



Fear of Cataract Surgery and Vision Loss: The Effects of Health Literacy and Patient Comprehension at an Academic Hospital-Based Eye Clinic

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Purpose: This qualitative study assessed the relationship between health literacy and perceptions surrounding fear of cataract surgery and fear of vision loss in patients presenting to a Midwestern, urban, safety-net hospital-based clinic setting.

Patients and Methods: Forty-two patients were recruited from the Hoxworth Eye Clinic at the University of Cincinnati Medical Center. The inclusion criteria were as follows: established patient at the clinic, age 50 or older, diagnosis of cataract by ICD-10 and/or physical exam, and no history of prior cataract surgery. Each patient completed a survey of demographic information and questions targeting their understanding and attitudes surrounding cataract pathology and treatment, and the Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF), a validated 7-item word recognition test assessing patient health literacy. Two-tailed t-tests assuming equal variances and chi-squared tests conducted in Excel were used in statistical analyses.

Results: In our cohort ($n = 42$), there was no association between score on the REALM-SF and fear of cataract surgery ($p = 0.87$), but there was a significant association between fear of cataract surgery and belief that cataract surgery would improve vision ($p = 0.03$). Conversely, there was no significant association between fear of vision loss and belief that cataract surgery would improve vision ($p = 0.92$). The factors underlying these findings may be further clarified when attitudes surrounding cataract surgery and vision are categorized based upon best corrected visual acuity (BCVA). Patients with BCVA worse than 20/40 in only one eye fear cataract surgery more than patients with BCVA more than 20/40.

Conclusion: In our patient population, neither health literacy nor understanding of cataract pathology was associated with fear of cataract surgery. However, given patients who feared cataract surgery were less likely to believe cataract surgery would improve vision, clarifying goals of surgery and addressing patient fears should be prioritized. Interestingly, this may be more important at earlier stages of non-visually significant cataracts for patients with good vision.

Plain Language Summary: This study represents an effort to delineate what role, if any, health literacy plays in the uptake of cataract surgery, specifically aiming to understand underlying patient fears of cataract surgery and vision loss. In our context of a safety-net hospital for underinsured and uninsured patients, we hoped to describe the etiologies behind why patients might be reluctant to pursue cataract surgery, which is a leading cause of reversible blindness. We surveyed patients in our safety-net academic hospital on their perceptions surrounding cataract surgery and vision loss and assessed their health literacy through a validated word recognition test. The results suggest that neither health literacy nor a specific understanding of cataracts is associated with fear of cataract surgery. Rather, vision is a critical factor in perception; patients with better vision fear cataract surgery more. Therefore, addressing patient concerns earlier on in the cataract surgery process may better alleviate fears of the procedure itself and vision loss. Expanding our study to patients with English as their second language, countries outside the United States, and community hospitals would encompass more vulnerable populations and improve the generalizability of these findings.

Keywords: vision loss, patient perceptions, safety-net eye clinic, cataract, health literacy

Introduction

Cataracts are a leading cause of reversible blindness worldwide with an estimated 95 million people worldwide adversely affected with cataracts.¹ They account for 50% of cases of blindness in middle- and low-income countries compared to 5% of developed countries.² However, even in high-income countries, such as the United States and Australia, prevalence of blindness and visual impairment is more common among economically poorer populations, making barriers to access universal, regardless of a country's economic status.³ Despite a success rate (defined as a Best Corrected Visual Acuity or BCVA better than 20/40) as high as 95% and improvements in post-operative quality of life, rates of cataract surgery uptake vary greatly from 14.4%–91.7% in a systematic review of low- and middle-income countries.^{4–7} Some studies suggest lack of knowledge as a key barrier to surgery uptake, which is defined as the proportion of people who, having been referred to surgery, have undergone surgery.⁸ This study aims to understand the potential relationship between health literacy and acceptance of cataract surgery.

It is clear that awareness and understanding of cataract as a pathological entity and the available surgical intervention likely remains poor, particularly for patients with inconsistent access to quality healthcare. For example, a cross-sectional study from Moradabad, India, illustrated that while nearly all (98.5%) participants were aware of cataract as their condition causing poor vision, only 57.6% knew that surgery was a cataract treatment.⁹ The disconnect in patient understanding of their health conditions is particularly interesting in light of a systematic review showing no statistically significant correlation between education or literacy with surgical uptake.⁴ In fact, a longitudinal study in China ($n = 16,663$) suggested that illiteracy was significantly associated with increased surgical uptake, which is the converse to the assumption that higher health literacy and baseline education lead to increased uptake of surgery.¹⁰

In the United States, few studies have drawn associations between health literacy and cataract surgery uptake, but disparities in rates of cataract surgery between groups provoke the question. In the Baltimore Eye Study, African American participants were 5 times as likely as Caucasian patients to have unoperated cataracts.¹¹ The reasons behind this disparity are multifactorial; for example, in the SEEING study which screened nursing home residents and referred them to surgery ($n = 2544$), fewer than 5% of African American participants underwent cataract surgery, indicating that there is more than just a disparity in access to ophthalmologic and optometric services.¹² This disparity in cataract surgery uptake is apparent not only in African American populations, but also in Latino populations with a cross-sectional study showing that 34% of Latino-identifying participants with visually significant cataracts did not ultimately undergo cataract surgery.¹³ While these studies demonstrate an association between race and cataract uptake, it is unclear the extent to which health literacy plays a role.

Despite the complex interplay between health literacy and surgery uptake, it is clear physicians play a critical role in patient decision-making; in a phone survey of 1000 respondents, of those who underwent surgery, 81% did so on the advice of their health care professional.¹⁴ In the same survey, the second most common reason (41%) cited to not have surgery was that their doctor had not recommended it, while the most common reason (43%) to not have surgery was that patients felt their vision was “fine for now.” Thus, patients appear to gauge the need for cataract surgery by their own perceptions of their vision and their doctors' perceptions of their vision, with both playing decisive roles. As some studies show that adequate counseling helps address patient fears and reduces likelihood of refusal of cataract surgery, understanding how vulnerable populations view cataracts and their management is critical.¹⁵

Material and Methods

Our cross-sectional survey study follows the tenets of the Declaration of Helsinki. Institutional Review Board approval was obtained and patients were recruited from the Hoxworth Eye Clinic at the University of Cincinnati Medical Center, a tertiary hospital-based eye clinic that largely serves Cincinnati's uninsured and underinsured population. Inclusion criteria were: being an established patient at the clinic, being age 50 or older, having English as their primary language, having a diagnosis of cataract by ICD-10 and/or physical exam and no history of prior cataract surgery. Patients gave informed consent. Patients completed a survey targeting their understanding of and attitudes surrounding cataract pathology and treatment and their fear of cataract surgery and fear of vision loss. Patients also completed the Rapid Estimate of Adult Literacy in Medicine – Short Form (REALM-SF), a validated and field-tested 7-item recognition test

assessing patient health literacy.¹⁶ The REALM-SF lists 7 medicine-related words: menopause, antibiotics, exercise, jaundice, rectal, anemia, and behavior; recognizing all 7 words correlates to a high school reading level with the associated capacity to read most patient education materials.¹⁷ Recognizing 4–6 words correlates to a seventh to eighth grade reading level, so these individuals may have difficulty reading patient education materials. Statistical analyses, specifically two sample t-tests using equal variances and chi-squared tests, were performed using Microsoft Excel (version 16.93.1).

Results

Demographic Information

Forty-two patients filled out the surveys with a mean age of 66.2 years. More than 80% of patients surveyed had a high-school level education or higher (Table 1). 40% of the patients reported a household income of under \$20,000 with an additional 20% reporting a household income between \$20,000 and \$50,000. Our surveyed patients were predominantly African American.

Table 1 Demographic Information of Study Respondents

N (%)	
Sex	
Male	17 (40.5%)
Female	25 (59.5%)
Race	
Caucasian	15 (35.7%)
African American	25 (59.5%)
Asian	2 (4.8%)
Education Level	
Less than High School	1 (2.4%)
Did Not Finish High School	5 (12.2%)
High School	14 (34.1%)
Some College	11 (26.8%)
College	5 (12.2%)
Graduate School	5 (12.2%)
Income	
Under \$20,000	17 (40.5%)
\$20,000-\$50,000	9 (21.4%)
\$50,000-\$100,000	4 (9.5%)
Over \$100,000	2 (4.8%)
Declined to Respond	10 (23%)

Health Literacy

Eighty percent of patients scored 7 points on the REALM-SF, indicating at least a 9th-grade reading level. Approximately 85.3% of patients surveyed had at least a high school education. The remaining 20% of patients, or 8 patients, scored 5 or 6 points on the REALM-SF. Points scored on the REALM-SF were statistically associated with level of education as shown in Table 2, validating the REALM-SF's measure of health literacy in association with reading level in this study. There was no association between score on the REALM-SF and fear of cataract surgery ($p = 0.87$, $t = -0.17$), indicating that health literacy did not affect whether patients feared cataract surgery. When asked multiple-choice questions surrounding knowledge of cataracts such as underlying pathology, symptoms, risk factors, and treatment options with responses shown in Table 3, there was no association between score on the REALM-SF, our measure for health literacy, and correct response relating to cataract knowledge. As laid out in Table 4, correct responses relating to knowledge of cataracts were not associated with fear of cataract surgery, fear of vision loss, or belief that cataract surgery will improve vision.

Table 2 REALM-SF Associations

Factor Associated with REALM-SF	p-Value	T or F Value
Level of Education	0.000000023	F=16.85
Knowledge of Cataract Pathology	0.04	$t = -2.312$
Fear of Cataract Surgery	0.87	$t = -0.17$

Table 3 Patient Responses to Cataract Knowledge Survey

	N (%)
What part of the eye is affected by cataracts?	
Lens	15 (35.7%)
Cornea	13 (31.0%)
Retina	12 (28.6%)
Optic Nerve	2 (4.8%)
Which is a common symptom of cataracts?	
Blurry Vision	34 (81.0%)
Floater	6 (14.3%)
Eye Pain	2 (4.8%)
Eye Redness	0 (0%)
What can increase the chance of developing a cataract? (Circle all that apply.)	
Age	37 (88.1%)
UV Radiation	20 (47.6%)
Injury	29 (69.0%)
Smoking	18 (42.9%)
Diabetes	35 (83.3%)
Myopia	13 (31.0%)

(Continued)

Table 3 (Continued).

	N (%)
How can a cataract be treated? (Circle all that apply)	
Surgery	36 (85.7%)
Eye Drops	17 (40.5%)
Glasses	17 (40.5%)
Oral Medications	10 (23.8%)
Diet	9 (19.0%)
No Treatment	0 (0%)

Table 4 Knowledge of Cataract Pathology Associations

Factor Associated with Knowledge of Cataract Pathology	p-Value	Chi-Squared Value
Fear of Cataract Surgery	0.61	0.25
Fear of Vision Loss	0.58	0.31
Belief that cataract surgery will improve vision	0.53	0.36

Attitudes Surrounding Cataract Surgery and Vision

Approximately 36% of patients reported fear of getting cataract surgery with more than half of those patients (53%) citing fear of vision loss as a contributing reason. No patients cited financial burden as a reason for fearing surgery. When asked separately about fear of vision loss, 52.4% of patients feared losing their vision. Of those patients, 55% worry monthly, 25% worry weekly, and 30% worry daily. As displayed in Table 5, there was a significant association between fear of cataract surgery and belief that cataract surgery would improve vision ($p = 0.03$, chi-squared value = 4.67). Conversely, there was no significant association between fear of vision loss and the belief that cataract surgery would improve vision ($p = 0.92$, chi-squared value = 0.010).

Further Insights of Attitudes Surrounding Cataract Surgery and Vision, as Categorized by Best Corrected Visual Acuity

Out of the 42 patients in the study cohort, 7 had BCVA worse than 20/40 in both eyes, indicating that the majority of participants surveyed had good vision, with BCVA worse than 20/40 in one eye (5 patients) or BCVA better than 20/40 in both eyes (30 patients) (Table 6). Despite both groups believing cataract surgery improves vision, patients with BCVA worse than 20/40 in both eyes do not fear cataract surgery as much as patients with BCVA worse than 20/40 in one eye, suggesting that for those with poorer vision overall, the benefits of vision improvement may outweigh the risks of cataract surgery. In contrast, the cohort with good vision (BCVA worse than 20/40 in neither eye) overwhelmingly made up those who feared cataract surgery while none of the patients with BCVA worse than 20/40 in both eyes feared cataract

Table 5 Fear of Cataract Surgery Associations

	p-value	Chi-Squared Value
Belief that cataract surgery would improve vision	0.03	4.67
Fear of Vision Loss	0.12	2.68

Table 6 Attitudes Surrounding Cataract Surgery and Vision Loss, Categorized by BCVA

	Total Study Cohort		Fear of Cataract Surgery		Fear of Vision Loss		Belief Cataract Surgery Improves Vision	
	N	%	N	%	N	%	N	%
BCVA less than 20/40 in both eyes	7	16.6%	0	0%	3	42.9%	7	100%
BCVA less than 20/40 in only one eye	5	12.0%	2	40%	1	20%	5	100%
BCVA less than 20/40 in neither eye	30	71.4%	10	33.3%	14	46.7%	26	86.7%

Abbreviations: REALM-SF, Rapid Estimate of Adult Literacy in Medicine – Short Form; BCVA, best corrected visual acuity.

surgery. Interestingly, in terms of fear of vision loss, 42.8% (3 of the 7) of the patients with BCVA worse than 20/40 in both eyes feared vision loss and the same percentage, 42.8% (15 of the 35) who had BCVA better than 20/40 feared vision loss.

Discussion

In our patient population drawn from a safety-net hospital-based eye clinic, fear of cataract surgery was not associated with an understanding of cataract pathology or of broader health literacy, defined 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.¹⁸

This finding aligns with previous international studies in low-income countries, such as an Ethiopian institutional-based cross-sectional design study identifying a lack of cataract awareness as one of the fewest cited reasons patients identified as a barrier to cataract surgery.¹⁹

It appears that fear of cataract surgery may instead be linked to the quality of patients' vision. In our study, patients with both eyes worse than 20/40, a somewhat arbitrary threshold utilized to indicate patients may have visually impairing cataracts, did not fear cataract surgery and believed it could improve their vision. While it may seem that the benefit of improving vision outweighs the risks for these patients, it is unclear whether patients have come to this conclusion via independent research or if they have received counseling from providers. In contrast, patients with one eye worse than 20/40 overwhelmingly believed that cataract surgery improves vision; however, this same cohort had higher rates of fear of vision loss and fear of cataract surgery. Patients with this level of visual acuity likely compensate well enough with the better-seeing eye so that the risks of surgery do not outweigh the benefits. From this standpoint, it could be more beneficial to counsel patients early on, prior to the development of visually significant cataracts, so patients are properly equipped to pursue cataract surgery when their symptoms become bothersome. Improved education about new safer surgical techniques with uncomplicated small incision cataract surgery, manual small incision cataract surgery and concurrent microinvasive glaucoma surgery in patients with ocular hypertension and glaucoma will also be needed.²⁰

Interestingly, approximately 40% of patients feared vision loss across all three categories of visual acuity, emphasizing that regardless of a patient's current vision, anxiety surrounding one's future vision remains. The presence of fear may persist, regardless of previous surgical experience, as studies are mixed with some suggesting greater anxiety prior to cataract surgery on their first eye compared to second eye cataract surgery,²¹ while others demonstrate there is no statistically significant difference in fear between patients prior to undergoing their first cataract surgery and patients undergoing their second cataract surgery.²²

Conclusion

In our patient population, neither health literacy nor understanding of cataract pathology correlated with fear of cataract surgery. However, patients who feared surgery were less likely to believe it would improve vision. Thus, addressing patient fears and clarifying surgical goals should be prioritized, particularly for those with early, non-visually significant

cataracts. This study, conducted in an urban safety-net hospital, has limited generalizability due to its small sample size of 42 patients, despite the relatively common nature of a cataract diagnosis.

We aimed to represent vulnerable patients in a safety-net population but given the nature of a cross-sectional survey study, the participants may not be representative. As we defined health literacy, only 20% of patients surveyed scored less than 7 points on the REALM-SF, and thus, would be considered “lower health literacy”. This may be secondary to the opt-in nature of the survey; the patients more willing to participate may be more health literate or less apprehensive of participation in studies that could expose documentation status. Additionally, the exclusion of non-English speakers due to the REALM-SF tool’s language limitation is another constraint. While patients with English as their second language are a vulnerable population, the need for interpretation and translation would have acted as confounders. Further research should include diverse environments and populations to investigate its generalizability: non-safety net hospitals, patients with English as their second language, insured patients, rural areas, other geographic regions outside of the Midwest, and countries other than the United States. Additionally, prospective studies, in which a cohort of patients with cataracts have their level of fear recorded prior to and after a counseling session targeted towards patient questions and concerns, are necessary to determine the value of education in the perioperative period for quelling patient fears.

Disclosure

The abstract of this paper was presented at the Association for Research in Vision and Ophthalmology Conference as a poster presentation with interim findings. The poster’s abstract was published in “2024 Abstract Issue” in Investigative Ophthalmology & Visual Science: <https://iovs.arvojournals.org/article.aspx?articleid=2799048>. The authors report no conflicts of interest in this work. This study was not supported by funding.

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