenberg & Jin, 2006), 36% of adults have basic, or below basic health literacy skills. Over half of adults (53%) were found to have intermediate health literacy. Only 12% of Americans have proficient health literacy skills to fully participate in self-management of their own health. Results of the study also found adults over the age of 65 had lower health literacy than younger adults. Central vision loss creates an additional barrier to health literacy for older adults with AMD. Research has shown an association between low health literacy and poor health-related quality of life, increased hospitalizations and a rise in the overall costs of health care for American adults (Berkman, 2011; Eltorai Ghanian, Adams, Born & Daniels., 2014). The economic burden of low health literacy on the U.S. economy is estimated between $106 billion and $238 billion dollars annually (Vernon, 2007).

Health literacy is demonstrated through skills in basic literacy when reading and understanding health information. Difficulty reading remains the most common complaint for patients who are referred for low vision rehabilitation (Rubin, 2013). For patients with AMD, vision loss in the central visual field makes reading challenging and inefficient (Chung, 2020; Owsley, McGwin, Lee, Wasserman & Searcey, 2009; Rubin, 2013). Additional time, attention and effort are needed to process and understand written text (Warren, DeCarlo & Dreer, 2016). According to Chung (2020), poor reading performance may be due to decreased visual acuity and contrast sensitivity in the peripheral visual field, and factors associated with the size and style of font.

Methods to improve reading performance are of great importance to older adults with AMD who participate in low vision rehabilitation. Common interventions include the use of optical devices such as magnifiers, and eccentric vision training to promote use of usable vision in the peripheral visual field (Chung, 2020; Harrison & Lazard, 2015). These interventions improve access to text; however, they do not increase understanding of complex written information. To promote health literacy, PEMs must match the reading and literacy skills of the target population (Badarudeen & Sabharwal, 2010). Existing research has shown that health care professionals are often unsure of how to meet the unique patient education needs of people with visual impairment (Chaudry, Brown & Brown, 2015; Harrison & Lazard, 2015; Zhang, Chen, Musch, Zhang & Wang, 2015).

A patient's ability to access, process and understand PEMs is heavily influenced by the medium used to communicate. The Center for Studying Health System Change (HSC) reports 75% of physicians provide written PEMs at the point of care (Carrier, 2009). Unfortunately, there is a disconnect between the readability of existing PEMs and the reading and comprehension skills of American adults. On average, most adults in the U.S. read between the eighth and ninth grade reading level; however, approximately 40% of older adults read at, or below, the fifth grade level (Doak & Doak, 2008). Most PEMs are written at, or above, the tenth grade level (Kirsch, Jungeblut, Jenkins & Kolstad, 1993; Davis, Crouch, Wills & Abdehou, 1990). Therefore, the majority of PEMs are too difficult for a significant portion of the adult U.S. population to understand (Doak & Doak, 2008). Providing PEMs that are readable and suitable is essential for promoting health literacy in older adults with AMD.

Readability and Suitability

Readability is an objective measure of reading skills required to easily understand written text (Badarudeen & Sabbharwal, 2010). Reading difficulty is measured with a formula that produces the grade level (i.e., number of years of education) needed to comprehend written text. To reach the largest audience, the American Medical Association (AMA) recommends PEMs be written below the sixth grade reading level (Weiss, 2007). For people with low literacy skills, the National Institutes of Health (NIH) Clear Communication Campaign suggests writing between the third and sixth grade reading level (NIH, 2018). There are approximately 40 different tools available to assess the readability of written text (D'Alessandro, Kingsley & Johnson-West 2001). There is no consensus as to which formula is best to assess the readability of PEMs; however, several tools have been used in health care settings (Wolf et al., 2012). For example, the Flesch-Kincaid Grade Level (FKGL) formula determines grade level using the average sentence length and the average syllables per word (Kincaid, 1975). The Simple Measure of Gobbledygook (SMOG) formula predicts grade level based on the number of words with three or more syllables in a sample of text (McLaughlin, 1969). Readily available readability metrics make it easy to assess the readability of existing PEMs for individual patient populations.

The suitability (i.e., appropriateness) of PEMs is another factor that may impact comprehension of health information (Wolf et al., 2012). The Suitability Assessment of Materials (SAM) (Doak, Doak & Root, 1996) was developed to objectively assess PEMs designed for a specific patient population. The SAM instrument is strongly correlated with readability level. For example, if readability (i.e., grade level) is high, the overall SAM score is usually low (less suitable) (Doak, Doak & Root, 1996). The opposite is also true. According to Legge (2007), reading comprehension is poorer in people with low vision due to slow reading speed and poor quality of visual input. Consequently, literacy demand (e.g., writing style, vocabulary and sentence construction) may impact processing and understanding. Assessing these factors may promote comprehension in populations at risk for low health literacy.

Research has explored the readability of existing PEMs across a variety of health conditions and subspecialties including orthopedics, pediatrics, trauma, dermatology and cardiology (Badarudeen & Sabharwal, 2010; D'Allesandro, Kingsley & Johnson-West, 2001; Eltorai, Ghanian, Adams, Born & Daniels, 2014; John, John, Hansberry, & Lambert, 2016; Kher, Johnson & Griffith, 2017). A handful of studies have explored the readability of online PEMs from websites that provide information on a variety of ophthalmic diagnoses. For example, Huang, Fang, Agarwal, Bhagat, Eloy and Langer, (2015) assessed the general readability of more than 300 online PEMs from major ophthalmologic association websites. The majority of PEMs were written above the reading level recommended by the AMA (Weiss, 2007) and NIH (NIH, 2018). None of the ophthalmologic associations included in this study were specific to AMD. Furthermore, a breakdown on the topics (i.e., eye conditions) was not reported in the findings. A study by John, John, Hansberry and Patel (2014) compared the readability of PEMs from three websites including the American Academy of Ophthalmology, American Association for Pediatric Ophthalmology and Strabismus, and the Royal College of Ophthalmologists. None of these websites met the recommended readability level for PEMs. John, John, Hansberry, Thomas, and Guo (2015) analyzed online PEMs specific to pediatric ophthalmology conditions. Edmunds, Barry, & Denniston, 2013). No studies have been published on both the readability and suitability of PEMs designed specifically for older adults with AMD.

Gaps in the Literature

Several gaps in the literature surround the unique patient education needs of people with low vision, especially patients with AMD (Beverly, Bath & Booth, 2004). The severity of visual impairment and its impact on functional health literacy has yet to be explored in this population. Harrison and Lazard (2015) advocate for development of population-specific tools for people with varying degrees of visual impairment. Additional research is needed to examine the impact of important design characteristics on comprehension of PEMs, and to find the best ways to simplify written health information to promote health literacy (Beverly, Bath & Booth, 2004; Harrison & Lazard, 2015). Future research should also explore how simplifying PEMs may influence reading comprehension in this population.

Purpose

The overarching purpose of this three-paper dissertation is to explore how vision loss impacts functional health literacy in older adults with visual impairment caused by AMD. The specific aims of this research are to: (1) Explore associations between functional health literacy and severity of visual impairment; (2) Determine the general readability and suitability of online PEMs designed for older adults with AMD; and, (3) Assess the overall quality of one PEM that has been simplified based on recommended guidelines for patients with low health literacy and low vision. Surprisingly few studies exist on these topics. Lack of existing evidence creates a great need for additional research on the specific health information needs of this population.

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CHAPTER II

EXPLORING ASSOCIATIONS BETWEEN HEALTH LITERACY AND VISUAL IMPAIRMENT IN OLDER ADULTS WITH AGE-RELATED MACULAR DEGENERATION

Background

Age-related macular degeneration (AMD) is a chronic health condition that causes permanent vision loss in the central visual field. According to the Centers for Disease Control and Prevention [CDC], AMD is the leading cause of vision loss for Americans ages 65 and older (CDC, 2018). As the older adult population continues to grow at a rapid pace, the number of older adults with AMD is expected to more than double from 2.07 million to 5.44 million by 2050 (National Eye Institute [NEI], 2019). People living with AMD gradually lose sight in the central visual field, whereas peripheral vision typically remains intact. Dandona and Dandona (2006) categorize three severity levels of visual impairment based on visual acuity as follows: moderate impairment: 20/70 to 20/160; severe impairment: 20/200 to 20/400; and, profound impairment: 20/500 to 20/2000. Central vision loss creates barriers to participation in everyday activities including reading. Difficulty reading typically begins at moderate levels of visual impairment (20/60 to 20/180); however, many people continue reading with an optical device until severity reaches profound levels (20/400 or less) (Warren, 2013).

Although AMD is not reversible, it is self-manageable. Clark (2003) describes self-management of a chronic health condition as achieving the highest degree of function and the lowest level of symptoms. For older adults with AMD, slowing the progression of vision loss is an important health outcome. Treatment typically involves regular visits to the eye doctor, vitamins and written handouts provided at the point of care. Older adults with AMD face unique challenges that limit participation in the self-management of chronic health conditions (O'Day, Killeen, & Lezzoni, 2004). Functional health literacy is a key component of the self-management process (Warren, 2013).

Health Literacy

The Institute of Medicine (IOM) defines health literacy as the degree to which individuals have the capacity to obtain, process and understand the basic health information and services needed to make appropriate health-related decisions (IOM, 2004). Health literacy is assessed by measuring skills in basic literacy such as numeracy and comprehension. Commonly used assessments for reading comprehension typically involve reading continuous text, analysis of graphics and the ability to skim for key words and phrases (Legge, 2007). Comprehension of written text is influenced by skills in basic literacy (ability to read, write and interpret written text), the physical properties of text (font style and size, contrast, spacing) and the visual capacities of the reader (Berkman, Sheridan, Donahue, Halpern, Viera & Crotty, 2011; Legge, 2007; Rudd, 2007). Timed assessments create additional barriers to reading performance for people with central vision loss who read more slowly than people without visual impairment (Warren, 2016). The match between these factors will determine how successfully text is read, processed and understood. For these reasons, tests that measure skills in basic literacy are often too demanding for people with low vision (Legge, 2007).

Low health literacy is a significant problem in the United States (U.S.) (Doak & Doak, 2008). The 2003 National Assessment of Adult Literacy (NAAL) survey (Kutner, Greenberg & Jin, 2006) is the most current assessment of skills in basic literacy and health literacy in

American adults. Findings from the survey were categorized into four categories of literacy performance: Below Basic, Basic, Intermediate and Proficient. Results of the survey found 36% of adults have basic, or below basic health literacy skills. Over half of adults (53%) have intermediate health literacy. Only 12% of Americans have proficient health literacy skills (i.e., sufficient level of health literacy to fully participate in self-management of health) (Kutner et al., 2006). The survey also found adults over age 65 are at greater risk of low health literacy. These findings correlate with the Agency for Health Care Research and Quality (AHRQ) which identifies age as a risk factor for low health literacy (Berkman et al., 2011). Visual impairment intensifies barriers to health literacy for older adults. Research has shown an association between low health literacy and poor health-related quality of life, increased hospitalizations and an increase in the overall costs of health care (Berkman et al., 2011; Eltorai Ghanian, Adams, Born & Daniels., 2014). Annually, the economic burden of low health literacy on the U.S. economy is estimated between $106 billion and $238 billion dollars annually (Vernon, 2007).

Historically, health care providers have relied on written handouts to deliver patient education. The Center for Studying Health System Change (HSC) reports 75% of physicians provide written patient education materials at the point of service (Carrier, 2009). Written text may not be an appropriate method for delivering education to every patient, especially older adults with AMD (Xiong, Calabrese, Cheong & Legge, 2018). Optical devices improve access to written text; however, they do not facilitate the cognitive processing required to apply health-related information. Warren (2013) provides guidelines for improving visibility and readability of health-related information including adjusting for the patient's reading level, using plain language and fewer words and sentences.

Few studies have explored the health information needs of older adults with AMD. Gaps in the literature include individuals with AMD not being treated as a unique group under the umbrella of low vision (Beverly, Bath & Booth, 2004). The impact of visual impairment on functional health literacy also needs to be explored in this population. Harrison and Lazard (2015) advocate for population-specific tools and strategies for people with varying severities of visual impairment. Additional research is needed before these tools and strategies can be realized.

Purpose

The purpose of this study was to explore associations between functional health literacy level and severity category of visual impairment in older adults with age-related macular degeneration (AMD). The information obtained from this study is needed to address gaps in the literature and inform future research.

Method

Design

A between-subjects study design was employed to explore differences in functional health literacy levels across three severity categories (moderate, severe and profound) of visual impairment. This study aimed to recruit a convenience sample of 15 to 30 older adults with AMD from one non-profit low vision clinic located in Grand Rapids, Michigan Each participant was assigned to one severity category of visual impairment based on distance visual acuity. Results from a test of functional health literacy were compared to examine the differences between severity categories.

Participants

This study was approved by the Institutional Review Board at Western Michigan University (see Appendix A). Participants met the following inclusion criteria: (1) age 65 years or older; (2) community dwelling; (3) own legal representative; (4) earned high school diploma; (5) English speaking; (6) diagnosis of AMD; (7) reading on a regular basis; (8) normal cognition; and (9) visual acuity between 20/60 and 20/1000 with best correction. Participants were assigned to one of three severity categories (moderate, severe, profound) of visual impairment based on distance visual acuity (Dandona & Dandona, 2006). Participants were excluded from the study for: (1) major eye disease or neurological condition affecting cognition or reading ability (e.g., cataracts, dyslexia, traumatic brain injury); and, (2) uncorrected major hearing loss.

Procedures

All inclusion and exclusion criteria, except for reading habits and normal cognition, were evaluated during a chart review that took place at the low vision clinic. Participants who met these criteria were contacted by the researcher to schedule a home visit. To assess the inclusion criteria for reading habits and normal cognition, the researcher administered the Reading Behavior Inventory (RBI) (Goodrich, Kirby, Wood, & Peters, 2006), and the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) during the home visit. Participants who met all inclusion criteria were administered the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian & Nurss, 1999). A description of each assessment including criteria for scoring and interpretation is provided below.

Reading Behavior Inventory (RBI)

The RBI consists of five questions about reading habits and preferences that are scored on a Likert scale. The test consists of five questions that are intended to identify regular reading habits such as the type of materials read, amount of time spent reading daily, and decline in reading performance in recent months. The RBI is administered orally and test items are scored on a five-item Likert scale. Question C asks how much time is spent reading on an average day. The response to this question confirmed whether the participant is still reading on a regular basis.

Short Portable Mental Status Questionnaire (SPMSQ)

The SPMSQ assesses cognitive function through recall of factual information (e.g., date, day of the week). Score interpretation according to Pfeiffer (1975): 0-2 errors indicates intact functioning; 3-4 errors indicates mild impairment; 5-7 errors indicates moderate impairment; 8-10 errors indicates severe intellectual impairment. Participants in this study were permitted up to three errors to indicate normal to very mild cognitive impairment. Warren, Decarlo & Dreer (2016) applied similar criteria to screen cognition in older adult participants with low vision.

Short Test of Functional Health Literacy in Adults (S-TOFHLA)

The S-TOFHLA measures functional health literacy through assessment of reading comprehension and numeracy. The assessment contains 36 fill-in-the-blank style test items with grade levels of written text that gradually increase from 4.3 to 10.4 (Gunning Fog Index, 1952). According to Baker et al. (1999), the resulting S-TOFHLA scores are interpreted as functional health literacy levels. Scores between 0-16 points indicate inadequate health literacy. Patients at this level should be unable to read and interpret health texts. Scores between 17-22 points indicate marginal health literacy. Patients at this level should have difficulty reading and interpreting most health texts. Modifications should be made in the health care setting to accommodate patients with inadequate and marginal health literacy levels (Baker et al., 1999). Scores between 23-36 points indicate adequate health literacy. Patients at this level should be able to read and interpret most health texts. The standard time to administer the S-TOFHLA assessment is seven minutes. Scores were recorded for timed (seven minute) and untimed testing conditions. The primary researcher recorded both time conditions for comparison based on a study by Warren, DeCarlo and Dreer (2016) that found poorer visual acuity contributes to slower reading speed and decreased comprehension of written health information.

Data Analysis

Statistical analysis was completed using IBM SPSS Statistics, Version 24 (IBM Corporation, Armonk, NY). A one-way analysis of variance (ANOVA) was used to determine differences between S-TOFHLA scores across severity categories (moderate, severe, profound) of visual impairment. Separate analyses were conducted to compare scores for timed and untimed testing conditions. The mean time required to complete the S-TOFHLA was calculated for each severity category. A value of $p < .05$ was used to determine statistical significance.

Results

Fifteen participants met the inclusion criteria for this study. Demographic information and key characteristics for study participants are displayed in Table 1. Participant ages ranged from 67-96 with an average age of 86. Educational attainment of participants included 46% with a high school diploma, 13% with some college, 20% who had earned a four-year degree, and

Table 1
Demographic Information and Key Characteristics

ID #	Age	Gender	Education Level	Visual Acuity	Severity Category	Optical Device	S-TOFHLA Score & Health Literacy Level (Timed vs Untimed)
1	84	Female	Grade 12	20/70	Moderate	Glasses; Magnifier	15 (Inadequate) 34 (Adequate)
2	78	Male	4 Years College	20/100	Moderate	Glasses; Magnifier	15 (Inadequate 33 (Adequate)
3	83	Male	Doctorate	20/200	Severe	Glasses; Magnifier	17 (Marginal) 35 (Adequate)
4	88	Female	2 Years College	20/800	Profound	CCTV	17 (Marginal) 33 (Adequate)
5	81	Female	1.5 Years College	20/100	Moderate	CCTV	13 (Inadequate) 32 (Adequate)
6	77	Female	Grade 12	20/500	Profound	CCTV	11 (Inadequate) 34 (Adequate)
7	91	Female	ABD	20/400	Severe	Magnifier; CCTV	3 (Inadequate) 33 (Adequate)
8	96	Male	Grade 12	20/70	Moderate	Glasses; Magnifier	17 (Marginal) 35 (Adequate)
9	89	Female	Grade 12	20/500	Profound	CCTV	8 (Inadequate) 33 (Adequate)
10	90	Male	6 Years College	20/200	Severe	Glasses; Magnifier	11 (Inadequate) 34 (Adequate)
11	92	Female	4 Years College	20/200	Severe	Glasses; Magnifier	7 (Inadequate) 29 (Adequate)
12	67	Female	Grade 12	20/70	Moderate	Large Print	17 (Marginal) 35 (Adequate)
13	91	Female	Grade 12	20/200	Severe	Magnifier; CCTV	10 (Inadequate) 32 (Adequate)
14	95	Female	4 Years College	20/500	Profound	CCTV	5 (Inadequate) 34 (Adequate)
15	88	Female	Grade 12	20/500	Profound	CCTV	13 (Inadequate) 27 (Adequate)

S-TOFHLA timed condition = 7-minutes; Untimed condition = unlimited time

20% who possessed a graduate degree. The visual acuities of participants ranged from 20/70 to 20/800. Participants were assigned to one severity category (moderate, severe, profound) of visual impairment based on visual acuity. In total, five participants were assigned to each severity category resulting in three equal groups.

S-TOFHLA scores and related health literacy levels varied greatly by time condition. For the standard (seven minute) time condition, 73% of participants had inadequate health literacy; whereas, 27% had marginal health literacy. Results for the untimed condition found 100% of participants had adequate health literacy. Table 2 displays functional health literacy levels by time condition.

Table 2
S-TOFHLA Functional Health Literacy Levels by Time Condition

Health Literacy Level	Time Condition	(*n* = 15), *n* (%)
Inadequate	Timed	11 (73%)
	Untimed	0
Marginal	Timed	4 (27%)
	Untimed	0
Adequate	Timed	0
	Untimed	15 (100%)

S-TOFHLA timed condition = 7-minutes; Untimed condition = unlimited time

Results of the ANOVA found no significant differences in S-TOFHLA scores between three severity categories for timed and untimed testing conditions, $F(2,12) = 2.768$, $p = .103$; and $F(3,27) = 1.853$, $p = .199$, respectively. The mean S-TOFHLA score for each severity category is represented in Table 3. The severe category had the lowest mean score for both time conditions.

Table 3
Mean S-TOFHLA Scores by Severity Category and Time Condition

Severity Category	Time Condition	Mean S-TOFHA Score (SD)
Moderate	Timed	15.40 (1.67)
	Untimed	34.40 (0.89)
Severe	Timed	9.60 (5.17)
	Untimed	32.60 (2.30)
Profound	Timed	10.80 (4.60)
	Untimed	33.20 (0.83)

S-TOFHLA timed condition = seven minutes; Untimed condition = unlimited time
SD = standard deviation

During analysis, data for the mean time required to complete the S-TOFHLA assessment violated the assumption for homogeneity of variances. Therefore, a one-way Welch ANOVA was conducted to decrease the chances of a Type I error. Results of the analysis found no statistically significant differences in mean total time between the severity categories, $F(2,7.49) = 3.188$, $p = .100$. Table 4 displays the mean total time for each severity category to complete the S-TOFHLA for the untimed testing condition. The severe category had the largest variation of data points from the mean as indicated by standard deviation.

Table 4
Mean Total Time Required by Severity Category

Severity Category	Mean Total Time (SD)
Moderate	13.80 (4.55)
Severe	18.60 (9.50)
Profound	23.00 (6.44)

SD = standard deviation

Discussion

This study explored associations between functional health literacy level and severity category of visual impairment in older adults with AMD. Data collection occurred under timed and untimed testing conditions. Similar to results found by Warren et al. (2016), participants in the present study exhibited a drastic improvement in test scores when the time constraint was removed. According to Legge (2007), older adults with low vision may deliberately slow their reading speed to improve reading comprehension. These findings suggest time may be an underrecognized factor of reading performance. More research is needed to determine the efficacy of timed reading assessments with this population.

During data collection, participants utilized the optical device of their choice to access written text. There were trends in the types of optical devices used in each severity category. For example, all participants in the severe category (visual acuity between 20/200-20/400) wore reading glasses and used hand-held magnifiers to access written text. According to Legge (2007), there are three general forms of magnification used for reading: enlarging the print size on the page, bringing the eye closer to the page, or using a magnifier. Participants in the severe category were observed to hold the paper and magnifier close to their face when reading a line of text. Several participants lost their place when attempting to return to the beginning of the next line. All participants in the profound category (visual acuity between 20/500-20/1000) used a closed caption television (CCTV) equipped with a zoom lens to access the S-TOFHLA. To read a line of text, participants moved a platform containing written text from right to left through the camera's field of view. Text size and contrast were altered quickly with the turn of a dial. All participants in this group, appeared comfortable and practiced when using the platform to navigate text.

The synthesis of results from this study brought some unexpected findings. The mean S-TOFHLA scores for participants in the profound category were higher than the severe category for both timed and untimed conditions. This finding was unanticipated considering there is a strong correlation between visual acuity and reading performance (Feng, Roth, Fine, Prenner, Modi & Feuer, 2017). One could assume the profound category, which included the most severely impaired participants, would obtain the lowest mean score. This was not the case.

Selection of optical devices may have influenced reading performance. For participants in the severe category, the smaller viewing area and increased effort required to read with a hand-held magnifier may have limited reading performance. The CCTV's ability to make text bigger and bolder may have enhanced performance of participants in the profound category. According to Legge (2007), in the design and prescription of optical devices, there is often a trade-off between magnification and field size. The larger the magnification (i.e., character size), the smaller the size of the visual field. Feng et al. (2017) found patients with varying degrees of visual impairment read significantly faster with back-lit electronic reading devices as compared to other devices. Similar to the results of this study, Feng found the advantage was even more pronounced in participants with lower visual acuity. Therefore, prescription of appropriate optical devices is important, even in the most severe cases of visual impairment (Legge, 2007). Additional research is needed to guide the selection and prescription of optical devices for older adults with AMD.

Limitations

This study has limitations. The results are restricted to the experiences of fifteen older adults with AMD. A small sample limits the statistical power and overall generalizability of results to the larger population with low vision. To ensure sufficient power for statistical analysis, a more suitable sample would include at least 30 participants in each severity category. In addition, the vast majority of the participants in the study were white. Health literacy is associated with race and socioeconomic status. Therefore, this creates a limitation for this study. Baseline data on the health literacy levels of participants prior to diagnosis of AMD is not available for comparison. Consequently, there is no way to know if health literacy levels have changed, or if this change is related to visual impairment. In addition, the previous careers of some participants created an unanticipated limitation. During analysis, it was realized all participants who scored in the marginal range of health literacy under the standard time condition were retired health care professionals. Therefore, formal training and education may have influenced test performance in these participants. Finally, the S-TOFHLA assessment is not intended for people with less than 20/50 visual acuity. Commonly used reading comprehension assessments are challenging for people with low vision (Legge, 2007). Timed tests add an additional demand for people with central vision loss. Future research should evaluate the efficacy of existing health literacy assessments for people with varying degrees of visual impairment.

Conclusion

This study found several associations between functional health literacy level and severity category of visual impairment that held clinical significance. In general, visual impairment may be an underrecognized barrier to functional health literacy and the self-management of chronic health conditions. Learning to self-manage AMD is essential for achieving health outcomes including slowing the progression of vision loss. Health care providers can promote self-management of AMD and other comorbid health conditions by providing written patient education materials that are easy to access, process and understand. To accommodate patients with low health literacy and low vision, modifications to health information should be made in the health care setting. Selection of appropriate optical devices is another important factor for reading performance of patient education materials. Health care providers should avoid use of health literacy assessments with time constraints for older adults with AMD. Timed tests may create unforeseen barriers to reading performance in this population. Additional research is needed to develop population-specific tools and assessments for people with central vision loss caused by AMD.

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CHAPTER III

READABILITY AND SUITABILITY OF ONLINE PATIENT EDUCATION MATERIALS FOR OLDER ADULTS WITH AGE-RELATED MACULAR DEGENERATON

Background

Age-related macular degeneration (AMD) is a chronic eye condition that leads to permanent vision loss in the central visual field. An estimated 1.8 million older adults are affected by AMD in the United States (U.S.) alone (Centers for Disease Control and Prevention [CDC], 2015). Difficulty reading is the most common complaint from patients seeking low vision rehabilitation services (Owsley, McGwin, Lee, Wasserman & Searcey, 2009; Rubin 2013). Central vision loss makes reading challenging and inefficient. Additional time, attention and effort are needed to process and understand written text (Warren, DeCarlo & Dreer, 2016). According to Chung (2020), poorer reading performance may be due to decreased acuity and contrast sensitivity in the peripheral visual field, and factors associated with the size and style of font (Chung, 2020). While these factors are not the focus of this study, they do represent best practices for developing patient education materials (PEMs) that are easy to read and understand. In low vision rehabilitation, techniques to increase reading performance are often addressed. Adaptations may include use of optical devices such as magnifiers and closed-circuit televisions (CCTVs), and eccentric viewing training which is learning to use the undamaged area of one's vision. These interventions improve access to text; however, they do not increase understanding of complex written information such as PEMs. To promote health literacy, the demands of written text must match the literacy capacities of the reader.

Health Literacy

Health literacy is defined as the degree to which individuals have the capacity to obtain, cognitively process and understand health information to make informed health-related decisions (Ratzan & Parker, 2000). Health literacy is demonstrated through skills in basic literacy when reading and understanding health information. Low health literacy is a significant problem in the U.S. (Doak & Doak, 2008). According to the American Medical Association (AMA), over one-third of American adults, approximately 89 million people, have inadequate health literacy (Weiss, 2007). Health literacy is the single best predictor of health outcomes (Badarudeen & Sabbharwal, 2010; Weiss, 2007).

Readability and Suitability

According to Legge (2007), there are two reasons why reading comprehension may be poorer in people with low vision. First, slower reading speed makes it difficult to maintain attention on text and integrate meaning across words and phrases. Second, the increased demands of decoding (i.e., translating print into words) and poorer quality of visual input may limit understanding. The readability and suitability of reading materials are additional factors that may impact reading performance in older adults with AMD. Readability is a quantitative assessment of the reading skills required to easily comprehend written material (Badarudeen & Sabbharwal, 2010). Readability is calculated by applying a mathematical formula to a sample passage of written text. A grade level (i.e., number of years of education needed to comprehend written text) is produced based on the number of syllables, words and sentences. Several formulas are used to assess readability; however, there is no consensus as to which formula is best to assess the readability of PEMs. The suitability (i.e., appropriateness) of written information is another important factor impacting comprehension of written health information (Wolf et al., 2012). For older adults with AMD, factors related to the layout and design of written information may support, or limit, comprehension of PEMs (Legge, 2007).

In 2016, the Program for the International Assessment of Adult Competencies (PIAAC) published the most current indicator of basic skills in literacy, numeracy and problem solving skills of American adults. The PIAAC defines literacy as “the ability to understand, evaluate, use and engage with written texts to participate in society, to achieve one’s goals and to develop one’s knowledge and potential” (Organization for Economic Cooperation and Development, 2013, p. 61). Findings from the survey indicated only 12% of American adults had proficient literacy skills. These results matched findings from the 2003 National Assessment of Adult Literacy (NAAL) survey (Kutner, Greenberg & Jin, 2006) which also found 12% of adult Americans had proficient health literacy skills to fully participate in the self-management of their own health. According to the Centers for Disease Control and Prevention [CDC] (2019), people with low literacy are more likely to report poor health outcomes.

Comprehension of written health information is influenced by several factors including the ability to read text, locate and use written information in documents, and to use numbers embedded in print materials (Rudd, 2007). According to the Pfizer Principles for Clear Health Communication (Doak & Doak, 2008), health outcomes are impacted by low health literacy in two ways: (1) a mismatch between reading abilities and the reading level of written health information; and (2) lack of health-related information that is easy to understand. Existing research indicates the impact of vision loss on health outcomes is often underestimated by health care providers (Chaudry et al., 2015; Zhang, Liang, Chen, Musch, Zhang & Wang, 2015). Health care providers who provide written PEMs must recognize how poor reading proficiency creates barriers to functional health literacy (Parker, 2000; Warren, 2013).

The Center for Studying Health System Change (HSC) reports 75% of physicians provide written PEMs on a routine basis (Carrier, 2009). Existing research has identified a discrepancy between the readability of PEMs and the average American adult's capacity to comprehend written health-related information (Badarudeen & Sabharwal, 2010; Kher, Johnson & Griffith, 2017; Stossel, Segar, Gliatto, Fallar & Karani, 2011). Most PEMs are written at, or above, the tenth grade reading level and include written information too advanced for most patients to understand (Davis, Crouch, Wills & Abdehou, 1990; Kirsch, Jungeblut, Jenkins & Kolstad, 1993). On average, American adults read between the eighth and ninth grade level (Kutner et al., 2006). The gap is even wider for older adults. According to the United States Government Accountability Office (GAO), the average Medicare recipient reads at, or below, the fifth grade reading level (GAO, 2006). The barriers to reading created by central vision loss put older adults with AMD at greater risk for low health literacy (Harrison, Mackert & Watkins, 2010; Kutner et al., 2006). To reach the needs of the largest range of adults, the American Medical Association (AMA) has recommended patient information be written below the sixth grade reading level (Weiss, 2007). For people with low literacy skills, the National Institutes of Health (NIH) Clear Communication Campaign suggests writing between the third and sixth grade reading level (NIH, 2018).

The internet has become the most widely accessible source of PEMs (Armstrong-Heimsoth, Johnson, Carpenter, Thomas & Sinnappan, 2019; John, John, Hansberry, Prashant & Suqin, 2015). A study by the Pew Internet and American Life Project found that 80% of American adults who use the internet have searched for online health information (Fox & Jones, 2011). Although it has become easier to access PEMs online, most American adults cannot process or understand the technical information within them to inform health-related decision making (Armstrong-Heimsoth et al., 2019). Determining whether existing PEMs meet the recommended guidelines for readability and suitability is a necessary first step for promoting health literacy and patient outcomes. This purpose of this study was to assess the general readability and suitability of readily available online PEMs designed for older adults with AMD. This research is needed to determine if existing online PEMs are appropriate (i.e., readable and suitable) for older adults with AMD, a population at greater risk for low health literacy (Harrison, Mackert & Watkins, 2010; Kutner et al., 2006).

Gaps in the Literature

Existing research has explored the readability of PEMs across a variety of health conditions and subspecialties (Badarudeen & Sabharwal, 2010; D'Allesandro, Kingsley & Johnson-West, 2001; Eltorai, Ghanian, Adams, Born & Daniels, 2014; Hansberry, Agarwal, Shah, Schmitt, Baredes, Setzen & Carmel, 2013; John, John, Hansberry, & Clark, 2016; Kher et al., 2017; Stossel et al., 2011). A major gap in the literature exists surrounding treating people with AMD as a unique group under the larger umbrella of low vision (Beverly, Bath & Booth, 2004). A handful of studies have explored the readability of online PEMs for a range of different ophthalmic diagnoses (Edmunds, Barry, & Denniston, 2013; Huang, Fang, Agarwal, Bhagat, Eloy & Langer, 2015; John, John, Hansberry & Patel, 2014; John, John, Hansberry, Thomas, & Guo, 2015). None of these studies have explored the readability of PEMs designed for older adults with AMD. The suitability (i.e., appropriateness) of PEMs is also important when determining the fit between written health-related information and the reading capacities of a target population. This is the first study to focus solely on the readability and suitability of online PEMs designed specifically for older adults with AMD. This study is needed to fuel future research and develop population-specific PEMs that meet the unique learning needs of older adults with AMD.

Research Questions

This study aims to answer the following research questions: (1) What is the general readability and suitability of online PEMs designed for older adults with AMD? (2) What percentage of online PEMs designed for older adults with AMD achieve the recommended readability level and suitability score? To the researcher's knowledge, this study is the first to focus on both readability and suitability of online PEMs designed specifically for older adults with AMD.

Method

This study was approved by the Institutional Review Board at Western Michigan University (see Appendix B). A convenience sample of online PEMs was sourced from the websites of professional organizations and institutions who provide patient education on AMD (Table 5). The researcher consulted with two low vision rehabilitation specialists to identify suitable sources of PEMs designed for older adults with AMD. The key words "age related macular degeneration (AMD)" were entered into the search engine on the home page of each organization's website. To find additional sources of information that may have been overlooked, the researcher conducted a search on Google.com using the key words "age-related macular degeneration." To be included in this study, PEMs had to be written by a professional society or clinical practice website, written in English and contain information related to AMD. Scientific articles, opinion pieces, patient forums and PEMs about similar topics (e.g., low vision and Stargardt disease) were excluded.

Procedures

Online PEMs were retrieved from websites of professional organizations and institutions. Written text was copied from the website and pasted into a Microsoft Word document (Microsoft Corporation, Redmond, Washington). To prepare the text for data analysis, all material unrelated to patient education was removed including copyright notices, disclaimers, date stamps, graphics, tables, author information, hyperlinks, in-text citations and reference lists. To achieve a uniform text style, each passage of text was highlighted and "right-clicked" to access the "styles" pane where the "clear formatting" option was selected. To improve the accuracy of readability calculations, the primary researcher "cleaned" the text prior to computer analysis. The process included removing bullets, paragraph breaks and some punctuation including quotation marks, parentheses, colons and semicolons. Numbers, decimals and percentages were converted to written form (e.g., "2.5%" was converted to "two point five percent"). To improve accuracy of word count, compound words were separated into root words (e.g., "age-related" was changed to "age related"), and dashes were removed (e.g., "two-to-three times" was changed to "two to three times").

Flesch-Kincaid Grade Level (FKGL) Formula

There are approximately 40 readability formulas available to calculate the grade level of written information (Doak, Doak & Root, 1996). Experts in the field have not come to an agreement on the best formula to assess readability of PEMs; however, several are used in health care settings (Badarudeen & Sabbharwal, 2010). The Flesch-Kincaid Grade Level (FKGL) formula measures readability (i.e., grade level) of written text using the average sentence length and syllables per word (Kincaid, 1975). The FKGL is one of the most widely used readability formulas (Albright, deGuzman, Acebo, Paiva, Faulkner & Swanson, 1996; Cooley, Moriarty, Berger, Selm-Orr, Coyle, & Short, 1995). For this study, readability was calculated using the FKGL formula embedded in Microsoft Word software. To enable the readability calculator, the user must select the "Review, Spelling & Grammar" functions in sequential order. A readability level is automatically displayed after the grammar and spell check process is complete. The FKGL formula was chosen for this study because it is quick and easy to administer, has been extensively validated, and correlates highly with other readability formulas (Badarudeen & Sabharwal, 2010).

Suitability Assessment of Materials (SAM)

When examining the match between written information and the capacities of the reader, it is important to consider design characteristics that may impact comprehension. Factors such as graphics, layout and typography can be difficult to assess in an objective manner. The Suitability Assessment of Materials (SAM) instrument (Doak et al., 1996) is a valid and reliable tool designed to assess the overall suitability (i.e., appropriateness) of health information for a specific audience. The SAM has been administered successfully in previous research on health literacy, including for patients with strokes, heart conditions and cancer (Eames, McKenna, Worrall & Read, 2003; Taylor-Clarke et al., 2012; Weintraub, Maliski, Fink, Choe & Litwin, 2004). The SAM instrument was selected to measure the suitability of each PEM across six categories: (1) content; (2) literacy demand; (3) graphics; (4) layout and typography; (5) learning stimulation; and (6) cultural appropriateness. A SAM percentage score and suitability rating were calculated for each PEM based on appropriateness of health information for the target audience, older adults with AMD. Interpretation of SAM percentage scores and suitability ratings are as follows: 0%-39% - Not Suitable; 40%-69% - Adequate; and, 70%-100% - Superior. Based on scoring and interpretation methods described by the authors, a SAM percentage score ≥ 70% is needed for PEMs to be considered suitable in this study.

Data Analyses

Statistical analysis was completed with IBM SPSS 25 software (IBM Corporation, Armonk, NY). Descriptive statistics were used to determine the mean FKGL readability level, SAM suitability score and percentage of online PEMs designed for older adults with AMD. Percentage of PEMs achieving the suggested readability level (≤ sixth grade) and suitability score (≥ 70%) was also calculated.

Results

One hundred online PEMs were evaluated from 16 professional organizations and institutions who provide patient education on AMD (Table 5). Based on results of the FKGL formula, the mean readability level of the PEMs included in this study was 9.3 (range 5.0-16.6). The majority (94%) of PEMs were written above the sixth grade reading level. Only six PEMs (6%) met the guidelines for readability level (≤ sixth grade) as suggested by the American Medical Association (Weiss, 2007) and National Institutes of Health (NIH, 2018). Seventeen PEMs (17%) were written above the 12th grade reading level.

Table 5

Range and Mean of FKGL Readability Levels by Organization or Institution

	Institution/Organization	Total PEMs	FKGL Range	Mean FKGL Readability Level
1	NIH National Eye Institute	6	5.9-12.0	8.3
2	American Macular Degeneration Foundation	12	8.4-16.6	11.7
3	American Academy of Ophthalmology	5	5.3-11.0	7.4
4	NIH U.S. National Library of Medicine	4	5.0-6.8	6.1
5	UC Irvine Health Macular Degeneration Partnership	9	7.2-12.6	10.1
6	Foundation Fighting Blindness	4	10.4-13.3	11.7
7	American Printing House for the Blind	9	10.1-13.6	12.1
8	Prevent Blindness	5	7.5-10.6	8.5
9	Merck Manual Patient Education	2	5.9-10.3	8.1
10	Bright Focus Foundation	15	9.0-13.1	10.4
11	Mayo Foundation for Medical Education and Research	5	8.7-10.9	9.7
12	Macular Degeneration Foundation	11	6.8-14.6	9.7
13	Centers for Disease Control and Prevention	3	7.0-11.9	8.4
14	Macular Degeneration Support	2	8.0-9.9	9.0
15	Lighthouse Guild	2	8.3-8.4	8.4
16	Macular Society	6	7.6-9.9	8.6
Total/Mean Scores		*n* = 100	5.0-16.6	9.3

FKGL = Flesch Kincaid Grade Level

Results of the SAM instrument (Table 6) found a mean suitability score of 53% (range 18%-78%), and a mean suitability rating of “adequate.” In total, 15 PEMs (15%) met the recommended suitability score (≥ 70%) for “superior” material. All six (100%) of the PEMs written below the sixth grade reading level fell into this category. Sixty two PEMs (62%) received a suitability rating of “adequate.” Twenty-three PEMs (23%) were rated “not suitable.” Thirteen of the 17 PEMs (76%) written at college reading level received a SAM rating of “not suitable.”

Table 6

Number and Percentage of SAM Suitability Ratings by Organization or Institution

	Institution/Organization	Total PEMs	Not Suitable	Adequate	Superior
1	NIH National Eye Institute	6	0 (0%)	4 (67%)	2 (33%)
2	American Macular Degeneration Foundation	12	8 (67%)	4 (33%)	0 (0%)
3	American Academy of Ophthalmology	5	0 (0%)	3 (60%)	2 (40%)
4	NIH U.S. National Library of Medicine	4	0 (0%)	1 (25%)	3 (75%)
5	UC Irvine Health Macular Degeneration Partnership	9	2 (22%)	6 (67%)	1 (11%)
6	Foundation Fighting Blindness	4	1 (25%)	3 (75%)	0 (0%)
7	American Printing House for the Blind	9	4 (44%)	5 (56%)	0 (0%)
8	Prevent Blindness	5	0 (0%)	3 (60%)	2 (40%)
9	Merck Manual Patient Education	2	0 (0%)	1 (50%)	1 (50%)
10	Bright Focus Foundation	15	0 (0%)	14 (93%)	1 (7%)
11	Mayo Foundation for Medical Education and Research	5	1 (20%)	3 (60%)	1 (20%)
12	Macular Degeneration Foundation	11	1 (9%)	10 (91%)	0 (0%)
13	Centers for Disease Control and Prevention	3	1 (33%)	2 (67%)	0 (0%)
14	Macular Degeneration Support	2	2 (100%)	0 (0%)	0 (0%)
15	Lighthouse Guild	2	0 (0%)	0 (0%)	2 (100%)
16	Macular Society	6	3 (50%)	3 (50%)	0 (0%)
Total/Mean Scores		*n* = 100	23 (23%)	62 (62%)	15 (15%)

SAM = Suitability Assessment of Materials

Discussion

Existing research has identified a mismatch between the readability of existing PEMs and the reading and comprehension skills of American adults (Kutner et al., 2006; Weiss, 2009). Central vision loss creates a barrier to health literacy for older adults with AMD. Evidence-based guidelines for readability have been published by national organizations including the AMA (Weiss, 2009) and the NIH (NIH, 2018). To reach the largest audience, these organizations suggest that PEMs be written below the sixth grade reading level. In addition, the suitability (i.e., appropriateness) of written health information should also be considered for older adults with

AMD. Attention should be given to graphics, layout and typography to determine if modification is needed to promote health literacy and patient outcomes in this population. PEMs written below the sixth grade reading level may still be difficult to process and understand. Literacy demand (e.g., writing style, vocabulary and sentence construction) and the physical properties of text (e.g., font style and size, contrast, spacing) may create additional barriers to processing and understanding of written information (Legge, 2007). Chung (2020) questions whether reading performance could be enhanced by modifying certain characteristics of text to better match the capabilities of the peripheral visual system.

The American Printing House (APH) for the Blind Guidelines for Print Document Design (Kitchel, 2011) provides helpful accommodations and strategies to improve the readability and visibility of PEMs for people with low vision. The APH believes the color, style, size and typeface of font impacts the readability and usability of a document. Therefore, the APH developed APHont specifically for readers with low vision. Currently, there is no scientific evidence to support the effectiveness of APHont over other styles of font. The APH guidelines include specific recommendations for document design including increased white space to create contrast; spacing between letters, words and paragraphs; formatting headings, lists and margins; and simple charts and graphics. At this time, there is no research showing the application of APH guidelines improves reading performance in people with low vision. Of the 100 PEMs included in this study, 98 were published several years after the APH guidelines were developed. Therefore, one could assume that most online PEMs designed for older adults with AMD are not held to higher standards to ensure usability for people with low vision.

The suitability of written health information for a given patient population is equally as important. In this study, all six (100%) of the PEMs that met the sixth grade readability guidelines received a suitability score (≥ 70%) for "superior" material; however, readability did not guarantee suitability. Factors related to layout and typography (e.g., clutter, contrast, and graphics) had the potential to significantly lower the suitability score of PEMs with satisfactory readability level. For example, the readability levels of PEMs that received a SAM score of "not suitable" ranged between grade 7.8 and 16.6. In contrast, the readability levels of PEMs receiving "superior" SAM scores ranged between grade 5.0 and 10.7. Literacy demand was another important factor in this study. Most of the PEMs included in this study provided general information on AMD; however, certain topics such as treatment and research included unavoidable medical jargon. These PEMs had the highest readability levels and lowest suitability scores in the sample. Due to the complexity of these topics and need for patient education, this limitation may be unavoidable.

With increasing dependence on the internet for health information, health care providers must take initiative to provide PEMs their patients can access, process and understand. Readily available readability metrics make it easy to assess the grade level of existing PEMs for individual patient populations (online readability calculators, Microsoft Word). The AMA (Weiss, 2009) and NIH (NIH, 2018) have issued evidence-based recommendations for PEMs for people with low health literacy. The American Printing House for the Blind (APH) published the Guidelines for Print Document Design (Kitchel, 2011) to improve the visibility and readability of written information for people with low vision. Applying these guidelines for patients with low health literacy and low vision may benefit patients and health care providers. PEMs that are easy to access, process and understand promote health literacy and informed health-related decision making. Functional health literacy is a key component for self-management of chronic health conditions such as AMD (Warren, 2013). Health care providers who become familiar with these guidelines will be better equipped to address the unique reading and comprehension needs of older adults with AMD.

Limitations

This study is limited because a single readability metric (the FKGL) was used to calculate the grade level of all PEMs included in this study. Readability metrics produce a grade level based on the number of syllables, words and sentences in a passage of written text. The greater the complexity of written text, the higher the grade level required to comprehend it. Although the results of this study show the mean readability of the PEMs included in this study are higher than the recommended guidelines, additional factors should be considered. For example, the words "age-related macular degeneration" are considered difficult to read simply based on the number of syllables involved. These words appeared frequently and cannot be replaced. Furthermore, the FKGL is not a direct measure of comprehensibility; therefore, there is a possibility the results of this study could underestimate the level of difficulty required to read health information. These limitations may impact the generalizability of results to the greater population of older adults with AMD.

Future Directions

The evidence-based guidelines for promoting health literacy and clear communication do not consider how age and visual impairment may create additional barriers to processing and understanding of written health information. Future research should address the need for treating older adults with AMD as a unique group under the larger umbrella of low vision. Additional studies are needed to determine the optimal design and presentation of PEMs for this population. Future research should also evaluate the benefits of PEMs that have been modified based on established guidelines for patients with low health literacy and low vision. Finally, future studies should explore the training needs of health care providers who want to create or modify PEMs for a target population. The results of this study will be used to inform future research that will guide researchers and health care providers in the selection, creation and modification of PEMs designed for a specific target population.

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CHAPTER IV

ASSESSING SIMPLIFIED PATIENT EDUCATION MATERIALS DESIGNED FOR OLDER ADULTS WITH AGE-RELATED MACULAR DEGENERATION

Background

Age-related macular degeneration (AMD), a chronic eye condition affecting mainly older adults, causes permanent vision loss in the central visual field. In the United States (U.S.) alone, an estimated 1.8 million older adults are affected by the disease (Centers for Disease Control and Prevention [CDC], 2015). Difficulty reading remains the most common complaint for patients referred for low vision rehabilitation (Rubin, 2013). In general, reading becomes challenging at moderate levels of visual impairment (20/60 to 20/180 Snellen acuity); however, many people continue reading with optical devices until severity reaches profound levels (20/400 or less) (Warren, 2013). Reading comprehension often becomes poorer due to difficulty decoding, slower reading speeds and inability to maintain attention on text to integrate meaning (Legge, 2007). Despite advances in the treatment of chronic eye conditions, there is no cure for AMD. With early diagnosis, treatment may slow the progression of vision loss. Although AMD is not correctable, it is manageable. Clark (2003) describes self-management as achieving the highest degree of function and the lowest level of symptoms. For older adults with AMD, slowing the progression of vision loss is an important health outcome. Functional health literacy is a key component of the self-management process (Warren, 2013).

Health Literacy

Functional health literacy is defined as one's capacity to obtain, cognitively process and understand health information in order to make informed health-related decisions (Ratzan & Parker, 2000). Health literacy is assessed by measuring skills in basic literacy as they are applied when reading and understanding health information. In the U.S., it has been found that low health literacy is a substantial problem among American adults (Doak & Doak, 2008). Results from the 2003 National Assessment of Adult Literacy (NAAL) survey (Kutner, Greenberg & Jin, 2006) found only 12% of American adults have health literacy skills proficient enough to fully participate in the self-management of their own health. Older adults over the age of 65 had lower health literacy than younger adults. Older adults with visual impairment are at even greater risk for low health literacy (Harrison, Mackert & Watkins, 2010; Kutner et al., 2006). Visual impairment creates an additional barrier to health literacy in this population due to increased difficulty accessing written text.

Readability

The ability to access, process and understand written health information is important for achieving positive patient outcomes. Readability is an assessment of the grade level required to easily read and understand written text (Badarudeen & Sabbharwal, 2010). Readability is calculated with a formula that produces the grade level, or number of years of education needed, to comprehend text. For example, the Simple Measure of Gobbledygook (SMOG) formula predicts grade level using the number of words with three or more syllables in a sample of sentences (McLaughlin, 1969). The Gunning Fog Index (GFI) calculates grade level based on the average words per sentence and the percentage of polysyllable words (Gunning, 1952). The Flesch-

Kincaid Grade Level (FKGL) formula measures grade level using the mean sentence length and syllables per word (Kincaid, 1975). There is no consensus as to which formula is best for evaluating patient education materials (PEMs).

The Center for Studying Health System Change (HSC) reports 75% of physicians provide written PEMs at the point of service (Carrier, 2009). Unfortunately, the reading and comprehension skills of some patient populations are overlooked during the development of these materials. Previous research has found that, on average, adults in the U.S. read between the eighth and ninth grade reading level (Doak & Doak, 2008). In addition, the average Medicare recipient reads at, or below, the fifth grade reading level (U.S. Government Accountability Office [GAO], 2006). Existing research on readability indicates PEMs are consistently written at a reading level that is too high for many American adults to comprehend. In general, the majority of PEMs are written at, or above, the 10^{th} grade reading level (Davis, Crouch, Wills & Abdehou,1990; Kirsch, Jungeblut, Jenkins & Kolstad, 1993). Thus, a disconnect exists between the readability of existing PEMs and the average reading and comprehension skills of American adults, including older adults with AMD.

A study by John, John, Hansberry, Prashant and Suqin (2015) assessed the readability of more than 200 online ophthalmology PEMs from three national organizations. Not one of the organizations met the recommended readability guideline for written materials below the sixth grade reading level. The authors suggest assessing the readability of existing PEMs and rewriting them at a lower grade level. Edmunds, Barry and Denniston (2013) assessed the readability of 160 online PEMs for 16 ophthalmic diagnoses including AMD. The PEMs collected from the websites of 60 national organizations varied by topic. Age-related maculopathy was one of 16 diagnoses included in the study. Not one of the PEMs had a readability score below the recommended sixth grade reading level. Williams, Muir and Rosdahl (2016) applied guidelines for writing easy-to-understand PEMs to 12 handouts designed for patients with glaucoma. Feedback solicited from study participants with glaucoma found that simplifying the PEMs significantly improved readability and suitability. A literature review by Badarudeen and Sabharwal (2010) explored potential solutions to enhance the readability of PEMs. The authors recommend pre-testing PEMs with their intended target population and modifying the reading level of existing patient handouts to enhance comprehension. Harrison and Lazard (2015) advocate for development of population-specific tools for promoting health literacy based on the unique physicality and severity level (i.e., visual acuity) of visual impairment.

Evidence-Based Guidelines

Evidence-based guidelines for developing PEMs for people with low health literacy have been published by national organizations including the American Medical Association (AMA) (Weiss, 2009), the National Institutes of Health (NIH) (NIH, 2014) and the Harvard T.H. Chan School of Public Health (Rudd, n.d.). In general, the guidelines recommend PEMs are written with plain language at a reading level below sixth grade. Guidelines for developing PEMs for people with low vision are not as common. Warren (2013) provides a summary of accommodations and strategies to improve the readability and visibility of written health information for older adults with low vision. The suggested strategies were originally compiled by the American Printing House for the Blind (APH) Guidelines for Print Document Design (Kitchel, 2011); and, the Pfizer Principles for Clear Health Communication (Doak & Doak, 2008). Additional research is needed to determine the optimal design and presentation of PEMs for older adults with AMD.

Several gaps in the literature exist surrounding the health information needs of people with visual impairment. Previous research examining the readability of simplified PEMs designed for older adults with visual impairment was not identified. A systematic review by Beverly, Bath and Booth (2004) found gaps related to treating patients based on their individual diagnoses (e.g., AMD, glaucoma, cataracts) instead of under the larger umbrella of low vision; and, actively involving patients in the research process. The impact of visual impairment caused by AMD on functional health literacy has yet to be studied. This research aims to address these gaps in the literature, as well as explore the disconnect between the readability of written health information designed for older adults with AMD and the average reading ability of this population.

Research Questions

This study addressed the following research questions: (1) For older adults with AMD, is there a significant difference in the readability, suitability and perceived comprehensibility of simplified PEMs as compared to the original format? (2) What are patient perceptions of the design characteristics of simplified PEMs? To date, this is the first study to assess the benefits of simplified PEMs in this population.

Method

Design

A within-subjects study design was used to determine differences between the original and simplified PEMs. Participants were recruited from low vision rehabilitation clinics located in West Michigan. This study aimed to recruit a convenience sample of 12 older adults with AMD.

Each participant was assigned to one severity category of visual impairment based on their distance visual acuity with best correction.

Participants

This study was approved by the Institutional Review Board at Western Michigan University (see Appendix C). Participants in this study met the following inclusion criteria: (1) adults age 50 or older; (2) physician documented primary diagnosis of AMD; (3) visual acuity between 20/60 and 20/1000 with best correction; (4) English speaking; (5) own legal representative; and, (6) minimal risk for cognitive impairment defined as no more than three errors on the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). Confirmation of diagnosis and visual acuity were provided by the referring low vision clinic. Visual acuity was assessed within the last 12-months. The wide range of visual acuities included in this study was inclusive of the visual severity categories (moderate – 20/70 to 20/160; severe – 20/200 to 20/400; and profound – 20/500 to 20/1000) based on distance visual acuity with best correction as described by Dandona and Dandona (2006). Participants were excluded from this study for the following reasons: (1) inability to read written text; (2) any major eye disease or neurological condition affecting ability to read (e.g., dyslexia, traumatic brain injury); and, (3) uncorrected major hearing loss.

Procedures

All inclusion and exclusion criteria, except normal cognition, were evaluated during a chart review that took place at the low vision clinic. Participants who met these criteria were contacted by the primary researcher to schedule a home visit. During the home visit, the Short

Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) was administered to confirm the inclusion criterion of normal cognition. In addition, the Rapid Estimate of Adult Health Literacy in Medicine – Short Form (REALM-SF) (Arozulluh, Yarnold, Bennett, Solltysik, Wolf, Lee & Davis, 2007) was utilized as a quick screen of health literacy levels. One PEM was simplified based on evidence-based guidelines for rewriting materials for people with low health literacy and low vision (Kitchel, 2011; Rudd, n.d.). The original and simplified PEMs were assessed for readability, suitability and comprehensibility. A description of each procedure, including criteria for scoring and interpretation, is provided below. The researcher also documented the different types of optical devices used by participants to access written information.

Short Portable Mental Status Questionnaire (SPMSQ)

The SPMSQ assesses cognitive function through recall of factual information (e.g., date, day of the week). Score interpretation according to Pfeiffer (1975): 0-2 errors indicates intact functioning; 3-4 errors indicates mild impairment; 5-7 errors indicates moderate impairment; 8-10 errors indicates severe intellectual impairment. Participants were permitted up to three errors indicating normal to very mild cognitive impairment. A study by Warren, Decarlo and Dreer (2016) applied similar scoring criteria when screening cognition in potential study participants.

Rapid Estimate of Adult Liteacy in Medicine – Short Form (REALM-SF)

The REALM-SF was administered to assess the health literacy level of each participant. Participants are asked to read aloud a list of seven health-related words. One point is awarded for each word that is pronounced correctly. According to Arozulluh et al., (2007), scores are interpreted using grade level equivalents: 0 – third grade and below; 1-3 – fourth to sixth grade; 4-6 – seventh to eighth grade; and 7 – high school.

Patient Education Material (PEM) Simplification Process

The PEM selected for this study, titled *Charles Bonnet Syndrome* (Lighthouse International, 2019), is readily available online (Appendix D). This topic was selected because it affects roughly one-third of people with low vision (Schultz & Melzack, 1991). The original PEM was simplified according to evidence-based guidelines for rewriting materials for people with low health literacy (Rudd, n.d.), and the American Printing House Guidelines for Print Document Design for people with low vision (Kitchel, 2011) (Appendix E). The simplification process involved completion of the steps in Table 7. In total, it took the primary researcher approximately 30 minutes to simplify the original PEM.

Table 7
Evidence-Based Guidelines and Suggested Accommodations for Simplifying PEMs

Harvard Guidelines for Rewriting Materials (Rudd, n.d.)

- Complex words and phrases replaced with simple words and phrases
- Excess words and modifiers removed
- Long sentences (exceeding 3 lines, or 15 words) broken up, or rewritten
- Medical jargon replaced with plain language
- Impersonal pronouns (person, folks, he, she) removed
- Use active voice and present tense
- Remove graphics to improve visibility

American Printing House Guidelines for Print Document Design (Kitchel, 2011)

- Font style changed from Helvetica to APHont
- Use only plain text (no italics, all caps, or fancy fonts)
- Font size increased from 10.5 point to 18 point

Table 7—continued

- Header font size increased from 19 point to 24 point
- Hyperlinks removed
- Contractions changed into two words
- Color of all font changed to black
- Create white space:
    - Margins indented 1 inch
    - Justify left margin
    - Unjustified right margin
    - Double spacing between paragraphs and graphics
- Block paragraph style with no indents

Readability Metrics

Word count and readability (i.e., grade level) were calculated using an online readability calculator (Online Utility, n.d.) embedded with the following metrics: (1) Simple Measure of Gobbledygook (SMOG) (McLaughlin, 1969); (2) Gunning Fog Index (GFI) (Gunning, 1952); and (3) Flesch-Kincaid Grade Level (FKGL) (Kincaid, 1975). A sample passage of text was cut from each PEM and pasted into a text box for calculation. To improve reliability, the researcher tested the same text sample by hand using the Fry Readability Formula (Fry, 1986). The Fry Formula was selected because it is widely accepted in the existing literature and does not require a large sample of text. For each PEM, the researcher tested three different 100-word passage of text. The average number of sentences and syllables was used to calculate the grade level of each PEM. The resulting data was entered into a Microsoft Excel spreadsheet for analysis.

Suitability Assessment of Materials (SAM)

The Suitability Assessment of Materials (SAM) instrument (Doak, Doak & Root, 1996) was used to objectively rate the suitability (i.e., appropriateness) of the original and simplified PEMs. The SAM evaluates twenty-two factors across six categories: (1) content; (2) literacy demand; (3) graphics; (4) layout and typography; (5) learning stimulation; and (6) cultural appropriateness. The information was evaluated using specific criteria for each SAM factor. Each category was scored between zero and two points based on the suitability of material: 2 points (superior); 1 point (adequate); 0 points (not suitable); and factors that did not apply (N/A). A percentage score was calculated for each individual category. These scores were summed to calculate a total suitability score which was interpreted based on scoring criteria established by Doak et al., (1996). A total suitability score between 0%-39% qualifies print material as *Not Suitable* for the intended population. Print materials earning a percentage score between 40%-69% are deemed *Adequate*. To meet the *Superior* criteria, print materials must earn a percentage score between 70%-100%. Research has shown the SAM instrument is strongly correlated with readability level (Doak et al., 1996). For example, if readability (i.e., grade level) is high, the overall SAM score is usually low (less suitable).

Consumer Information Rating Form (CIRF)

Each study participant completed one Consumer Information Rating Form (CIRF) (Koo, Krass & Aslani, 2007) for both PEMs. The CIRF was developed to quantify comprehensibility (i.e., design quality and usefulness) of written health information as perceived by the consumer. The two-page form consists of 17 test items across three categories: (1) comprehensibility; (2) utility; and, (3) overall design quality. The researcher presented the original PEM first and instructed participants to read it using the optical device of their choice. When participants were finished reading, the researcher administered the CIRF to rate comprehensibility. Considering the majority of participants have difficulty reading and writing due to central vision loss, the researcher offered to assist with reading test items aloud and recording responses as needed. Each test item was scored on a five-point scale with higher scores indicating greater quality and usefulness of information. After the original PEM was evaluated, the researcher encouraged participants to take a ten-minute break before presenting the simplified PEM. Data was transferred to a Microsoft Excel spreadsheet for analysis.

Semi-Structured Interviews

Completion of the CIRF was followed by a brief semi-structured interview. The researcher asked open-ended questions to gather additional input on personal preferences and the quality and usefulness of the original and simplified PEMs. The qualitative data collected during the interview process was used to enrich the quantitative findings of the SAM instrument and CIRF scores. On average, each interview lasted approximately 10 minutes. The interview questions are available in Table 11 of the results section.

Data Analyses

Statistical analysis was completed with IBM SPSS 25 software (IBM Corporation, Armonk, NY). The SAM instrument was used to objectively rate the suitability of health information for older adults with AMD. A total suitability score was calculated for each PEM. Descriptive statistics were used to determine the mean difference in SAM suitability scores. Paired-samples *t*-tests were used to determine whether differences in readability (grade level) and CIRF scores (comprehensibility) between the original and simplified PEMs were statistically significant. A value of $p < .05$ was used to determine significance for this study. Data was inspected for outliers and assumptions of normality.

Thematic analysis of interview transcripts followed the steps of the Framework Method (Ritchie & Lewis, 2003). Audio recordings of interviews were transcribed verbatim. The primary researcher identified common themes by comparing significant statements from as many perspectives as possible. The Framework Method is not aligned with any specific theoretical approach; therefore, it can be adapted for use with many qualitative approaches that aim to generate themes (Gale, Health, Cameron, Rashid & Redwood, 2013). The primary researcher coded themes independently. To increase dependability of results, a mixed methods design was applied to combine quantitative and qualitative research methods. Prior to data collection, the researcher objectively rated the suitability of the original and simplified PEMs with the SAM instrument. During the home visit, the researcher administered the CIRF form to measure comprehensibility of each PEM while simultaneously conducting semi-structured interviews. Through data-source triangulation, the researcher was able to collect multiple forms of data to gain a more complete understanding of the differences between the readability and suitability of the PEMs, and increase understanding of participants' perceptions of comprehensibility.

Results

Twelve participants met the inclusion criteria for this study (Table 8). Participants ranged in age from 67 to 93 years with a mean age of 83. Four participants were men and eight were women. One participant was Hispanic and 11 were non-Hispanic white. English was the primary language spoken by all participants. Education level ranged from Grade 5 to a Master's degree, with the majority (83%) of participants having a high school diploma. Visual acuity ranged from 20/70 to 20/800 with a mean acuity of 20/350. Half (50%) of participants used a hand-held magnifier, and 33% used a closed-circuit television (CCTV) to read. Based on the scores of the REALM-SF, 58% of participants scored in the high school reading level (e.g., should be able to read most patient education materials), and 42% scored in the seventh to eighth grade reading level (e.g., will struggle with most patient education materials).

Table 8
Participant Characteristics

ID #	Age	Gender	Race/ Ethnicity	Education Level	Visual Acuity	Severity Category	Optical Device	REALM-SF Score
1	76	Male	White	Grade 12	20/250	Severe	Bioptic Lenses	7 (high school)
2	88	Female	White	1-year college	20/800	Profound	CCTV	5 (grade 7-8)
3	75	Female	Hispanic	Grade 5	20/250	Severe	Hand-held magnifier	7 (high school)
4	67	Female	White	1-year college	20/700	Profound	Glasses	4 (grade 7-8)
5	75	Female	White	Grade 12	20/70	Moderate	Hand-held magnifier	7 (high school)
6	82	Male	White	Bachelor's degree	20/150	Moderate	CCTV	4 (grade 7-8)
7	87	Female	White	Grade 12	20/100	Moderate	Hand-held magnifier	6 (grade 7-8)
8	93	Female	White	2-years college	20/400	Severe	CCTV	7 (high school)
9	91	Female	White	Grade 12	20/700	Profound	Glasses; CCTV	7 (high school)
10	92	Male	White	Master's degree	20/250	Severe	Hand-held magnifier	7 (high school)
11	87	Male	White	Grade 10	20/500	Profound	Hand-held magnifier	7 (high school)
12	85	Female	White	Grade 12	20/80	Moderate	Hand-held magnifier	6 (grade 7-8)

After the original PEM was simplified, the total word count was reduced from 601 to 191, a decrease of 69%. A paired-samples *t*-test determined whether differences for readability levels between the original and simplified PEM were statistically significant. Data are mean ± standard deviation, unless otherwise stated. Data analyses revealed a decrease in mean readability (i.e., grade level) between the original PEM (12.42 ± .96) and simplified PEM (6.50 ± 1.78) across four readability metrics. The simplified PEM elicited a statistically significant decrease of 5.9 (95% CI 4.18 to 7.67) grade levels from the original. The simplified PEM also produced a statistically significant decrease in readability level as compared to the original, $t(3) = 10.84$, $p < .002$. Differences between the original and simplified PEMs are presented in Table 9.

Table 9

Word Count, SAM Score and Mean Readability Levels for Original and Simplified PEMs

Word Count		**SAM Score**		**SMOG**		**GFI**		**FKGL**		**FRY**	
O	**S**	**O**	**S**	**O**	**S**	**O**	**S**	**O**	**S**	**O**	**S**
601	191	20%	82%	10.9	5.7	15	7.6	11.8	5.7	12	7

Note. "O" = original PEM; *"S"* = simplified PEM
SAM = Suitability of Materials Instrument; *SMOG* = Simple Measure of Gobbledygook;
GFI = Gunning Fog Index; *FKGL* = Flesch-Kincaid Grade Level; *FRY* = Fry Readability Formula

The Consumer Information Rating Form (CIRF) was administered to assess participant perceptions of comprehensibility (i.e., design quality and usefulness) of the original and simplified PEMs (Table 10). Paired-samples *t*-tests were used to determine whether any differences in CIRF scores were statistically significant. Data analysis revealed an increase in comprehensibility between the original PEM (33.92 ± 5.23) and simplified PEM (53.00 ± 3.0). The simplified PEM elicited a statistically significant increase of 19.08 (95% CI 15.04 to 23.10) in CIRF scores when compared to the original. The simplified PEM also elicited a statistically significant improvement in comprehensibility based on SAM score as compared to the original

PEM, $t(12) = 10.32$, $p < .001$. The original PEM suitability score (20%), fell into the "not suitable material" category; whereas, the simplified PEM suitability score (82%), fell into the "superior" category.

Table 10

Mean CIRF Scores for Original and Simplified PEMs

Test Item	Consumer Information Rating Form (CIRF) Question	Original PEM	Simplified PEM
1.	How easy or hard is it to read the information?	2.8	4.5
2.	How easy or hard is it to understand the information?	2.9	4.6
3.	How easy or hard is it to remember the information?	2.6	3.8
4.	How easy or hard is it to find important information?	2.7	4.2
5.	How likely is it you would read the handout?	2.4	4.8
6.	How likely is it you would use the information?	2.2	4.8
7.	How likely is it you would keep the handout?	2.5	4.7
8.	How organized is the handout?	3.4	4.4
9.	How attractive is the handout?	3.0	4.3
10.	How is the text size?	2.4	4.3
11.	How is the tone of the handout?	3.5	4.3
12.	How helpful is the handout?	3.5	4.3
13.	How is the spacing between lines?	2.9	4.4

Semi-structured interviews were conducted to gather additional input from study participants. The interview questions, resulting themes and supporting quotes are summarized in Table 11. Over half (58%) of participants stated their health care providers did not provide them with written PEMs. Those who did receive PEMs (25%) reported they could not read them because the text was too small. When comparing the original and simplified PEMs, the majority of participants stated the simplified version was easier to read (75%), understand (83%), locate information (92%) and remember information (92%).

Qualitative data analysis also revealed themes related to reading challenges, optical devices and patient-provider interactions. The majority of participants expressed frustration over the time and energy it takes to decode written text into words, and how this makes it difficult to remember what was just read. Over 50% of participants stated PEM's containing intricate graphics and long words made their optical devices less effective. Finally, approximately 50% of participants in this study expressed concern that their doctors did not fully understand what it was like to live with low vision.

Table 11

Interview Questions, Themes and Supporting Quotes

Question	Response (*n* = 12), *n* (%)
Personal Preferences	
Do your health care providers offer you written handouts?	"Yes" (*n* = 3) (25%) "Only my low vision eye doctor does" (*n* = 2) (17%) "No" (*n* = 7) (58%)
Do you read them? If not, why?	"Yes" (*n* = 5) (42%) "No, my doctor does not provide them" (*n* = 7) (58%)
Is there anything you do not like about these handouts?	"No, the print is too small" (*n* = 3) (25%) "No contrast" (*n* = 1) (8%) "Difficult words and medical jargon" (*n* = 1) (8%) "My doctor does not provide them" (*n* = 7) (58%)
Differences in Quality: *Was there a difference in your ability to read the original and simplified handouts?*	Font on the simplified handout was easier to read (*n* = 9) (75%) Simplified handout had more information (*n* = 1) (8%) Font was too small on original handout (*n* = 1) (8%) Unable to interpret graphic on original handout (*n* = 1) (8%)
Was there a difference in your ability to understand information between the two handouts?	Simplified handout was easier to understand (*n* = 10) (83%) None (*n* = 2) (17%)
Was there a difference in your ability to locate information between the two handouts?	Simplified handout was easier to locate information (*n* = 11) (92%) No (*n* = 1) (8%)

Table 11—continued

Was there a difference in your ability to remember information between the two handouts?	Simplified handout was easier to remember (*n* = 11) (92%) No (*n* = 1) (8%)
Question	**Response**
Themes	**Supporting Quotes**
Challenges	"Reading is challenging with AMD because it takes a long time and you have to remember what you've read before. It's fatiguing." "You should highlight the main points in the first paragraph to help me decide if I want to read the rest." "It's very difficult to read. By the time I read one word, I forget it when I read the next." "I keep forgetting what I have read because I am concentrating on decoding the words." "It's getting difficult to read. I can see the beginning and end of a word, but that's it." "I don't read as much as I used to. It takes me longer so I am picky about what I read."
Optical Devices	"Longer words are harder to read with a CCTV." "Standard size print is blurry, even with my magnifying glass. I would not read it. I would just throw it out." "Use line drawings instead of photos to make graphics more visible on my CCTV." "The size of paper makes a difference with a CCTV. Larger paper is tiring because you have to constantly move it left to right."
Patient-Provider Interactions	"The doctor does not understand my vision loss. Even some eye doctors do not seem to understand. It is hard for people without vision loss to understand what it is like to live with low vision." "Doctors should be more generous with their knowledge. This handout taught me about Charles Bonnet Syndrome. I want to know more about it. If I had not read it, I would not know." "At this point, I would prefer to have my health information provided orally instead of written." "I don't think many doctors understand this condition and how it changes your life." "Most doctors are not very understanding of what it's like to live with low vision. They don't understand that I can see some things, but not all things." "It is important to get as much information as you can from your doctor in an accessible format."

Discussion

For the participants in this study, there was a statistically significant improvement in the readability, suitability and comprehensibility of a simplified PEM when compared to its original format. Furthermore, participant perceptions on design characteristics indicated the simplified PEM was easier to read, understand and remember information. This is the first study to assess readability, suitability and comprehensibility of PEMs designed for older adults with AMD. Similarities exist between the findings of this study and existing research on the health information needs of people with visual impairment. Comparable to Williams et al. (2016), this study applied the recommended guidelines for writing easy-to-understand PEMs to written health information and solicited feedback from people with the condition of interest. In both studies, the readability and suitability of simplified PEMs was significantly improved. Based on participant feedback in this study, the simplified PEM made it easier to read, understand and remember information. This finding has implications for promoting health literacy in older adults with AMD. In general, patients who are able to access, process and understand written health information will be more likely to apply it to everyday life.

This study followed recommendations for future research found in existing literature which suggests pre-testing PEMs with the intended target population to improve readability and enhance comprehension (Badarudeen & Sabharwal, 2010; John et al., 2015; Rudd, n.d; Williams et al., 2016). Furthermore, this study embraced the notion that actively involving patients in the research process is a valuable tool. Participant feedback on design characteristics was helpful when making comparisons between the original and simplified PEMs. In addition, themes derived from the interviews provided insight into underlying challenges related to reading, use of optical devices and patient-provider interactions. These themes have important implications for helping health care providers understand the impact of visual impairment on functional health literacy.

Research has shown PEMs are consistently written at a level too complex for the average American to understand (Badarudeen & Sabharwal, 2010; Davis et al., 1990; Doak & Doak, 2008; Kirsch et al., 1993; Williams et al., 2016). Evidence-based guidelines for writing easy-to-understand health information have been published by national organizations (Doak & Doak, 2008; NIH, 2014; Rudd, n.d.; Weiss, 2007). It is important to note that most health literacy guidelines do not consider how the physical properties of text (e.g., font style and size, contrast, spacing) could negatively influence reading performance and comprehension in people with visual impairment. Older adults with AMD are at even greater risk for low health literacy (U.S. Government Accountability Office, 2006). The APH Guidelines for Print Document Design were created so individuals with visual impairments could more easily access and understand written text (Kitchel, 2011). Applying the guidelines for low health literacy and low vision will help health care providers promote health literacy in this unique population.

Strengths and Limitations

This study has strengths and limitations. First, this study addressed specific gaps in the literature, including addressing the need for population-specific tools and strategies and treating older adults with AMD as a unique group within the larger umbrella of individuals with low vision. In addition, this study actively involved people with visual impairment in the research process. Conducting semi-structured interviews allowed the researcher to gather valuable feedback that can be applied to future research. The results of this study were limited to a small sample of older adults with AMD in one geographic location, an urban college town. The researcher did not collect information regarding the year each participant was diagnosed with AMD, or how long they have been using optical devices to access written information. Another limitation is the lack of randomization in administration order of the PEMs presented to participants. Due to data collection taking place during a single home visit, participants were exposed to information on Charles Bonnet Syndrome via the original PEM prior to receiving the simplified version. This may have contributed to participant perceptions that the simplified PEM was easier to read. Although the majority of participants stated the simplified PEM was easier to understand than the original, the researcher did not objectively assess reading comprehension during this study. In addition, the qualitative interview data was analyzed only by the primary researcher. These limitations may impact the reliability of results to the greater population of older adults with AMD located in different areas of the country.

Future Directions

Due to rapid growth of the aging population, the prevalence of AMD is expected to rise over the next 20 years (CDC, 2015). Additional research is needed to determine the optimal design and presentation of educational materials provided to older adults with AMD. Reading comprehension was not quantified in this study. Therefore, future research should explore how the simplification process may influence reading comprehension in this population. Furthermore, additional studies need to address the unique health literacy needs of older adults with AMD under the umbrella of low vision. It is important for researchers to continue actively involving people with visual impairment in the research process. Results of this study show older adults with low health literacy and AMD have unique health information needs. A variety of evidence-based guidelines, accommodations and strategies are readily available to guide the PEM simplification process. The guidelines utilized in this study for patients with low health literacy and low vision have been compiled into a checklist for convenience (Appendix F). Health care providers should apply these guidelines to PEMs designed for older adults with AMD to ensure they are readable, suitable and understandable. Additional research is needed to ensure condition-specific PEMs become the standard of care in the future.

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CHAPTER V

CONCLUSION

The purpose of this three-paper dissertation was to explore functional health literacy in older adults with age-related macular degeneration (AMD). Older adults with AMD face unique challenges that limit participation in the self-management of chronic health conditions (O'Day, Killeen, & Lezzoni, 2004). Several gaps in the literature surround treating people with AMD as a distinctive group of individuals under the larger umbrella of people with low vision (Beverly, Bath & Booth, 2004). For example, one major gap in the literature is how the varying severities of visual impairment may impact functional health literacy in older adults with AMD. In addition, further research is needed to examine the impact of design characteristics on comprehension of PEMs, and to identify the best way to simplify written health information to promote health literacy and comprehension (Beverly et al., 2004; Harrison & Lazard, 2015). Lack of existing research evidence creates demand for additional studies to help health care providers understand the unique health information needs of older adults with AMD.

Study One

The first study explored differences in functional health literacy levels of 15 older adults with AMD across three severity categories of visual impairment as defined by Dandona and Dandona (2006) based on visual acuity: moderate impairment = 20/70 to 20/160; severe impairment = 20/200 to 20/400; and profound impairment = 20/500 to 20/2000. The Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian &

Nurss, 1999) was used to measure health literacy. Scores were recorded for standard (seven minute) and unlimited time conditions. Differences between severity categories were not statistically significant; however, several findings still hold clinical significance. In general, visual impairment may be an underrecognized barrier to self-management of chronic health conditions. Selection of appropriate optical devices is an important factor of reading performance across all severity categories. Existing health literacy measures are limited for people with visual impairment. Finally, time constraints may be a factor during assessment of health literacy in older adults with AMD.

One could assume participants in the profound category would obtain the lowest mean S-TOFHLA score. This was not the case. Participants in the severe category obtained the lowest mean score for both time conditions. Furthermore, a drastic improvement in test scores was observed when the standard time constraint was removed. This finding is consistent with existing research by Warren, DeCarlo and Dreer (2016) who investigated whether older adults with AMD demonstrated lower health literacy than older adults without low vision. These findings suggest time may be an underrecognized factor of reading performance. Future research should explore the efficacy of timed tests, and potential barriers and facilitators to reading performance in this population. In addition, the optical devices used to access written test materials may have influenced test performance. In the severe category, the hand-held magnifier’s smaller viewing area may have limited performance. The ability of a closed circuit television (CCTV) to make text bigger and bolder may have enhanced the performance of participants in the profound category of impairment. Prescribing CCTVs to patients before they reach the profound category of impairment may be beneficial. Additional research is needed to explore the use of optical devices for older adults with varying degrees of visual impairment caused by AMD.

Study Two

Study two aimed to determine the general readability (i.e., grade level) and suitability (i.e., appropriateness) of 100 online PEMs written by 16 professional organizations and institutions supplying patient education on AMD. The Flesch-Kincaid Grade Level (FKGL) formula (Kincaid, 1975) was utilized to calculate readability in the sample. The Suitability of Materials (SAM) instrument (Doak, Doak & Root, 1996) was used to objectively measure the suitability of PEMs for the population of interest. The majority (94%) of PEMs included in this study were written above the recommended sixth grade reading level (NIH, 2017; Weiss, 2007). Only six of the 100 PEMs (6%) achieved the recommended readability level and suitability score. These findings are consistent with the results of existing studies that have explored readability and suitability of websites providing PEMs designed for patients with various ophthalmic conditions (John, John, Hansberry Prashant & Suqin, 2015; Williams, Muir & Rosdahl, 2016).

Although the results show the mean readability and suitability of the PEMs in this study scored higher than the recommended guidelines, additional factors should be considered. For example, the words “age-related macular degeneration” are considered difficult to read simply based on the number of syllables. These words appeared frequently in PEMs for older adults with AMD and cannot be replaced. Furthermore, topics related to treatment and research are more likely to have higher readability levels and lower suitability scores due to medical jargon that is unavoidable. With increasing dependence on the internet for health information, health care providers must take initiative to provide PEMs their patients can access, process and understand. Health care providers who utilize the guidelines for developing PEMs for people with low health literacy and low vision will be better equipped to address the unique educational needs of older adults with AMD. For example, ensuring readability is below the sixth grade level, replacing complex words with plain language and increasing font size to 18 point or larger.

Study Three

The third study explored differences in readability, suitability and comprehensibility of one PEM designed for older adults with AMD in both original and simplified formats. The original PEM was simplified based on evidence-based guidelines for rewriting materials for people with low health literacy (Rudd, n.d.), and the American Printing House Guidelines for Print Document Design for people with low vision (Kitchel, 2011). This study also collected participant perceptions of the design characteristics of both PEMs. Readability was calculated with an online readability calculator (Online Utility, n.d.) embedded with the Simple Measure of Gobbledygook (SMOG) (McLaughlin, 1969), Gunning Fog Index (GFI) (Gunning, 1952) and Flesch-Kincaid Grade Level (FKGL) (Kincaid, 1975). The Suitability Assessment of Materials (SAM) instrument (Doak et al., 1996) objectively rated the appropriateness of the original and simplified PEMs. Finally, the Consumer Information Rating Form (CIRF) (Koo, Krass & Aslani, 2007) was administered to measure participant perceptions of comprehensibility including design quality and usefulness of the original and simplified PEMs. The original PEM was administered first, followed by the simplified PEM. Finally, semi-structured interviews were conducted to gather additional insight on the quality of both PEMs.

The simplified PEM elicited statistically significant improvements in readability, suitability and comprehensibility as compared to the original PEM. The simplified PEM was described by the majority of participants as easier to read, understand, locate information and remember. This finding may suggest patients who are able to access, process and understand written health information with simple accommodations will be more likely to apply it to everyday life. Furthermore, simple accommodations may improve processing and understanding. Collecting feedback on the design characteristics from people with AMD was helpful for making comparisons between the original and simplified PEMs. Additional research is needed to determine the optimal design of PEMs for older adults with AMD. This information is needed to ensure condition-specific PEMs become the standard of care in the future.

Themes derived from semi-structured interviews acknowledged challenges related to reading, use of optical devices to access written text and patient-provider interactions. The majority of participants indicated their health care providers did not provide PEMs at the point of care. Over half of the participants in this study believed their doctors did not fully understand what it was like to live with low vision. This feedback aligns with existing research which suggests the impact of vision loss on health outcomes is often underestimated by health care providers (Chaudry, Brown & Brown, 2015; Zhang, Liang, Chen, Musch, Zhang & Wang, 2015). These findings have important implications for improving patient and provider interactions.

Strengths and Limitations

One of the strengths of this dissertation is how it addressed several gaps in the literature. For example, study one explored differences in functional health literacy levels of older adults with AMD as a unique group under the larger umbrella of low vision. Study two is the first to focus on readability and suitability of online PEMs designed specifically for older adults with AMD. In study three, the simplified PEMs was pre-tested with the intended target population to improve readability and enhance comprehension. In addition, conducting semi-structured interviews to collect feedback actively involved study participants in the research process.

One limitation of this dissertation is the small sample size of participants that were included in each study. Such small samples limit the overall generalizability of results to the larger population of adults with AMD. This may have improved the readability and visibility of PEMs even further. The results are restricted to the experiences of a small group of older adults with AMD from the same geographic location. Such a small sample limits the overall generalizability of results to the larger population of older adults with low vision. Future studies could be strengthened by including a much larger sample of participants to ensure sufficient power for statistical analysis.

Conclusion

This three-paper dissertation aims to inform clinical practice about several factors that may influence functional health literacy in older adults, including those with AMD. Several audiences including researchers, policymakers and health care providers working with individuals with visual impairments (e.g., ophthalmologists, optometrists, occupational therapists, orientation and mobility specialists and certified low vision therapists) will benefit from the information gleaned from these studies. In general, health care providers who work with older adults that have AMD. Most importantly, older adults with AMD will benefit from health care providers and specialists who understand their challenges and educational needs as related to PEMs. The findings gleaned from these studies have important implications for increased understanding of the impact of visual impairment on functional health literacy. This includes the disconnect between the readability of written health information and the average reading ability of this population. A variety of evidence-based guidelines and strategies are readily available to guide the PEM simplification process for patients with low health literacy and low vision (Kitchel, 2011; NIH, 2014; NIH 2018). Although additional research is needed to develop a PEM standard of care, health care providers could begin applying the established guidelines to develop readable, suitable and understandable PEMs for specific patient populations.

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Appendix A

HSIRB Approval Letter 2018

WESTERN MICHIGAN UNIVERSITY

Institutional Review Board
FWA00007042
IRB00000254

Date: February 22, 2018

To: Linda Shuster, Principal Investigator
Jennifer Fortuna, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number 18-02-11

This letter will serve as confirmation that your research project titled "Health Literacy in Older Adults with Varying Degrees of Visual Impairment" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes in this project (e.g., ***you must request a post approval change to enroll subjects beyond the number stated in your application under "Number of subjects you want to complete the study***)." Failure to obtain approval for changes will result in a protocol deviation. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

Reapproval of the project is required if it extends beyond the termination date stated below.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: **February 21, 2019**

Office of the Vice President for Research
Research Compliance Office
1903 W. Michigan Ave., Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276
WEBSITE: wmich.edu/research/compliance/hsirb

CAMPUS SITE: 251 W. Walwood Hall

Appendix B

HSIRB Approval Letter 2019

WESTERN MICHIGAN UNIVERSITY

Institutional Review Board
FWA00007042
IRB00000254

Date: May 7, 2019

To: Linda Shuster, Principal Investigator
Jennifer Fortuna, Student Investigator for Dissertation

From: Amy Naugle, Ph.D., Chair

Re: Approval not needed for IRB Project Number 19-05-08

This letter will serve as confirmation that your project titled "Determining Readability and Suitability of Online Patient Education Materials for Older Adults with AMD" has been reviewed by the Western Michigan University Institutional Review Board (IRB). Based on that review, the IRB has determined that approval is not required for you to conduct this project because you are not collecting personal identifiable (private) information about individuals and your scope of work does not meet the Federal definition of human subject.

45 CFR 46.102 (f) Human Subject

(f) *Human subject* means a living individual **about whom** an investigator (whether professional or student) conducting research obtains:

(1) Data through intervention or interaction with the individual, or
(2) Identifiable private information.

Intervention includes both physical procedures by which data are gathered (for example, venipuncture) and manipulations of the subject or the subject's environment that are performed for research purposes. *Interaction* includes communication or interpersonal contact between investigator and subject. *Private information* includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record). Private information must be individually identifiable (i.e., the identity of the subject is or may readily be ascertained by the investigator or associated with the information) in order for obtaining the information to constitute research involving human subjects.

"**About whom**" – a human subject research project requires the data received from the living individual to be about the person.

Thank you for your concerns about protecting the rights and welfare of human subjects.
A copy of your protocol and a copy of this letter will be maintained in the IRB files.

Office of the Vice President for Research
Research Compliance Office
1903 W. Michigan Ave., Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276
WEBSITE: wmich.edu/research/compliance/hsirb

CAMPUS SITE: Room 251 W. Walwood Hall

Appendix C

HSIRB Approval Letter 2019

WESTERN MICHIGAN UNIVERSITY
Institutional Review Board
FWA00007042
IRB00000254

Date: June 3, 2019

To: Linda Shuster, Principal Investigator
Jennifer Fortuna, Student Investigator for Dissertation

From: Amy Naugle, Ph.D., Chair

Re: IRB Project Number 19-05-25

This letter will serve as confirmation that your research project titled "Assessing Readability of Simplified Patient Education Materials for Older Adults with AMD" has been **approved** under the **expedited** category of review by the Western Michigan University Institutional Review Board (IRB). The conditions and duration of this approval are specified in the policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes to this project (e.g., ***add an investigator, increase number of subjects beyond the number stated in your application, etc.***). Failure to obtain approval for changes will result in a protocol deviation.

In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the IRB for consultation.

The Board wishes you success in the pursuit of your research goals.

A status report is required on or prior to (no more than 30 days) June 2, 2020 and each year thereafter until closing of the study.

When this study closes, submit the required Final Report found at https://wmich.edu/research/forms.

Note: All research data must be kept in a secure location on the WMU campus for at least three (3) years after the study closes.

Office of the Vice President for Research
Research Compliance Office
1903 W. Michigan Ave., Kalamazoo, MI 49008-5456
PHONE: (269) 387-8293 FAX: (269) 387-8276
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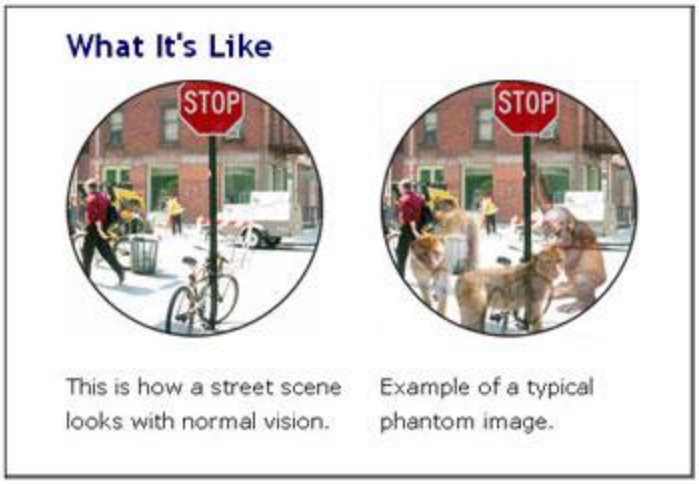
CAMPUS SITE: Room 251 W. Walwood Hall

Appendix D

Original Patient Education Material (PEM)

Charles Bonnet Syndrome

People with Charles Bonnet syndrome can vouch for the cliché that things aren't always as they seem. This syndrome, named for the eighteenth-century philosopher who first described it, is characterized by visual hallucinations. People may see anything from abstract patterns to birds and babies and white sandy beaches. These hallucinations tend to occur during down time--say, while getting a haircut or waiting in line at the dollar store.



The folks who perceive these visions know they're just mirages, of sorts. That is, the images are illusions, not delusions. The difference is that a person with delusions is convinced that what she sees is real. Patients with Charles Bonnet syndrome may initially second-guess themselves but they ultimately accept that their perceptions have no substance.

Cause

The cause of this disorder is thought to be a misfire in the brain similar to the neurological mixup that occurs in patients with phantom limb syndrome. As vision wanes, the brain continues to interpret visual imagery in the absence of corresponding visual input, just as it sometimes continues to process pain signals from a limb that's no longer there.

Symptoms

Charles Bonnet syndrome has one principal symptom: the periodic occurrence of hallucinatory visions. Sometimes the hallucinations are very animated and detailed.

A person who has such visual illusions may wonder if he's becoming mentally ill or developing senile dementia. He may hesitate to tell his doctors or loved ones about the problem for fear they'll draw that very conclusion.

Risk factors

Roughly one third of patients with low vision develop Charles Bonnet syndrome, including those with **age-related macular degeneration**, **cataracts**, **diabetic retinopathy**, and other eye disorders. The hallucinations are more likely to occur when the person is awake, alone, and in dim light, or when he or she is physically inactive or lacks distractions, such as television.

Turning on an extra lamp or two, staying physically and mentally occupied, spending time with family or friends, and participating in social activities can reduce the frequency and vividness of the hallucinations. Each patient must learn what works for him or her. A positive attitude is the key.

Diagnosis

Your eye care professional is the best healthcare professional to diagnose this condition. In addition, your eye care provider will already be aware of any underlying vision disorders you have that may be associated with the syndrome. A thorough eye examination to rule out additional problems and a few targeted questions about your symptoms are usually all that's needed to diagnose the syndrome. Sometimes consultation with a neurologist or other specialist is necessary to rule out any serious disorders that may mimic Charles Bonnet syndrome, such as stroke and Parkinson's disease. The diagnosis may be complicated by the fact that many patients have multiple medical problems, such as diabetes and heart disease, for which they take several medications.

Treatment

Fortunately, the saying "This, too, shall pass" is also true for those with Charles Bonnet syndrome. After a year or perhaps 18 months, the brain seems to adjust to the person's vision loss, and the hallucinations begin to recede.

In the meantime, of course, the underlying visual impairment should be treated or monitored. Idle time should be kept to a minimum. If the person is found to be depressed, therapy or pharmacologic treatment may be in order. Antiseizure medications have been shown to calm the hallucinations in some patients, and antianxiety agents can be used in those who find the visions upsetting. For most patients, though, just knowing that they aren't becoming mentally ill and that the symptoms will eventually subside is all the treatment they need.

Appendix E

Simplified Patient Education Material (PEM)

Charles Bonnet Syndrome

For people with Charles Bonnet syndrome, things are not always as they seem. This condition causes hallucinations in people with vision loss.

What Is It Like?

Charles Bonnet syndrome causes detailed visual images such as patterns, people and animals. People with this condition know these images are not real.

Cause

Hallucinations appear when the brain tries to process images based on decreased visual input.

Risk Factors

Around 30% of people with low vision develop this condition.

Symptoms

Charles Bonnet syndrome causes visual hallucinations. The images tend to appear in dim light and during down time when the brain and body are not as active.

Diagnosis

Your eye doctor is the best person to diagnose this condition. You will need an eye exam and to answer some questions. You may not feel like talking about your symptoms. Your eye doctor is already aware you are at risk for this condition.

Treatment

After 12 to 18 months, the brain will adjust to vision loss. Your symptoms should lessen with time. A positive attitude is key.

In the meantime, there is something you can do:

- Visit your eye doctor on a regular basis.
- Improve lighting. Turn on a lamp or two.
- Avoid down time. Keep your mind and body active.

Appendix F

Checklist for Patient Education Materials for Low Health Literacy and Low Vision

Checklist for Patient Education Materials for Low Health Literacy and Low Vision

This checklist will assist with rewriting PEMs so they are easier to access, process and understand.

	Guideline	Description/Suggestion	✓
1	Calculate the readability (grade level) of the original and simplified PEMs.	PEMs should be written at, or below 5th grade level. The *Online Utility* readability calculator is free online. Use the Flesch Kincaid Grade Level (FKGL) formula. See link below.	
2	Assess the suitability of the original and simplified PEMs.	Use the Suitability Assessment of Materials (SAM) instrument to rate the appropriateness of both PEMs. See link below.	
3	Highlight all long words, complex words and phrases.	Replace long words and complex words and phrases with short words and phrases that use plain language.	
4	Highlight all long sentences.	Shorten sentences that exceed 3 lines, contain more than 15 words, or 62 characters per line (standard print), or 39 characters per line (large print).	
5	Highlight all medical jargon.	Replace medical terminology with plain language.	
6	Highlight all sentences using passive voice.	Use active voice to clarify who is performing the action. Make the person the subject of the sentence.	
7	Check that information is up-to-date.	Make sure all information contained in the PEM is current (published less than 10 years ago).	
8	Make sure the purpose of the PEM is clear.	Use plain language. Focus on what the patient wants to know. State the purpose in the title and/or introduction.	
9	Use a readable font.	Use a wide san-serif font (such as APHont, Antique Olive, Tahoma, Verdana or Helvetica) size 18 point or larger.	
10	Use white space to make the page more readable.	Indent 1" at margins; justified left margin; unjustified (ragged) right margin; spacing 1.25 between lines; double space between paragraphs; block paragraph style with no idents.	
11	Use headings and sub-headings.	Include headings and subheadings to serve as navigational aids and make the document easier to follow.	
12	Avoid all caps or all bold for continuous text.	An all caps or bold message is received as a shouted message and is difficult to read due to the crowding effect.	
13	Avoid italics.	Italics are more difficult to read than regular typefaces. **Bold** or <u>underscore</u> is preferred to italics.	
14	Use lists to improve sentence structure.	Break down lists into groups of similar items to display points better. Make sure lists fall at the end of a sentence.	
15	Use bullets for lists of 3+ items.	Bullets make lists more readable and memorable.	
16	Print on light-colored paper with plain backgrounds.	Light-colored paper (off white, cream, ivory, yellow or pink) and plain backgrounds are best for black text.	
17	Maps, charts, graphs and graphics should maintain the same standards as text for readability.	Keep only graphics needed to understand the text. Text should not be laid over and under graphic content. Charts and graphs should be simple and have good contrast. Simple black and white line drawings are preferred over grayscale.	

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