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Assessment of Modified Patient Education Materials for People with Age-Related Macular Degeneration

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Assessment of Modified Patient Education Materials for People with Age-Related Macular Degeneration

Abstract

Background: Existing research on health literacy identifies a disconnect between the readability of patient education materials (PEMs) and the reading abilities of American adults. For people with age-related macular degeneration (AMD), central vision loss creates an additional barrier to health literacy. This study explored how evidence-based guidelines for creating easy-to-understand written materials influenced the usability of PEMs in people with AMD.

Methods: Evidence-based guidelines were applied to modify one PEM. Standardized tools quantified differences in readability and suitability between the original and modified PEM. Twelve people with AMD rated the comprehensibility (design quality) and shared personal preferences during semi-structured interviews.

Results: The modified PEM showed statistically significant improvements in readability, suitability, and comprehensibility. Mean readability decreased 5.9 grade levels. Suitability increased from 20% (not suitable) to 82% (superior). Comprehensibility also improved significantly. The majority of the participants indicated the modified PEM made information easier to read (75%), understand (83%) and locate (92%). Qualitative analysis revealed themes related to reading challenges, optical devices, and patient-provider interactions.

Conclusion: Applying evidence-based guidelines for low health literacy and low vision created a significant improvement in the usability of written health information. Actively involving people with AMD in the research provided valuable insight. Additional research is warranted.

Comments

The authors report no potential conflicts of interest.

Keywords

health literacy, age-related macular degeneration, patient education materials, readability

Credentials Display

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Age-related macular degeneration (AMD) is a chronic eye condition that causes permanent vision loss in the central visual field. In the United States alone, an estimated 1.8 million people are affected by AMD (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 because of difficulty decoding, slower reading speeds, and the inability to maintain attention on text to integrate meaning (Legge, 2007). There is no cure for AMD; however, 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).

Functional health literacy is defined as one's capacity to access, 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 when reading health information. In the United States, low health literacy is a substantial problem among American adults (Doak & Doak, 2008). The results from the 2003 National Assessment of Adult Literacy (NAAL) survey found only 12% of American adults have health literacy skills proficient enough to fully participate in the self-management of their own health (Kutner et al., 2006). People 65 years of age and older had lower health literacy than younger adults. Older adults with visual impairment are at an even greater risk for low health literacy (Harrison et al., 2010; Kutner et al., 2006). Difficulty reading creates an additional barrier to health literacy in this population.

The Center for Studying Health System Change reports 75% of physicians provide written patient education materials (PEMs) at the point of service (Carrier, 2009). Unfortunately, the reading and comprehension skills of patient populations is often overlooked during the development of these materials. Readability is calculated with a formula that produces the grade level, or number of years of education needed, to comprehend text (Badarudeen & Sabbharwal, 2010). Existing research shows that the average American adult reads between the eighth- and ninth-grade level (Doak & Doak, 2008). In addition, the average Medicare recipient reads at, or below, the fifth-grade level (United States Government Accountability Office, 2006). Existing research also indicates the majority of PEMs are written at or above the 10th-grade reading level (Davis et al., 1990; Kirsch et al., 1993). Thus, a disconnect exists between the readability of PEMs and the average reading abilities of American adults.

Evidence-based guidelines for developing easy-to-understand written materials for people with low health literacy have been published by national organizations, including the American Medical Association (Weiss, 2007), the National Institutes of Health (2018), and the Harvard T.H. Chan School of Public Health (Rudd, n.d.). In general, the guidelines recommend writing with plain language at a reading level below the sixth grade. Warren (2013) provides a summary of accommodations and strategies to improve the readability and visibility of written health information for people with low vision. The suggested strategies were compiled in 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). According to the American Printing House for the Blind, characteristics of print (e.g., color, style, size, and typeface) impact the readability and usability of written text. Additional research is needed to determine the optimal design and presentation of PEMs for people with AMD.

Literature Review

Several studies have examined the readability of PEMs. A study by John et al. (2015) assessed the readability of more than 200 online ophthalmology PEMs from three national organizations. Not one PEM

met the recommended readability guideline for written materials below the sixth-grade reading level. The authors recommended assessing the readability of frequently used PEMs and rewriting them at a lower grade level. Edmunds et al. (2013) assessed the readability of 160 online PEMs from 60 national organizations providing information on 16 ophthalmic diagnoses, including AMD. Not one PEM had a readability score below the recommended sixth-grade reading level. Williams et al. (2016) applied guidelines for creating easy-to-understand written materials to 12 handouts designed for patients with glaucoma. Feedback solicited from the study participants with glaucoma found that modifying 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 recommended pre-testing PEMs with their intended target population and modifying the reading level of existing patient handouts to enhance comprehension. Harrison and Lazard (2015) advocated 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.

Gaps in the Literature

Gaps in the literature exist surrounding the health information needs of people with visual impairment. Previous research examining the readability of modified PEMs designed for people with visual impairment was not identified. A systematic review by Beverly et al. (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 to explore the disconnect between the readability of written health information designed for people with AMD and the average reading ability of this population.

Purpose

This study aims to answer the following research questions:

1. How do evidence-based guidelines for creating written materials for people with low health literacy and low vision influence usability of PEMs in people with AMD?
2. What are patient perceptions of a PEM that has been modified based on these guidelines?

To date, this is the first study to assess the benefits of modified PEMs for people with AMD.

Method

Design

This study employs a convergent mixed methods design (Creswell & Creswell, 2018) to assess and compare the usability of one PEM presented in its original and modified formats. Quantitative data on readability, suitability, and comprehensibility were collected with standardized instruments. Qualitative data on patient perceptions of design characteristics were captured during semi-structured interviews. Qualitative and quantitative findings were analyzed separately before merging them during mixed methods data analysis. The results were interpreted to compare the original and modified PEMs.

Participants

This study was approved by the Institutional Review Board at Western Michigan University. Informed consent was obtained from each participant prior to data collection. A convenience sample of participants was recruited from low vision rehabilitation clinics located in Grand Rapids and Kalamazoo, MI. To be included in this study, participants had to meet the following criteria: (a) 50 years of age or older, (b) physician documented primary diagnosis of AMD, (c) visual acuity between 20/60 and 20/1000 with best correction, (d) English speaking, (e) own legal representative, and (f) minimal risk for cognitive

impairment as determined by no more than three errors on the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). English speaking was selected as an inclusion criterion because the PEMs presented to the participants were written in the English language. Confirmation of diagnosis and visual acuity were provided by the referring low vision clinics. Visual acuity was assessed within the last 12 months. The participants were excluded from this study for: (a) inability to read written text, (b) any major eye disease or neurological condition affecting ability to read (e.g., dyslexia, traumatic brain injury), and (c) 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. The participants who met these criteria were contacted by the primary researcher to schedule a home visit. During the home visit, the SPMSQ (Pfeiffer, 1975) was administered to confirm the inclusion criterion of normal cognition. In addition, the Rapid Estimate of Adult Literacy in Medicine – Short Form (REALM-SF) (Arozullah et al., 2007) was used as a quick screen of health literacy levels. One PEM was modified based on evidence-based guidelines for creating written materials for people with low health literacy and low vision (Kitchel, 2011; Rudd, n.d.). The original and modified PEMs were assessed for readability, suitability, and comprehensibility. Quantitative data collection was followed by semi-structured interviews to gather insight into patient perceptions of design characteristics. A description of each procedure, including criteria for scoring and interpretation, is provided below.

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), is as follows: 0–2 errors indicates intact functioning, 3–4 errors indicates mild impairment, 5–7 errors indicates moderate impairment, and 8–10 errors indicates severe intellectual impairment. The participants were permitted up to three errors indicating normal to very mild cognitive impairment. A study by Warren et al. (2016) applied similar scoring criteria when screening cognition in potential study participants.

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

The REALM-SF was administered to assess the health literacy level of each participant. The 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 Arozullah 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 Modification Process (PEM)

The PEM selected for this study, titled "Charles Bonnet Syndrome" (Lighthouse International, 2019), is readily available online (see Appendix A). This topic was selected because the syndrome affects roughly one-third of people with low vision (Schultz & Melzack, 1991). The original PEM was modified 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) (see Appendix B). A brief overview of the guidelines used to modify the PEM are listed in Table 1. A detailed checklist was used to modify the PEM for people with low health literacy and low vision (see Appendix C).

Table 1
Evidence-Based Guidelines and Suggested Accommodations for Modifying 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
• 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:
  o Margins indented 1 inch
  o Justify left margin
  o Unjustified right margin
  o Double spacing between paragraphs and graphics
• Block paragraph style with no indents

Readability Indices

Word count and readability (i.e., grade level) were calculated with an online readability calculator (Online Utility, n.d.) embedded with the following indices: (a) Simple Measure of Gobbledygook (SMOG) (McLaughlin, 1969), (b) Gunning Fog Index (FOG) (Gunning, 1952), and (c) Flesch-Kincaid Grade Level (FKGL) (Kincaid et al., 1975). The SMOG formula calculates grade level based on the number of words with three or more syllables in a sample of sentences. The FOG calculates grade level based on the average words per sentence and the percentage of polysyllable words. The FKGL formula measures grade level using the mean sentence length and syllables per word. Three 100-word sample passages of text were cut from each PEM for analysis. To improve reliability, the researcher retested the readability levels of the same samples of text by hand with the Fry Readability Formula (Fry, 1968). The Fry Readability Formula was selected because it is widely accepted in the existing literature and does not require a large sample of text.

Suitability Assessment of Materials

The Suitability Assessment of Materials (SAM) instrument was used to objectively rate the suitability (i.e., appropriateness) of the original and modified PEMs (Doak et al., 1996). The SAM evaluates 22 factors across six categories: (a) content, (b) literacy demand, (c) graphics, (d) layout and typography, (e) learning stimulation, and (f) cultural appropriateness. 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 suitability percentage score that was interpreted based on criteria established by Doak et al. (1996). A suitability percentage 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 criteria for "superior" material, a PEM must earn a SAM percentage score between 70%–100%. 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

The Consumer Information Rating Form (CIRF) was developed to quantify consumer perceptions of comprehensibility (i.e., design quality and usefulness) of written health information (Koo et al., 2007). The CIRF consists of 17 test items across three categories: comprehensibility, utility, and overall design quality. Each participant completed one form for each PEM. The primary researcher presented the original PEM first and instructed the participants to read it with the optical device of their choice. When the participants were finished reading, the researcher administered the CIRF to rate comprehensibility. Each test item was scored on a 5-point scale with higher scores indicating greater quality and usefulness of information. After the original PEM was evaluated, the researcher encouraged the participants to take a 10-min break before repeating the same procedure with the modified PEM.

Semi-Structured Interviews

Completion of the CIRF was followed by a brief semi-structured interview. The purpose of the interview was to identify patient perceptions through significant statements and common themes. The researcher developed seven interview questions to gather additional insight on factors surrounding the design quality and usability of the original and modified PEMs. On average, each interview lasted approximately 10 min. The interview questions and responses are reported in Table 5.

Data Analyses

Statistical analysis was completed with IBM SPSS 25 software. Data collected with standardized instruments and semi-structured interviews were used to compare one PEM presented in its original and modified format. Readability levels were quantified using four indices. Descriptive statistics were used to determine the mean readability level and suitability score for each PEM. Paired-samples *t*-tests determined whether differences in readability level and the CIRF scores 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. Following a convergent mixed methods design (Creswell & Creswell, 2018), qualitative and quantitative findings were analyzed separately. Thematic analysis of interview transcripts followed the steps of the Framework Method, which can be adapted for use with many qualitative approaches that generate themes (Gale et al., 2013; Ritchie & Lewis, 2003). The primary researcher transcribed audio recordings of each interview verbatim. Common themes were coded by comparing significant statements from as many perspectives as possible. Internal validity was enhanced through data-source triangulation. Multiple forms of data were collected to gain a more complete understanding of PEMs and patient perceptions. Findings from quantitative and qualitative data analysis were merged during mixed methods analysis.

Results

Twelve participants met the inclusion criteria for this study (see Table 2). The participants ranged from 67 to 93 years of age with a mean age of 83 years. Four of the 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 the 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 the participants used a handheld magnifier, and 33% used a closed-circuit television (CCTV) to read. Based on the scores of the REALM-SF, 58% of the 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 2
Participant Characteristics

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

For the modified PEM, the word count was reduced from 601 to 191, a decrease of 69%. The modified PEM elicited a statistically significant improvement in suitability based on the SAM percentage score as compared to the original, $t\ (12) = 10.32$, $p < .001$. The original PEM suitability score (20%) fell into the "not suitable material" category, whereas the modified PEM suitability score (82%) fell into the "superior" category. A paired-samples *t*-test revealed a decrease in mean readability (i.e., grade level)

between the original PEM (12.42 ± .96) and modified PEM (6.50 ± 1.78) across four indices. The modified PEM elicited a mean decrease of 5.9, 95% CI [4.18, 7.67] grade levels. The modified PEM also produced a statistically significant decrease in readability levels as compared to the original, t (3) = 10.84, $p < .002$. The differences in word count, suitability, and readability are presented in Table 3.

Table 3
Word Count, SAM Score, and Mean Readability Levels for Original and Modified PEMs

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

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

The CIRF was administered to collect the participants' perceptions of comprehensibility (i.e., design quality and usefulness) of the original and modified PEMs (see Table 4). A paired-samples *t*-test was used to determine whether any differences in the CIRF scores were statistically significant. Data analysis revealed an increase in comprehensibility between the original PEM (33.92 ± 5.23) and the modified PEM (53.00 ± 3.0). The modified PEM elicited a statistically significant increase of 19.08, 95% CI [15.04, 23.10] in the CIRF scores when compared to the original. The majority of the participants found the modified PEM made the information easier to read (75%), understand (83%), locate (92%), and remember (92%).

Table 4
Mean CIRF Scores for Original and Modified PEMs

Test Item	Consumer Information Rating Form (CIRF) Question	Original PEM	Modified 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 identified common themes and personal preferences (see Table 5). Qualitative data analysis revealed themes related to reading challenges, optical devices, and patient-provider interactions. The majority of the 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 the participants stated the PEMs containing intricate graphics and long words made their optical devices less effective. Over half (58%) of the participants stated their primary health care provider does not provide PEMs. Those who received PEMs on a regular basis reported they could not access the information because the text was too small. Finally, approximately 50% of the participants in this study expressed that their doctors do not fully understand what it is like to live with low vision.

Table 5
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?	"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 modified handouts?	Font on the modified handout was easier to read (*n* = 9) (75%) Modified 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?	Modified 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?	Modified handout was easier to locate information (*n* = 11) (92%) No (*n* = 1) (8%)
Was there a difference in your ability to remember information between the two handouts?	Modified 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 just 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."
	"Line drawings 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."
	"I don't think doctors understand how this condition 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

The findings of this study illustrate the disconnect between the readability of PEMs and the reading abilities of people with AMD, a population at greater risk for low health literacy. There are parallels between the experiences of the participants in this study and existing research on the health information needs of people with visual impairment. Similar 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 diagnosed with the condition of interest. In both studies, readability and suitability was significantly improved after modifying written health information. In this study, the participants also reported the modified PEM made the information easier to read, understand, and remember. These findings have implications for the clinical practice of health care providers (i.e., occupational therapists, optometrists, and ophthalmologists) providing services to people with AMD. In general, patients who can access, process, and understand PEMs will be more likely to apply health information in everyday life.

This study embraced the notion that actively involving people with AMD in the research process provides valuable insight. The participant feedback on the design quality and usefulness of the original and modified PEMs reinforced the notion that there is a disconnect between the readability of written health information and the average reading ability of this population. In addition, themes derived from semi-structured interviews acknowledged challenges related to reading, use of optical devices, and patient-provider interactions. These challenges create underlying barriers to health literacy that are often addressed in low vision rehabilitation but overlooked by other health care providers.

Limitations

The results are limited to the experiences of 12 people with AMD who were located in the same general geographic location. Such a small sample may limit the generalizability of results to the larger population of people with AMD. The researcher did not randomize administration of the original and modified PEMs. Because data collection took place during a single home visit, the participants were exposed to information on Charles Bonnet syndrome via the original PEM prior to receiving the modified version. This may have contributed to the participants' perceptions that the modified PEM was easier to read. Although the majority of the participants stated the modified PEM was easier to understand, the researcher did not objectively assess reading comprehension during this study. In addition, the qualitative interview data was analyzed solely by the primary researcher. These limitations may impact the reliability of results, as well as generalizability to the greater population of people with AMD.

Future Directions

Additional research is needed to address the health literacy needs of people with AMD under the umbrella of low vision. Future research is warranted to determine the optimal design of educational materials provided to people with AMD. Reading comprehension was not quantified in this study. Therefore, future research should explore how modified PEMs influence reading comprehension in this population. These studies are needed to ensure condition-specific PEMs become the standard of care in the future.

Conclusion

The results of this study show that people with AMD have unique needs when it comes to patient education. Existing evidence-based guidelines do not consider how the physical properties of text (e.g., font style and size, contrast, spacing) may negatively influence reading performance and comprehension in people with AMD. Health care providers working in low vision rehabilitation should hold PEMs to a higher standard of usability. Heeding existing guidelines for low health literacy and low vision will ensure PEMs are readable, suitable, and understandable. A summary of the guidelines used for PEM modification in this study have been compiled into a checklist for convenience (see Appendix C). Several audiences, including researchers, policymakers, and health care providers (i.e., occupational therapists, optometrists, and ophthalmologists), will benefit from the information gleaned from this study. Most importantly, older adults with AMD will benefit from health care providers with greater understanding of the unique challenges and educational needs of this population.

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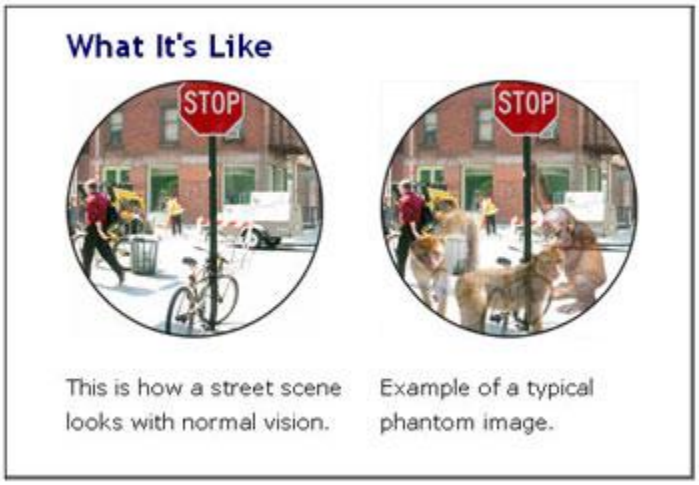
Appendix A
Original Patient Education Material (PEM)

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 mix-up 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.

Note. Retrieved from http://web.archive.org/web/20200119171015/http://li129-107.members.linode.com/about-low-vision-blindness/vision-disorders/charles-bonnet-syndrome

Appendix B
Modified 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 C
Checklist for Modifying PEMs for People with Low Health Literacy and Low Vision

	Guideline	Description/Suggestion	✓
1	Calculate the readability (grade level) of the original and modified 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 modified 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 subheadings.	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 underscore 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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