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# Glaucoma patient-provider communication about vision quality-of-life

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## Abstract

**Objective**—The purpose of this study was to: (a) describe the extent to which ophthalmologists and glaucoma patients discuss vision quality-of-life during office visits, and (b) examine the

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association between patient and ophthalmologist characteristics and provider-patient communication about vision quality-of-life.

**Methods—**Patients with glaucoma who were newly prescribed or on glaucoma medications were recruited at six ophthalmology clinics. Patients' visits were video-tape recorded and quality-of-life communication variables were coded. Generalized estimating equations were used to analyze the data.

**Results—**Two hundred and seventy-nine patients participated. Specific glaucoma quality-of-life domains were discussed during only 13% of visits. Older patients were significantly more likely to discuss one or more vision quality-of-life domains than younger patients. African American patients were significantly less likely to make statements about their vision quality-of-life and providers were less likely to ask them one or more vision quality-of-life questions than non-African American patients.

**Conclusion—**Eye care providers and patients infrequently discussed the patient's vision quality-of-life during glaucoma visits. African American patients were less likely to communicate about vision quality-of-life than non-African American patients.

**Practice Implications—**Eye care providers should make sure to discuss vision quality-of-life with glaucoma patients.

## Keywords

glaucoma; quality-of-life; vision loss; communication; patient question-asking

## 1. Introduction

Glaucoma is one of the leading causes of blindness and visual disability. An estimated 1.5 million Americans suffer from glaucoma while approximately 120,000 of them have been blinded by the disease [1]. Between 9 and 12% of all blindness in the United States is attributed to glaucoma [1]. One of the goals of Healthy People 2020 is to reduce glaucoma-related visual impairment [2].

The loss of visual abilities can profoundly impact a person's quality of life by limiting everyday tasks such as reading or walking [3]. Work in other disease areas has found that physicians tend to focus on symptoms and treatments rather than on patients' ability to participate in meaningful life activities [4, 5]. This may be because it is difficult for patients to bring up meaningful life activities during medical visits naturally or some patients might prefer that their physicians start the quality-of-life discussion [6]. Nonetheless, empowering and involving patients in decisions made during medical visits can improve patient quality-of-life [7-12].

It is important for ophthalmologists to discuss vision quality-of-life with glaucoma patients during visits to assess what aspects of the patient's vision are being negatively impacted by the disease. To our knowledge, prior research has not examined the extent to which ophthalmologists and glaucoma patients discuss specific aspects of a patient's vision quality of life such as seeing at night or adjusting to bright lights. The objectives of the study were to: (a) describe the extent to which ophthalmologists and glaucoma patients discuss vision

quality-of-life during visits, and (b) examine the association between patient and ophthalmologist characteristics and provider-patient communication about vision quality-of-life.

## 2. Methods

### 2.1 Procedure

Enrollment for this study took place between 2009 and 2012. The study was conducted at six ophthalmology clinics located in four states in the United States. Four clinics were academic sites and two were private clinics. The academic sites were outpatient clinics that were affiliated the ophthalmology departments of universities. Providers completed a short demographic questionnaire after supplying written consent. English-speaking adults with glaucoma were referred by clinic staff to research assistants based at each clinic. Patient consent was then obtained. The eligibility criteria was that the patient had to: (1) speak English, (2) be at least 18 years old, (3) have a diagnosis of glaucoma or be considered a glaucoma suspect, (4) score at least 6 out of 10 on a mini mental status exam, and (5) be prescribed at least one glaucoma medication at the current medical visit. The medical visit was then video-tape recorded. Video-tapes were kept if they fit into one of two criteria: (a) the patient was diagnosed with glaucoma and glaucoma medications were prescribed for the first time or (b) patients had a glaucoma diagnosis and were already on glaucoma medications. Immediately after the visit, patients were interviewed.

The Institutional Review Boards at the University of North Carolina, Duke University, Emory University, and the University of Utah approved this study. The study was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) and was HIPAA compliant. The physicians **and patients** were blinded to the study's specific research questions.

### 2.2 Measurement

**2.2.1 Socio-demographic and Clinical Measures—**Self-reported patient age and years of education were **recorded** as self-reported continuous variables in years. Patient gender was **recorded** as a dichotomous variable (male, female). Self-reported race was **recorded** as a categorical variable (white, African American, Asian, Native American, and Hispanic). Self-reported race was then recoded into a dichotomous variable (African American and non-African American). Therefore, we wanted to be able to examine if there were differences between African American and non-African American patients because previous studies have found that African American glaucoma patients often have worse patient outcomes [1, 2, 13-24]. The number of glaucoma medications a patient was taking was recorded as a continuous variable and then recoded as a dichotomous variable because the majority of patients were on one or two medications (one medication versus two or more). Whether the patient was a new user of glaucoma medications was recorded as a dichotomous variable (yes/no). Glaucoma severity was extracted from the patients' medical records. The severity of glaucoma for each eye was classified using the mean deviation of the eye from the last reliable visual field and recorded as mild, moderate, or severe [25]. The length of the visit was measured in minutes.

Self-reported provider age was measured in years as a continuous variable. Self-reported provider gender was measured as a dichotomous variable. Self-reported provider race was measured as a categorical variable (White, African American, Asian, Native American, and Hispanic).

Each subject received the Rapid Estimate of Adult Literacy in Medicine (REALM) so that we could control for patient reading level in our analyses [26]. This is a validated, rapid screening instrument designed to identify patients who have difficulty reading common medical and lay terms that are routinely used in patient education materials [26]. We chose the REALM because it has high face validity and high criterion validity and it only takes two to three minutes to administer and score [26]. Patient scores on the REALM correspond to reading levels (score of 0-60=eighth grade and below, 61-66=ninth grade and above).

The 12-item Duke Social Support Index was used to measure social support; it has an internal consistency of 0.81 [27, 28]. Items are scored on a scale of 1 to 3, resulting in a total score range of 3 to 21, with higher scores indicating a higher level of perceived social support.

We used the 9-item validated Patient Health Questionnaire (PHQ) to measure depressive symptoms[29]. Scores on the PHQ range from 0 to 27 with higher scores indicating increased depressive symptoms[29].

**2.2.2 Communication Measures—**All video-tapes were transcribed and identifiers were removed. A coding tool was developed using the 15-item Glaucoma Quality of Life-15 (GQL-15) scale as a guide[30]. The GQL-15 is a validated quality-of-life instrument[30]. We took the fifteen areas which are considered important quality of life areas for glaucoma patients and created a coding tool which research assistants used to code whether these fifteen important quality-of-life areas were discussed during patient visits [30]. The coders recorded whether a discussion occurred during the visit (yes/no) in the following <u>fifteen</u> domains: reading items up close, seeing at night, adjusting to bright lights, adjusting to dim lights, seeing objects from the other side, walking on uneven ground, bumping into objects, crossing the road, finding dropped objects, going from a light to dark room, or vice versa, judging distance of foot/step to curb, recognizing faces, tripping over objects, walking after dark, and walking on steps or stairs. Coders recorded whether the provider or patient initiated the discussion in each quality-of-life area. Coders also recorded if glaucoma-related vision loss was discussed and whether the provider or patient initiated the discussion. Since patients had more than one eye condition and it was difficult to ascertain which condition they were talking about when discussing vision quality-of-life, the coders recorded any discussions that occurred.

Using this tool, two research assistants with medical backgrounds coded the same 30 transcripts to establish inter-rater reliability using the intraclass correlation coefficient. Inter-rater reliability was 1.0 for whether one or more of the GQL-15 quality-of-life domains were discussed, 1.0 for whether glaucoma-related vision loss was discussed, 1.0 for whether the provider asked the patient one or more questions about their vision quality-of-life, 0.92 for

whether the patient made one or more statements about their vision quality-of-life, and 0.79 for whether the patient asked one or more questions about their vision quality-of-life.

**2.2.3 Analysis—**We set the a priori level of statistical significance at p < 0.05. First, we ran descriptive statistics. Second, we examined the bivariate relationships between variables using Pearson correlation coefficients, chi-square statistics, and t-tests as appropriate. We conducted generalized estimating equations (GEE) to examine how patient age, gender, race, health literacy, depressive symptoms, newly prescribed glaucoma medications, social support, glaucoma severity, length of visit, physician age, and physician gender were associated with a discussion of one or more specific vision quality-of-life domains, a discussion of glaucoma-related vision loss, whether the patient makes one or more statements about vision quality-of-life, and whether the ophthalmologist asks the patient one or more questions about vision quality-of-life. Ophthalmologist race could not be used in the GEE analyses because there was only one African American physician. We nested patients within physicians when running our GEE. We did not conduct a GEE predicting patient question-asking because too few patients asked questions about their vision quality-of-life.

## 3. Results

Fifteen physicians who cared for glaucoma patients agreed to participate in the study; one physician refused to participate for a participation rate of 94%. Fourteen physicians were White and one was African American. Ten physicians were male (66.7%). Physician age ranged from 26 to 66 years (mean 40.8 years, standard deviation 11.7 years).

Eighty-six percent (N=279) of eligible patients who approached the research assistant to learn more about the study were enrolled in the study. We did not have information on the characteristics of those who chose not to participate. We had useable office visit video-tapes for 276 out of the 279 patients.

Table 1 presents the patient demographics. Forty-one percent of the sample was male and 35.5% were African American. Eighteen percent of patients were prescribed glaucoma medications for the first time. Thirty-seven percent of visits included discussions of eye conditions other than glaucoma such as cataracts, retinal issues, and macular degeneration.

Table 2 presents the specific 15 quality-of-life domains that were discussed during the visits and whether glaucoma-related vision loss was discussed during visits. During 13 percent of the visits one or more of the specific glaucoma quality-of-life domains were discussed. The quality-of-life domains most often discussed included: reading items up close (9.3%) and seeing at night (3.6%). Many of the quality-of-life domains were not discussed at all. Out of the 35 visits in which specific vision quality-of-life domains were discussed, one area was discussed in 28 visits, two domains in 6 visits, and four domains in 1 visit. Overwhelmingly, patients initiated the discussion of quality-of-life domains. Patients always initiated the discussion of walking on uneven ground, adjusting to bright lights, adjusting to dim lights, and seeing objects from the other side. Patients initiated the discussion of reading 73% of the time (19 out of 26) and seeing at night 90% of the time (9 out of 10).

Table 3 presents the GEE results predicting whether one or more of the 15 specific glaucoma quality-of-life-domains were discussed. Older patients were significantly more likely to discuss one or more specific quality-of-life domains than younger patients (odds ratio=1.04, 95% confidence interval 1.01, 1.09). No other patient characteristics, including glaucoma severity, were significantly associated with whether one or more quality-of-life domains were discussed during visits.

Glaucoma-related vision loss was discussed during 12% of visits. Providers initiated the discussion about vision loss 71% (24 out of 34) of the time. Table 3 presents the GEE results predicting whether glaucoma-related vision loss was discussed during visits. African American patients were significantly less likely to discuss glaucoma-related vision loss during visits than non-African American patients (odds ratio=0.35, 95% confidence interval 0.16, 0.79). Patients with more depressive symptoms (odds ratio=1.14, 95% confidence interval 1.06, 1.22) and those who had longer medical visits (odds ratio=1.03, 95% confidence interval=1.01, 1.05) were significantly more likely to discuss glaucoma-related vision loss. Vision loss was significantly less likely to be discussed during visits with female ophthalmologists (odds ratio=0.53, 95% confidence interval=0.35, 0.79).

Patients made statements about their vision quality-of-life during 19% of the visits. An example of a patient making a statement about their vision quality-of-life is included below.

Patient-"Like I said I bowl and I used to be able to put in one and I could see…"

Doctor-"Down the lane?"

Patient-"The pins. Well I can see down there now. But I used to be able to put on the glasses and it would sharpen them. Like the pins might have a little fuzz to them but when I…"

Doctor-"Not sharp? It's possible that maybe you've switched a little bit."

Table 4 presents the GEE results predicting whether patients made statements about their vision quality-of-life. Older patients were significantly more likely to make one or more statements than younger patients (odds ratio=1.02, 95% confidence interval=1.01, 1.04), whereas African American patients were significantly less likely to make one or more statements than non-African American patients (odds ratio=0.55, 95% confidence interval=0.33, 0.91).

Patients asked one or more questions about their vision quality-of-life during 5.4% of visits. When patients asked questions, they asked about being able to preserve their sight and being able to see to read and to drive. Some sample patient questions about their vision quality-of-life are included below:

"Now as long as I do this should I be able to maintain my eyesight?"

"What are the chances of me retaining my sight?"

"Can I see with it? I mean can I drive?"

"I'm not going to go blind am I?"

Providers asked questions about vision quality-of-life during 12% of visits. An example of an ophthalmologist talking with a patient about quality-of-life is below:

Doctor-"would you say you vision is…?"

Patient-"I'd say it is okay."

Doctor-"Okay so you're able to drive, read watch television, do the things you want to do?"

Patient-"Yeah, I don't watch television. I'll read, I read books in my spare time activity."

Table 5 presents the GEE results predicting whether the ophthalmologist asked one or more questions about vision quality-of-life. Ophthalmologists were significantly less likely to ask one or more questions about vision quality-of-life during visits with African American patients (odds ratio=0.16, 95% confidence interval=0.04, 0.68). Ophthalmologists were significantly more likely to ask patients who had more depressive symptoms one or more questions about quality-of-life (odds ratio=1.11, 95% confidence interval=1.01, 1.24). Ophthalmologists were also significantly more likely to ask patients one or more questions about quality-of-life during longer medical visits (odds ratio=1.02, 95% confidence interval=1.01, 1.03).

## 4. Discussion and Conclusion

### 4.1 Discussion

We found that providers and glaucoma patients infrequently discussed the patient's vision quality-of-life. Vision quality-of-life domains were coded even if patients had more than one eye condition. Our findings are similar to prior research done in dermatology which found that little information concerning quality-of-life was elicited during dermatology outpatient visits [31]. Similarly, Underhill et al. [32] found that most of the cancer providers that they interviewed expressed a need for guidance on how to have sensitive symptom and quality-of-life communication with patients.

Our coding tool was developed using the glaucoma quality-of-life questionnaire that asks patients about 15 different domains of vision quality-of-life. It is interesting that patients and providers infrequently discussed these important quality-of-life domains, and if they did, it was the patient who usually brought up the concerns. Providers should consider talking with patients more about their vision quality-of-life. Future research should examine if optometrists and other eye care providers discuss quality-of-life and vision loss more often than ophthalmologists. David et al. [31] found that nurses had more quality-of-life discussions with patients than dermatologists did in outpatient dermatology clinics.

Ophthalmologists were significantly more likely to ask patients one or more questions about vision related loss and glaucoma related vision loss was significantly more likely to be discussed during longer visits. Ophthalmologists should consider asking about glaucoma related vision loss even if it might increase length of visit, because it might help them be

able to make better treatment related decisions if they understand how the patient's glaucoma is impacting their quality-of-life. Providers could ask an open-ended question such as "How would you say your vision is?" and then probe with more specific prompts such as "are you able to drive?", "are you able to read?", or "are you able to do the things you want to do?" Providers could ask patients what vision quality-of-life domains are most important to them and discuss strategies on how to improve their quality-of-life if it is possible. Also, patients could be encouraged to ask their providers questions about their vision quality-of-life.

Providers should also regularly monitor a patient's vision quality-of-life over time by asking questions about glaucoma-related vision quality-of-life at each visit. Providers should especially consider asking African American and younger patients about their vision quality-of-life since African American and younger patients were less likely to make statements about and ask questions about their vision quality-of-life. Additionally we found that ophthalmologists were significantly more likely to discuss glaucoma-related vision loss with patients with more depressive symptoms and they were more likely to ask glaucoma patients with more depressive symptoms about their vision related quality-of-life.

Future research should test interventions designed to improve ophthalmologist-glaucoma patient communication about quality-of-life. In the cancer area, during the visits of patients who completed an electronic quality-of-life questionnaire prior to visits with their providers, there was a significant increase in the number of provider questions about daily activities and emotional functioning [9]. The researchers also found discussing quality-of-life results helped build rapport and improve communication between the patient and their provider during the visits [9]. In primary care settings, Daaleman et al. [33] implemented a geriatric quality-of-life module that appeared during the intake portion of a visit in the electronic health record. Researchers found that if the quality-of-life module was used during visits that then audio-taped visits were rated as more patient-centered [34]. Interventions like these could be modified and tested in ophthalmology settings.

Female physicians were less likely to discuss glaucoma-related vision loss with patients than male physicians. Much of this could be due to patients not initiating a vision quality-of-life discussion with them. Future research should examine why female physicians were less likely to discuss glaucoma-related vision loss. Our results are contrary to prior work which has found that female physicians tend to be more patient-centered than male physicians [35, 36]. Future research using larger physician samples should examine how ophthalmologist gender is associated with communication during glaucoma visits to help understand why we found results that are contrary to prior work [35, 36].

This study has several limitations. Providers and patients both knew the visit was being recorded but they did not know the study hypotheses. Our study is limited in that we could not track the characteristics of non-participants so we cannot compare the characteristics of participants and non-participants. Another limitation is that our study was exploratory in nature so the results should be interpreted with care and our work should be followed with additional confirmatory studies. Additionally, our study lacked variation in physician race and how race might affect physician-patient communication and adherence.

### 4.2 Conclusion

Eye care providers and patients infrequently discussed the patient's vision quality-of-life during glaucoma visits. African American patients were less likely to communicate about vision quality-of-life than non-African American patients. Despite our study limitations, our research presents new information on how infrequently eye care providers and patients discuss vision quality-of-life and what demographic characteristics influence whether vision quality-of-life is discussed.

### 4.3 Practice Implications

Eye care providers and patients should attempt to discuss vision quality-of-life more during glaucoma visits. Providers could ask patients what vision quality-of-life domains are most important to them and discuss potential strategies on how to improve their quality-of-life. Also, patients could be encouraged to ask their providers questions about their vision quality-of-life.

I confirm all patient/personal identifiers have been removed or disguised so the patient/ person(s) described are not identifiable and cannot be identified through the details of the story.

## Acknowledgments

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**Highlights**

- African American patients were less likely to talk about vision quality-of-life.

- Specific glaucoma quality-of-life domains were only discussed during 13% of visits.

- Glaucoma-related vision loss was only discussed during 15% of visits.

- Providers were less likely to ask African Americans about vision quality-of-life.

- Older patients were more likely to discuss vision quality-of-life domains.

**Table 1**

**Subject Characteristics (N=279)**

|  | Percent (N) |
|---|---|
| **Gender** | |
| Male | 40.9 (144) |
| Female | 59.1 (165) |
| **Race** | |
| African American | 35.5 (99) |
| Non-African American | 64.2 (179) |
| **Newly prescribed glaucoma medications at visit or was on glaucoma medication before visit** | |
| Newly prescribed at visit | 18.3 (51) |
| Was on glaucoma medications before visit | 81.7 (228) |
| **Glaucoma severity (worse eye)** | |
| Mild | 58.1 (162) |
| Moderate | 19.7 (55) |
| Severe | 16.1 (45) |
| **Rapid Estimate of Adult Literacy in Medicine** | |
| Eighth grade or lower | 14.0 (39) |
| Ninth grade or higher | 84.2 (235) |
|  | **Range; Mean (Standard Deviation)** |
| **Age in years** | 21 to 93; 65.8 ± 12.8 |
| **Patient Health Questionnaire (PHQ)-9 score** | 0 to 18; 2.18 (3.3) |
| **Duke Social Support Index** | 9 to 21; 17.8 (1.9) |
| **Length of Visit in minutes** | 2.3 to 86.5; 19.2 (15.9) |

**Table 2**

**Discussions about glaucoma quality-of-life domains and glaucoma-related vision loss (N=275)**

| Domains discussed | Percent (N) |
|---|---|
| Glaucoma quality-of-life | |
| Reading items up close, such as newspapers, magazines, online articles | |
| Reading items up close, such as newspapers, magazines, online articles | 9.3 (26) |
| Seeing at night | 3.6 (10) |
| Adjusting to bright lights | 1.8 (5) |
| Adjusting to dim lights | 0.4 (1) |
| Seeing objects coming from the other side | 0.4 (1) |
| Walking on uneven ground | 0.4 (1) |
| Bumping into objects | 0 (0) |
| Crossing the road | 0 (0) |
| Finding dropped objects | 0 (0) |
| Going from a light to dark room, or vice versa | 0 (0) |
| Judging distance of foot/step to curb | 0 (0) |
| Recognizing faces | 0 (0) |
| Tripping over objects | 0 (0) |
| Walking after dark | 0 (0) |
| Walking on steps or stairs | 0 (0) |
| Glaucoma-related vision loss | 12.2 (34) |

**Table 3**

**Generalized estimating equation predicting whether one or more glaucoma quality-of-life-15 domains are discussed and whether glaucoma-related vision loss is discussed (n=275)**

| | One or more quality-of-life 15 domains discussed Odds Ratio 95% Confidence Interval | Glaucoma-related vision loss discussed Odds Ratio 95% Confidence Interval |
|---|---|---|
| REALM 8th grade and below | 0.39 (0.08, 1.99) | 1.02 (0.99, 1.04) |
| Patient Age | 1.04 (1.01, 1.09)** | 0.99 (0.95, 1.03) |
| Patient Gender-Female | 1.10 (0.48, 2.53) | 1.90 (0.63, 5.77) |
| Race-African American | 2.07 (0.85, 4.91) | 0.35 (0.16, 0.79)* |
| Patient Health Questionnaire (PHQ)-9 Raw Score | 0.97 (0.83, 1.13) | 1.14 (1.06, 1.22)*** |
| Newly prescribed glaucoma medications | 0.44 (0.07, 2.69) | 0.71 (0.23, 2.25) |
| Duke Social Support Index | 0.97 (0.76, 2.69) | 0.99 (0.80, 1.22) |
| Glaucoma severity | 1.01 (0.99, 1.03) | 0.97 (0.94, 1.01) |
| Length of visit | 1.02 (0.99, 1.04) | 1.03 (1.01, 1.05)* |
| Physician Age | 0.99 (0.96, 1.04) | 0.98 (0.97, 1.01) |
| Physician Gender-Female | 1.43 (0.75, 2.72) | 0.53 (0.35, 0.79)** |

*
p <0.05,

**
p <0.01,

***
p <0.001

**Table 4**

**Generalized estimating equation predicting whether the patient makes one or more vision glaucoma quality-of-life statements (n=275)**

|  | One or more statements Odds Ratio 95% Confidence Interval |
| --- | --- |
| REALM 8th grade and below | 1.00 (0.99, 1.03) |
| Patient Age | 1.02 (1.01, 1.04) [*] |
| Patient Gender-Female | 1.80 (0.99, 3.29) |
| Race-African American | 0.55 (0.33, 0.91) [*] |
| Patient Health Questionnaire (PHQ)-9 Raw Score | 1.03 (0.94, 1.12) |
| Newly prescribed glaucoma medications | 0.58 (0.26, 1.30) |
| Duke Social Support Index | 0.95 (0.84, 1.07) |
| Glaucoma severity | 0.99 (0.97, 1.01) |
| Length of visit | 1.02 (0.99, 1.04) |
| Physician Age | 0.98 (0.97, 1.01) |
| Physician Gender-Female | 0.99 (0.58, 1.69) |

[*]
$p < 0.05$,

[**]
$p < 0.01$,

[***]
$p < 0.001$

**Table 5**

**Generalized estimating equation predicting whether the ophthalmologist asks one or more questions about vision quality-of-life (n=275)**

|  | Odds Ratio 95% Confidence Interval |
|---|---|
| REALM 8th grade and below | 1.01 (0.97, 1.04) |
| Patient Age | 0.98 (0.94, 1.04) |
| Patient Gender-Female | 1.18 (0.38, 3.71) |
| Race-African American | 0.16 (0.04, 0.68) * |
| Patient Health Questionnaire (PHQ)-9 Raw Score | 1.11 (1.01, 1.24) * |
| Newly prescribed glaucoma medications | 0.31 (0.08, 1.20) |
| Duke Social Support Index | 0.99 (0.84, 1.18) |
| Glaucoma severity | 0.99 (0.94, 1.04) |
| Length of visit | 1.02 (1.01, 1.03) ** |
| Physician Age | 0.99 (0.96, 1.02) |
| Physician Gender-Female | 1.47 (0.60, 3.59) |

*
p <0.05,

**
p <0.01,

***
p <0.001