Exploring Associations Between Health Literacy and Visual Impairment in Older Adults with Age-Related Macular Degeneration (AMD)

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Abstract

Background: Age-related macular degeneration (AMD) is the leading cause of vision loss for Americans 65 years of age and older. Central vision loss makes reading challenging. Health literacy assessments that measure skills in basic literacy are often too demanding for people with AMD. The impact of central vision loss on functional health literacy has yet to be explored in the literature.

Methods: A between-subjects study design was employed to explore associations between functional health literacy and visual acuity in older adults with AMD. The Short Test of Functional Health Literacy in Adults (S-TOFHLA) was used to measure health literacy in participants across three severity categories (moderate, severe, profound) of visual impairment. Scores were recorded for timed (7 min) and untimed testing conditions for comparison.

Results: For the timed condition, 73% of the participants had inadequate health literacy and 27% had marginal health literacy. For the untimed condition, 100% of the participants had adequate health literacy. The severe category had the lowest mean S-TOFHLA score for both time conditions. This finding was unanticipated considering the strong correlation between visual acuity and reading performance.

Conclusion: All of the participants exhibited a drastic improvement in test scores when the time constraint was removed. Time may be an underrecognized factor of reading performance in older adults with AMD.

Keywords

Cover Page Footnote

Credentials Display

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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 65 years of age and older (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, 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 et al., 2004). Functional health literacy is a key component of the self-management process (Warren, 2013).

The Institute of Medicine 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 (2004). Health literacy is assessed by measuring skills in basic literacy, such as numeracy and comprehension. Assessments commonly used 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 (the 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 et al., 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 et al., 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 often are too demanding for people with low vision (Legge, 2007).

Low health literacy is a significant problem in the US (Doak & Doak, 2008). The 2003 National Assessment of Adult Literacy survey (Kutner et al., 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 participate fully in self-management of health) (Kutner et al., 2006). The survey also found adults 65 years of age or older are at a greater risk of low health literacy. These findings correlate with the Agency for Health Care Research and Quality, 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, 2011; Eltorai et al., 2014). The economic burden of low health literacy on the U.S. economy is estimated between $106 billion and $238 billion dollars annually (Vernon et al., 2007).

Health care providers have historically relied on written handouts to deliver patient education. The Center for Studying Health System Change 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 et al., 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 using 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 et al., 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 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 in West Michigan. Each participant was assigned to one severity category of visual impairment based on distance visual acuity. The results from a test of functional health literacy were compared to examine the differences between severity categories.

Participants

This study was approved by the Western Michigan University Institutional Review Board. The participants met the following inclusion criteria: (a) 65 years of age or older, (b) community dwelling, (c) own legal representative, (d) earned high school diploma, (e) English speaking, (f) diagnosis of AMD, (g) reading on a regular basis, (h) normal cognition, and (i) visual acuity between 20/60 and 20/1000 with best correction. The 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 (a) major eye disease or neurological condition affecting cognition or reading ability (e.g., cataracts, dyslexia, traumatic brain injury) and (b) uncorrected major hearing loss.

Procedures and Instruments

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. The 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 et al., 2006) and the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975) during the home visit. The participants who met all inclusion criteria were administered the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker et al., 1999). A description of each assessment, including criteria for scoring and interpretation, is provided below.

RBI

The RBI is intended to identify regular reading habits, such as the type of materials read, the amount of time spent reading daily, and the decline in reading performance in recent months. The RBI is administered orally and test items are scored on a 5-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.

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. The participants in this study were permitted up to three errors to indicate normal to very mild cognitive impairment. Warren et al. (2016) applied similar criteria to screen cognition in older adult participants with low vision.

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, 1952). According to Baker et al. (1999), the resulting S-TOFHLA scores are interpreted as functional health literacy levels. Scores between 0 and 16 points indicate inadequate health literacy. Patients at this level should be unable to read and interpret health texts. Scores between 17 and 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 and 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 7 min. Scores were recorded for timed (7 min) and untimed testing conditions. The primary researcher recorded both time conditions for comparison based on a study by Warren et al. (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, 2016). 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 the study participants are displayed in Table 1. The participants' ages ranged from 67

to 96 years of age with an average age of 86 years of age. Educational attainment of the participants included 46% with a high school diploma, 13% with some college, 20% who had earned a 4-year degree, and 20% who possessed a graduate degree. The visual acuities of the participants ranged from 20/70 to 20/800. The participants were assigned to one severity category (moderate, severe, profound) of visual impairment based on visual acuity. Five of the participants were assigned to each severity category resulting in three equal groups.

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)

Note. S-TOFHLA timed condition = 7-min; Untimed condition = unlimited time.

S-TOFHLA scores and related health literacy levels varied greatly by time condition. For the standard (7 min) time condition, 73% of the participants had inadequate health literacy; whereas 27% had marginal health literacy. The results for the untimed condition found 100% of the 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%)

Note. S-TOFHLA timed condition = 7-min; Untimed condition = unlimited time.

The results of the ANOVA found no significant differences in S-TOFHLA scores between the 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)

Note. S-TOFHLA timed condition = 7-min; 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. The 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)

Note. *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), the 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, the participants used 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 of the 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. The participants in the severe category were observed to hold the paper and magnifier close to their face when reading a line of text. Several of the participants lost their place when attempting to return to the beginning of the next line. All of the 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, the 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 of the 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 the 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 et al., 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 the 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 the performance of the 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 backlit electronic reading devices as compared to other devices. Similar to the results of this study, Feng et al. (2017) 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

The results of this study are restricted to the experiences of 15 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 the generalizability of this study. Baseline data on the health literacy levels of the 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 of the participants created an unanticipated limitation. During analysis, it was realized that all of the 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 lower 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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