Functional Health Literacy in Patients With Glaucoma in Urban Settings

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Objective: To assess the relationship between health literacy and compliance, disease awareness, and disease progression in patients with glaucoma.

Methods: A cross-sectional observational study of 204 English-speaking patients treated for glaucoma for at least 1 year at Kresge Eye Institute was conducted. Health literacy was assessed using the standardized Test of Functional Health Literacy in Adults (TOFHLA). An oral questionnaire assessed patients' demographic information and glaucoma understanding. A retrospective medical record review was conducted to record parameters indicating glaucoma severity.

Results: One hundred two participants (50%) were categorized as having poor functional health literacy (mean [SD] TOFHLA score, 18.4 [7.5]) and 102 participants (50%) had adequate health literacy (mean [SD] TOFHLA score, 42.8 [5.1]). The poor health literacy group showed significant differences in income, education, medication compliance, glaucoma understanding, and missed appointments compared with the adequate health literacy group ($P < .001$). Patients with poor health literacy showed a greater visual field loss on initial presentation (mean deviation [SD], −10.58 [9.3] dB) compared with the adequate health literacy group (mean deviation [SD], −7.79 [6.9] dB; $P = .02$) and significantly worse visual field parameters when comparing pattern SDs on the recent and the initial visual fields (pattern SD change [SD], 0.19 [2.5] dB in the poor health literacy group vs −0.7 [2.2] dB in the adequate health literacy group; $P = .02$).

Conclusions: Patients with poor health literacy had poorer compliance, worse disease understanding, and greater disease progression compared with the adequate health literacy group, highlighting the need to promote health literacy in patients with glaucoma.

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Health literacy, as a discrete form of literacy, is increasingly important in health care. The US Department of Health and Human Services defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." The American Medical Association's Council on Scientific Affairs more specifically defines functional health literacy as "the ability to apply reading and numeracy skills in a healthcare setting." These skills include the ability to (1) read consent forms, medicine labels and inserts, and other written health care information, (2) understand written and oral information given by physicians, nurses, pharmacists, and insurers, and (3) act on necessary procedures and directions, such as medication and appointment schedules.

Recent research has examined the effect of patients' literacy skills on health and health care. Numerous studies have demonstrated that health materials, such as discharge instructions, consent forms, and medical education brochures, are often written at levels that exceed patients' reading skills. Patients with low health literacy and chronic diseases have less knowledge of their disease and its treatment and fewer correct self-management skills than literate patients. These factors likely contribute to higher hospitalization rates among patients with poor functional health literacy compared with those with adequate health literacy. While many patients with poor literacy are unaware of their deficiency, others feel shame and are unwilling to disclose their reading problem to health care professionals. Poor health literacy has been found to be common among patients with long-term...
medical conditions, such as type 2 diabetes, asthma, AIDS, and hypertension.15,10,21-24

Although the extent to which health literacy is associated with or causally related to outcomes is unclear, there are reasons to believe that poor health literacy may contribute to poor outcomes. Patients with poor health literacy have greater difficulty naming and describing their indications,23 more frequently hold health beliefs that interfere with adherence,23 and are more likely to have a poor understanding of their condition and its management.15,10,21

We investigated the association between health literacy and glaucoma awareness and outcomes among patients in an urban eye clinic. Vision experts estimate that half of those affected with glaucoma may be unaware they have it, because symptoms may not occur during the early stages of the disease.26 Assessing the association of health literacy and glaucoma awareness and outcomes may have important clinical implications for the care of individual patients as well as strategic implications for the reduction of racial, ethnic, and socioeconomic disparities in glaucoma care.

**METHODS**

**SETTING AND STUDY PARTICIPANTS**

The study protocol was approved by the institutional review board of Wayne State University, Detroit, Michigan. The study population consisted of 231 patients from the clinics at the Kresge Eye Institute at Wayne State University treated between September 2004 and January 2006. Patients were considered eligible for the study if they were older than 18 years, spoke English, and had a diagnosis of glaucoma for at least 1 year before enrollment. Patients who had a concomitant retinal pathology (which could affect retinal nerve fiber layer [RNFL] thickness on optical coherence tomography [OCT] or their Humphrey visual field [Carl Zeiss Meditec, Jena, Germany]) and/or a documented psychiatric disorder (which may interfere with accurate health literacy measurement) were excluded.22 Psychiatric disorders were excluded by medical record review. We also excluded patients who had a best-corrected visual acuity of less than 20/50 in the better eye (unable to read 14-point type of the literacy test). Written consent was obtained from patients before enrollment. To facilitate comprehension of the study and consent process, the research assistants read the consent form to all patients (patients with significant hearing disabilities who had difficulty comprehending the consent were excluded). Patients were then administered the reading comprehension section of the English version of the Test of Functional Health Literacy in Adults (TOFHLA), a reliable and validated instrument used to assess health literacy if the score was 31 to 50. Adequate health literacy consists of 50 items covering preparation for an upper gastrointestinal tract radiographic procedure (passage A), Medicaid’s “Rights and Responsibilities” passage (passage B), and informed consent (passage C), which was to be completed in 12 minutes. The reading comprehension scale uses the Cloze procedure,31 a technique that uses reading passages with every fifth word missing; the patient must select the appropriate missing word from a list of 4 possible answers. According to the Gunning-Fog index (an index to grade readability), the reading levels for the reading comprehension sections were grade 4.3 for passage A, grade 10.4 for passage B, and grade 19.5 for passage C. The TOFHLA reading comprehension section is scored on a scale of 1 to 50. We categorized patients as having poor health literacy if the TOFHLA score was 0 to 30, and as having adequate health literacy if the score was 31 to 50. Adequate health literacy indicates an ability to successfully complete most tasks required to function in the health care setting, though comprehending more difficult information (materials written at higher than a 10th-grade reading level) may still be difficult. Patients with poor functional health literacy have a decreased ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials and cannot understand medical instructions required to successfully function as a patient. They also have difficulty processing oral communication and conceptualizing risk. Because socioeconomic factors, glaucoma awareness, and compliance may affect the patients’ glaucoma control, we assessed these domains as part of the survey questionnaire.

During the medical record review, the patients’ visual field parameters (pattern SD [PSD] and mean deviation [MD]), Humphrey Swedish Interactive Threshold Algorithm [SITA]—Fast) on initial presentation and at the most recent visit as well as their average RNFL thickness on OCT (numeric value and color category, Stratus, Carl Zeiss Meditec) at the most recent visit were noted. The visual field data were included for the participants in whom it was reliable and the same testing strategy (Humphrey SITA-Fast) had been used for the initial and the most recent visual field analyses. These parameters were used as indicators of glaucoma severity. The OCT data were included for all the participants in which they were available, though we could not use the data in a longitudinal fashion because the technology had become available just shortly before the commencement of this study. The recent visual field and OCT measurements had been done within 3 months of the interview and test date. Additionally, the frequency of missed appointments per year was derived from the medical records and used as a surrogate marker for patient compliance.

**STATISTICAL ANALYSIS**

Categorical variables were compared using an unadjusted $\chi^2$ test and continuous variables were compared with the $t$ test or
analysis of variance. The 2 health literacy groups (poor and adequate) were compared to determine whether there is a significant difference in demographic characteristics (race, sex, education, income, and insurance coverage) and compliance (assessed by the number of missed appointments per year and self-reported frequency of missed eye drops) between the 2 groups. The physicians’ subjective interpretation of the patients’ reading level was also compared with their literacy category (ascertained from the TOFHLA score) without the physician knowing the patients’ TOFHLA scores. The 2 groups were statistically compared for insight and awareness of different aspects of glaucoma care and knowledge (graded as good or poor).

We conducted statistical analyses to evaluate any differences in glaucoma parameters between the 2 literacy groups. During the study design phase, it had been randomly decided to use the right eye for analyses (a priori). Specific parameters including PSD and MD (on initial presentation, most recent visit, and the difference between them) were compared between the 2 literacy groups. The average RNFL thickness (categorized by OCT color) was also compared between the 2 literacy groups. For all analyses, P < .05 was used to determine final statistical significance. All statistical analyses were performed with Statview software, version 5.0 (SAS Institute Inc, Cary, North Carolina).

RESULTS

Based on an initial medical record screening, 231 patients were asked to participate in the study. Of these, 16 were excluded (concomitant retinal pathology [n=10], diagnosed psychiatric condition [n=3], and hearing disability [n=3]). Eleven patients refused to participate (main reasons for refusal: “not wanting to answer any personal questions” or “not wanting to take any tests”). Thus, we enrolled 204 patients in our study.

The demographic characteristics and the mean TOFHLA scores of the study participants are summarized in Table 1 and the relationship between TOFHLA scores and level of education is shown in the Figure. One hundred two participants (50%) had poor functional health literacy (TOFHLA score, 0-30), and 102 participants (50%) had adequate literacy (TOFHLA score, 31-50). Patients with poor health literacy were more likely than patients with adequate health literacy to be African American, to have received only some high school education or less, to have an annual income of less than $20,000, and to have only Medicaid insurance coverage (as opposed to commercial insurance, as in the adequate group). Fifty-six percent of African American participants had poor health literacy compared with only 16% of white participants (P=.002). There is a significant difference in the participants’ level of education (P < .001), income (P < .001), type of insurance (P < .001), and marital status (P = .05) between the 2 literacy groups. Six participants, all of whom belonged to the adequate literacy group, declined to disclose their income (Table 1). The physicians’ qualitative assessment of the participants’ reading level correlated with the measured literacy level (P < .001).
In multivariate analyses of the demographic variables (Table 2), race/ethnicity, education, and household income were all significantly associated with health literacy. Being of white race, having an education of some college or more, and having a household income of $20,000 or greater was associated with a lower likelihood of having poor health literacy.

As presented in Table 3, the mean (SD) number of missed appointments per year in the poor literacy group (1.9 [0.9]) was significantly higher than that in the adequate literacy group (0.5 [0.5]; P < .001). The self-reported frequency of missed eye drops in the poor health literacy group was found to be significantly higher than that in the adequate health literacy group (65 participants in the poor literacy group reported having missed taking eye drops ≥2 times/mo compared with only 34 participants in the adequate health literacy group, P < .001).

Patients in the adequate literacy group had a better conception of their health in general. Sixty-five participants from the adequate health literacy group thought that they had good health compared with only 37 participants from the poor health literacy group (P < .001). More patients in the adequate health literacy group felt they had received glaucoma education compared with the poor health literacy group (P = .01). Patients with adequate health literacy felt they had a better understanding of their overall glaucoma care, medications, treatment, prevention of its consequences, and the benefits of lowering eye pressure (P < .001) compared with participants with poor health literacy (Table 4).

The comparison of the visual field parameters between the 2 groups (right eye, a priori) is presented in Table 5. Patients with poor health literacy showed a greater MD (SD) (greater visual field loss) on initial presentation (−10.38 [9.3] dB) compared with the adequate health literacy group (−7.79 [6.9] dB, P = .02). The recent visual field also showed a significantly worse MD in the poor health literacy group (−11.49 [9.8] dB) than in the adequate health literacy group (−7.45 [7.7] dB, P = .004) (Table 5). Participants with poor health literacy showed significantly worse visual field parameters when comparing their visual field on initial presentation with their most recent visual field (recent visual field PSD – initial visual field PSD=0.19 [2.5] dB in the poor health literacy group compared with −0.7 [2.19] dB in the adequate group, P = .02; recent visual field MD – initial visual field MD=−1.75 [6.8] dB in the poor health literacy group compared with −0.32 [3.19] dB in the adequate health literacy group, P = .02) (Table 5).

There was no statistically significant difference in average RNFL thickness on OCT between the 2 groups, though a higher number of participants in the poor health literacy group had a compromised RNFL (65% in the red color category on OCT) compared with the adequate group (49% in the red color category on OCT; P = .09) (Table 5).
This study examines functional health literacy in an urban population of patients with glaucoma. We found that among patients with glaucoma, half of the respondents had poor health literacy. This figure is somewhat consistent with statistics on general reading ability from the 1993 National Adult Literacy Survey, which reported that 44% of adults were at a low reading level.18 Our study demonstrates that poor health literacy in patients with glaucoma in urban settings is related to socioeconomic factors, compliance, and understanding of glaucoma. It also highlights that patients with poor health literacy and poor compliance with glaucoma treatment had worse visual field results on follow-up examinations. Muir et al32 have also found a positive correlation between low health literacy and adherence to glaucoma medications using a different tool: the Rapid Assessment of Health Literacy in Medicine. Missing appointments has been correlated with lower adherence rates to prescribed regimens in other studies as well.33-35 Results from part 3 of the Advanced Glaucoma Intervention Study are similar to some of our results, especially with respect to socioeconomic differences and severity of glaucoma on visual fields between white and black patients. The Advanced Glaucoma Intervention Study enrolled 332 black and 249 white patients. Relatively fewer black patients (31%) than white patients (78%) had completed high school. Although the 2 groups had similar intraocular pressures on enrollment, visual field defects on average were found to be substantially more severe in black than in white participants.36

In the current health care environment, in which scientific advances and market forces place greater technical and self-management demands on patients, poor health literacy may be a particularly important barrier to chronic disease care. According to the National Adult Literacy Survey, 75% of Americans with a long-term illness had limited literacy.18 From the public health perspective, health literacy may represent an important variable explaining the prevalence of poor health outcomes among patients with glaucoma as well as some of the socioeconomic and ethnic disparities in glaucoma outcomes. Glaucomatous visual loss is often preventable with current drug regimens and surgical techniques, provided that intervention occurs in the early stages. Because of its higher prevalence in African American and Latino populations, poor health literacy may contribute to higher rates of advanced glaucoma in these populations. Although African American individuals are a high-risk group and more likely to develop glaucoma, they may be less aware of the disease and less likely to initiate glaucoma treatment.37,38 Also, glaucoma in African American individuals is more advanced at the stage of discovery and more commonly leads to blindness in this group.39-44

Ontiveros et al45 showed that African American individuals are less likely than white individuals to have a primary care physician and to undergo glaucoma screening, though all the respondents were eligible for Medicare and had access to a university medical center within a short driving distance. There is evidence suggesting that African American individuals may be undertreated for adherence rates to prescribed regimens in other studies as well.33-35 Results from part 3 of the Advanced Glaucoma Intervention Study are similar to some of our results, especially with respect to socioeconomic differences and severity of glaucoma on visual fields between white and black patients. The Advanced Glaucoma Intervention Study enrolled 332 black and 249 white patients. Relatively fewer black patients (31%) than white patients (78%) had completed high school. Although the 2 groups had similar intraocular pressures on enrollment, visual field defects on average were found to be substantially more severe in black than in white participants.36

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### Table 4. Comparison of Perceived Glaucoma Insight and Understanding Between Health Literacy Groups

<table>
<thead>
<tr>
<th>Concept</th>
<th>Perceived Understanding</th>
<th>Adequate Health Literacy Group</th>
<th>Poor Health Literacy Group</th>
<th>P Valuea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall glaucoma care</td>
<td>Good</td>
<td>74</td>
<td>14</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>28</td>
<td>88</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Medications</td>
<td>Good</td>
<td>78</td>
<td>11</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>24</td>
<td>91</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Prevention of long-term complications</td>
<td>Good</td>
<td>80</td>
<td>30</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>22</td>
<td>72</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Treatment</td>
<td>Good</td>
<td>79</td>
<td>15</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>23</td>
<td>87</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Benefits of lowering eye pressure</td>
<td>Good</td>
<td>83</td>
<td>16</td>
<td>&lt;.001</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>19</td>
<td>86</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

aχ² Test.

### Table 5. Comparison of Glaucoma Parameters in the Right Eye (A Priori) Between Healthy Literacy Groups

<table>
<thead>
<tr>
<th>Glaucoma Parameter</th>
<th>Adequate Health Literacy Group</th>
<th>Poor Health Literacy Group</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pattern SD, mean (SD), dB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>5.5 (3.7)</td>
<td>5.5 (3.1)</td>
<td>.89a</td>
</tr>
<tr>
<td>Recent</td>
<td>4.8 (3.6)</td>
<td>5.5 (3.3)</td>
<td>.19a</td>
</tr>
<tr>
<td>Changeb</td>
<td>−0.70 (2.19)</td>
<td>0.19 (2.52)</td>
<td>.02a</td>
</tr>
<tr>
<td>Mean deviation, mean (SD), dB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial</td>
<td>−7.79 (6.9)</td>
<td>−10.58 (9.3)</td>
<td>.02a</td>
</tr>
<tr>
<td>Recent</td>
<td>−7.45 (7.7)</td>
<td>−11.49 (9.8)</td>
<td>.004a</td>
</tr>
<tr>
<td>Changeb</td>
<td>0.26 (3.90)</td>
<td>−1.75 (6.78)</td>
<td>.02a</td>
</tr>
<tr>
<td>OCT color (RNFL average), No. (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Green</td>
<td>35 (50.7)</td>
<td>22 (34.9)</td>
<td>.09c</td>
</tr>
<tr>
<td>Red</td>
<td>34 (49.3)</td>
<td>41 (65.1)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: OCT, optical coherence tomography; RNFL, retinal nerve fiber layer.

aUnpaired t test.
bRecent−initial measurement.
cχ² Test.
glaucoma owing to the underuse of medical facilities and that they may seek medical care for glaucoma later in the course of the disease.46

Our study has a number of limitations. First, its cross-sectional design did not allow us to ascertain whether poor health literacy was causally associated with worse glaucoma outcomes. It is possible that health literacy is simply a marker for other factors that represent unmeasured confounders, such as one’s health-seeking behavior or psychological makeup. Our study does not elucidate mechanisms through which poor health literacy may result in worse glaucoma outcomes. Glaucoma care requires that a host of concepts and skills be conveyed by a team of health care providers and successfully carried out by the patient. Patients must recognize the signs and symptoms and often must perform self-administration of multiple eye drops. Therefore, glaucoma outcomes may be especially sensitive to problems in communication, empowerment, and self-treatment. It is possible that patients with poor health literacy are less likely to recognize signs and symptoms of glaucoma and present to care later and are less compliant and therefore are more likely to have worse glaucoma outcomes. Also, although psychiatric disorders had been excluded by medical record review (since this could have affected the ability to remember or recall things), a Mini-Mental Status Examination was not specifically conducted.

Results from this study have important implications for all levels of the health care delivery system—patient, physician, and organization. Health literacy is not only important for self-treatment of chronic conditions; it also affects the spectrum of health care, from prevention and screening to history taking and explanation of diagnosis and treatment. Because symptoms only appear in the advanced stages of glaucoma, patients are often unaware of their disease, with only 50% of cases known to the health care system in developed countries.47 Our study confirms the findings of the Baltimore Eye Survey that this lack of awareness is higher in patients with lower educational levels.48 Because early detection of glaucoma is the key to preventing its progression, the need to enhance health literacy of glaucoma awareness, particularly among high-risk groups, is crucial. Awareness of the possible outcomes of glaucoma as well as the importance of compliance with treatment need to be stressed. The perceptions that patients have of their illness can also have a significant effect on management, as the belief that glaucoma is treatable is likely to result in better compliance to a drug regimen.49 Health literacy has been shown to be an important factor affecting disease course, especially in chronic diseases that require an appropriate insight and knowledge and self-treatment (medication adherence and compliance) as outpatients. This should be taken into account while designing studies that evaluate disease progression.

It is crucial to promote literacy and awareness and to better understand the attitudes that patients with poor health literacy have toward glaucoma, so that monitoring and treatment of glaucoma can be more effective. Programs directed to increasing glaucoma awareness and treatment availability in the high-risk poor health literacy population may ultimately result in prevention of visual loss.

Our study demonstrated that physicians can readily identify patients with poor health literacy skills. Because physician communication is very important in treatment compliance, physicians must be aware of their patients’ health literacy skills.

The patient who walks through the examination room door may have gained access to a medical facility, but access to effective health care will remain elusive if communication barriers have not been fully addressed. Future research should focus on effective health-education techniques and the causal pathway of how poor health literacy influences health and chronic disease outcome. Closing the gap in health literacy is an essential component in reducing disparities in glaucoma care. Screening patients for poor literacy is a first step. However, the real challenge is in shaping effective public health communication that is culturally and linguistically appropriate for patients and promotes compliance with medications and follow-up treatment with their physicians. In addition, there is a need to improve physician communication, which should consider the needs and competencies of patients with poor health literacy.46–51

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