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African American Patient Preferences for Glaucoma Education

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Abstract

Purpose—The objectives of the study were to examine: (a) the types of questions that African American patients have about glaucoma for their providers and (b) how patients' socio-demographic characteristics are associated with where and from whom they would like to learn about glaucoma and glaucoma medications.

Methods—Forty-nine Adult African American patients with glaucoma were recruited at a private ophthalmology clinic where they completed a questionnaire for this cross-sectional study.

Results—African American patients had a mean of 3.9 questions for their ophthalmologists; the questions that patients checked as having most often were "What is my prognosis with glaucoma?" (49%) and "What is my intraocular pressure?" (45%). Seventy-six percent of patients preferred that an educational program about glaucoma be offered at the doctor's office and 39% preferred it be offered at a community or senior citizen center. Ninety percent said that the education program should be offered by doctors. Patients under the age of seventy were significantly more likely to want a program on the Internet than patients age seventy and over (Pearson chi-square=4.7, p=0.03). If an educational program was developed patients reported being most interested in the following topics, glaucoma medications (84%), what is glaucoma and what does it mean to have it (83%).

Conclusions—African American patients have many questions about glaucoma for their eye care providers. African American patients would prefer glaucoma educational programs be offered at their provider's office. Our findings could be used to develop educational programs for African American patients with glaucoma.

Keywords

African American; glaucoma; educational needs; disparities; communication

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Between 9% and 12% of blindness in the United States is attributed to glaucoma.[1] The prevalence of open-angle glaucoma in African Americans ranges from 4% (age 50 to 59) to 13% (age 80-89).[2] Prevalence studies in the United States have found that the prevalence of glaucoma and blindness from glaucoma are higher in African Americans than Caucasians; African Americans are five times more likely to be diagnosed with glaucoma than Caucasians and are six times more likely to go blind from it.[3] Thus, glaucoma remains the leading cause of irreversible blindness among African Americans.[4]

Proper use of glaucoma medications can lower intraocular pressure and reduce the progression of glaucoma.[5] Our prior work found that African Americans were significantly less likely to be educated about glaucoma by their providers and they were significantly less likely to be adherent to their glaucoma medications.[6-9] Additionally, prior research also found that African Americans were less likely to be adherent to their glaucoma medications than Caucasians.[10-12]

Prior studies have demonstrated that educational interventions targeted to African Americans can have a positive effect on the utilization of eye care services and on the beliefs about the importance of annual eye exams. Studies involving African Americans have found that distribution of educational material and telephone follow-up that emphasized the importance of routine eye care improved the rate of diabetic retinopathy screening.[13-15] Additionally, research has shown that education targeted to African Americans which conveyed the importance of the annual eye care exam was retained 3 to 6 months later.[16-18] However, these studies primarily targeted education to patients about the importance of routine eye exams or diabetic retinopathy screening, and not glaucoma.[16-18]

The National Eye Institute, the Office of Women's Health at the National Institutes of Health, and the Glaucoma Research Foundation all emphasize the importance of improving African American patients' understanding of glaucoma and its treatment so disparities in outcomes can be reduced.[3, 19, 20] Prior work has also found that African American eye care patients were more likely to be interested in learning about glaucoma than patients of other races.[21]

To our knowledge, little is known about how African American patients want to learn about glaucoma, who they would like to learn it from, what questions they have about glaucoma, and what types of educational programs they would like offered. Therefore, the objectives of the study were to examine: (a) the types of questions that African American patients have about glaucoma for their providers and (b) how patients' socio-demographic characteristics are associated with where and from whom they would like to learn about glaucoma and glaucoma medications.

METHODS

Procedures

This study was approved by the University of North Carolina Institutional Review Board. This study was conducted at a single private practice site and used a cross-sectional design. Consecutive patients who were scheduled for their routine glaucoma medical visit at this

private practice were approached by the clinic-based research assistant to see if they wanted to learn about the study. Patients were eligible for the study if they: (a) had a diagnosis of glaucoma, (b) were English speaking, (c) were age 18 or older, (d) were African American, and (e) were using one or more topical hypotensive medications for glaucoma. If patients agreed to participate and met eligibility criteria, then they were asked to complete the questionnaire prior to their medical visit. Patients received $10 for completing the questionnaire.

Measurement

Demographic Characteristics—Patient years of education was measured as a continuous variable. Age was measured in categories and then recoded into less than seventy years versus seventy years or older. Gender was measured as a dichotomous variable. The number of glaucoma medications a patient was taking was measured as a continuous variable. Length of time with glaucoma was measured with the following response categories: two years or less, more than two years to less than five years, or five years or more. Which eye the patient has glaucoma in was measured as right, left, or both. Whether the patient administers their own drops was measured using the following response categories: always, most of the time, some of the time, or never.

Educational Needs and Preferences for Educational Programs

Patients were presented with a list of eighteen questions about glaucoma and glaucoma medications. The list of questions was created using the transcripts of actual video-taped glaucoma visits from a National Eye Institute study that included patients from six ophthalmology clinics.[22] Our prior research team which oversaw the coding of patient question-asking from the transcripts of patients visits included five ophthalmologists and three communication/health behavior experts and the methods are described elsewhere.[14] In addition to the 18 questions on the list that patients could check, there was an area where patients could write in any other questions that they had.

In the current study, patients were asked to check which questions they wanted to ask their providers about glaucoma and glaucoma medications. Then, a summary score of the number of questions each patient checked was created.

Additionally, patients were asked where they would like an educational program about glaucoma to be located: friends and/or family members, doctor's office, pharmacy, internet, television, at a community center or senior citizen center, church, or other (with space to write where the other place was). Patients could choose more than one place. Dichotomous (yes/no) variables were then created for each location that patients stated where they would like a glaucoma educational program to be held. Patients were also asked: (a) who should present the educational program on glaucoma: doctor, nurse, pharmacist, ophthalmic technician, a patient with glaucoma, or other (with space to write in who else they think should present it) and (b) what topics they would want covered in an educational program about glaucoma: how to use eye drops, what is glaucoma and what it means to have it, what is intraocular pressure, glaucoma medications and other glaucoma treatments, and other (with space to write in other topics they wanted covered). Patients could choose more than

one response for each of these variables. Patients were also asked whether they wanted to learn about glaucoma and glaucoma medications individually or in groups.

Analysis

Descriptive statistics were run for all variables. Next, bivariate relationships were assessed using t-tests, Pearson correlation coefficients, or Pearson chi-square statistics.

RESULTS

Forty-nine African American patients were enrolled and completed the study. Table 1 presents the patient demographics. The study population was 63% female and 90% were age 60 years or older. Most patients had glaucoma for 5 years or longer, and patients had a mean of 12.8 years of schooling. More educated patients were significantly more likely to administer their eye drops always on their own than less educated patients (t-test= 2.9, p=0.03). Older patients were significantly more likely to be on fewer glaucoma medications than younger patients (Pearson correlation coefficient=−0.34, p=0.01).

Patients had a mean of 3.9 questions for their ophthalmologists (standard deviation 3.2; range 0 to 14). Table 2 presents the questions that patients stated they wanted to ask their ophthalmologist. The questions that patients checked as having most often were: “What is my prognosis with glaucoma?” (49%), “What is my intraocular pressure?” (45%), “Where should I store my glaucoma medications? (37%)”, “What are the side effects of my glaucoma medications?” (33%) and “How long will I be using my glaucoma medications (33%)?”. None of the patient socio-demographics were significantly associated with the number of questions that patients had for their ophthalmologists.

Table 3 presents where patients reported currently learning about glaucoma and glaucoma medications. Patients most commonly cited the doctor's office as the place where they go to learn about glaucoma (43%) and glaucoma medications (25%). The Internet was the second most common place that patients reported looking for information about glaucoma (16%) and glaucoma medications (10%).

Table 3 also presents where patients reported that they would like to learn about glaucoma and glaucoma medications. Not surprisingly, 76% of patients preferred that an educational program about glaucoma be offered at the doctor's office. Eighty percent of the patients said they would want to be educated individually and not in groups.

Patients also suggested that glaucoma education programs should be offered at community centers or senior citizen centers (39%), on television (37%), at churches (29%), at pharmacies (25%), and on the Internet (22%). Female patients were significantly more likely to want a glaucoma education program at a church than male patients (Pearson chi-square=4.25, p=0.039). More educated patients were significantly more likely to want an educational program at a church (t-test=2.6, p=0.02) and at a community center (t-test=3.5, p=0.001) than less educated patients. Patients under the age of seventy were significantly more likely to want a program on the Internet than patients age seventy and over (Pearson chi-square=4.7, p=0.03).

Ninety percent said that the education program should be offered by doctors, an option overwhelmingly preferred over ophthalmic technicians (25%), pharmacists (16%), nurses (10%), or patients with glaucoma (10%). More educated patients were significantly more likely to want an ophthalmic technician to offer an educational program than less educated patients (t-test= 2.5, p=0.02). Female patients were also significantly more likely to want an ophthalmic technician to offer an educational program than male patients (Pearson chi-square=5.5, p=0.02).

If an educational program was developed, patients reported wanting the following topics most often: glaucoma medications (84%), what is glaucoma and what does it mean to have it (83%), how to use eye drops (76%), and what is intraocular pressure (63%). None of the patient socio-demographics were significantly associated with what topics patients wanted glaucoma educational programs to focus on.

DISCUSSION

Even though the majority of the patients in our sample had glaucoma for more than five years, they had an average of almost four questions each for their ophthalmologists which means that even patients who have had glaucoma for years have questions for their eye care providers. Almost half of all patients had a question about their prognosis with glaucoma and about their intraocular pressure. Almost a third of patients wanted to know about their glaucoma medication side effects.

Although the vast majority of the patients reported wanting a glaucoma education program at their doctor's office, it is interesting the second most popular choice was a community center or senior citizen center. Ophthalmology clinics and practices should consider offering educational programs to improve patient understanding of their glaucoma and enhance satisfaction with care. Herndon et al[23] found that only 28% of respondents reported changing eye doctors for reasons related to glaucoma, such as doctor providing little explanation about glaucoma or the medications used to treat it, patient having a differing view on goal intraocular pressure, patient having side effects with eye drop medications, and doctor switching eye drop medications too frequently, and of those, 60% cited poor communication as the reason. Improving patient understanding of their glaucoma and glaucoma medications could improve African American patient adherence to their glaucoma medications and their outcomes.[12] Thus, educational programs may also help reduce racial disparities in clinical outcomes for glaucoma patients. We also found that almost 30% of patients stated they would like an educational program at a church. Glaucoma specialists should consider offering educational and outreach programs at community centers and churches with African American patients.

African American patents under the age of seventy were more likely to want a program on the Internet. Perhaps Internet-based educational programs could be developed and presented either on-line or in the locations where the patients wanted to attend programs (e.g. doctor's office, community center). Doctors were the individuals that glaucoma patients most wanted to deliver an educational program followed by ophthalmologic technicians. Therefore, if Internet-based programs are developed, patients may prefer that physicians present the

educational information to patients followed next by ophthalmic technicians and pharmacists.

Less than a quarter of the patients stated that they would like a glaucoma educational program at a pharmacy. However, pharmacists are a potentially good source of information for patients, especially in regards to any glaucoma medication-related questions (e.g. medication side effects, administration of drops) they might have. Yet patients may not be aware of this because in many states, patients are only given an offer to receive pharmacist counseling about their medications.[24] If they refuse the offer, they do not receive any counseling. In fact since "glaucoma medications" was the top topic that patients wanted an educational program on, ophthalmology clinics might want to partner with local pharmacies to create educational programs that are focused on glaucoma medications to provide additional information about glaucoma medication, such as how to instill eye drops, how often the medication should be used, and the typical side effects of the medications as well as being available to answer any questions that patients may have about their glaucoma medications.

A limitation of our study is that we recruited patients from only one ophthalmology clinic so the results may not be generalizable to other settings. Another limitation is that the clinic could not track the characteristics of patients who declined to participate because of patient privacy protected by the Health Insurance Portability and Accountability Act (HIPAA). Additionally, the majority of our sample was age sixty or older and they had glaucoma for five or more years; hence, future research should include younger African American patients with glaucoma and those who have had glaucoma less than five years. Additionally, we did not collect information on patients' socioeconomic status so future research might include this as a measure. Another limitation is that we did not ask the participants whether they had asked the questions they said they had in a previous visit with their provider. Even if they had asked these questions in a previous visit, our findings could indicate that the provider did not fully explain the answers or that the patient was not satisfied with the answer received because the patient still recorded having the questions. Also, researcher bias may have been introduced by selecting questions to include on the list from the most commonly asked questions from a previous study that we conducted.[22] However, the questions selected for inclusion were the ones most frequently asked by glaucoma patients to their doctors and patients could write in other questions that they might have.

Our study provides important new information on how, what, and where African American patients want to learn more about glaucoma. Our findings could be used to develop future educational programs that are tailored specifically to the preferences of African American patients. Patients prefer that ophthalmologists deliver glaucoma educational programs, yet this may not always be possible. Alternative providers such as pharmacists or ophthalmic technicians, may be well suited to present the educational program depending on the topic and framework of the program.

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Table 1

Patient Demographic Characteristics (N=49).

	Percent (N)
Gender	
Male	36.7 (18)
Female	63.3 (31)
Race	
African American	100.0 (49)
Age	
18-59	10.0 (5)
60-69	18.4 (9)
70-79	40.8 (20)
80+	30.6 (15)
Number of Glaucoma Medications	
One	32.7 (16)
Two	44.9 (22)
Three	20.4 (10)
Four or more	2.0 (1)
Drop administration	
Sometimes or always gets help administering their drops	20.4 (10)
Always administers drops on their own	79.6 (39)
Which eye has glaucoma	
Right eye	2.0 (1)
Left eye	4.1 (2)
Both eyes	83.7 (41)
Length of time with glaucoma	
More than 1 year, but less than 2 years	2.0 (1)
More than 2 years, but less than 5 years	14.3 (7)
5 years or longer	83.7 (41)
	Range; Mean (Standard Deviation)
Years of schooling	6-20; 12.8 (3.2)

Table 2

Questions patients have most often for their providers about their glaucoma and glaucoma medications (N=49)

	Percent (N)
What is my prognosis with glaucoma?	49.0 (24)
What is my intraocular pressure?	44.9 (22)
Where should I store my glaucoma medications?	36.7 (18)
What are the side effects of my glaucoma medications?	32.7 (16)
How long will I be using glaucoma medications?	32.7 (16)
How much will my glaucoma medications cost?	30.6 (15)
Is it okay for me to take my glaucoma medications with other medications?	26.5 (13)
What is my goal intraocular pressure?	24.5 (12)
What should I do if I miss a dose of my glaucoma medication?	16.3 (8)
What can I do to lower the pressure in my eye(s)?	16.3 (8)
What is glaucoma and what causes it?	16.3 (8)
How long will a bottle of my glaucoma medication last?	14.3 (7)
Can you show me how to use my eye drops?	12.2 (6)
How does glaucoma affect my eyesight?	8.2 (4)
How is glaucoma treated?	8.2 (4)
In which eye(s) do I use my glaucoma medication and how many drops do I put in at once?	4.1 (2)
How many times a day do I use my glaucoma medications?	2.0 (1)
How long will it take for the glaucoma medications to start working?*	2.0 (1)
Ultimately, if all else fails, will I lose my eye sight?*	2.0 (1)
What signs should cause me to call the doctor?*	2.0 (1)
Is there a program to help with medication cost?*	2.0 (1)
When will I see better?*	2.0 (1)
Will my eyesight get worse in my left eye?*	2.0 (1)

*denotes that the participant wrote in this question

Table 3

Where patients reported learning more about glaucoma and glaucoma medications currently, where and by whom they would like a glaucoma education program to be offered, and what topics they would like covered in a glaucoma education program (N=49).

	Percent (N)
Where do you currently learn more about glaucoma?	
Friends or family members	6.1 (3)
Doctor's office	42.9 (21)
Pharmacy	6.1 (3)
Internet	16.3 (8)
Television	14.3 (7)
Community center or senior citizen center	2.0 (1)
Church	0.0 (0)
Other	4.1 (2)
Reading every article that can be found	2.0 (1)
Reading pamphlets and books	2.0 (1)
Where do you currently learn more about glaucoma medications?	
Friends or family members	0.0 (0)
Doctor's office	24.5 (12)
Pharmacy	8.2 (4)
Internet	10.2 (5)
Television	8.2 (4)
Community center or senior citizen center	0.0 (0)
Church	0.0 (0)
Other	0.0 (0)
If we developed a program to help glaucoma patients learn more about glaucoma and glaucoma medications, where should we offer a program?	
Friends or family members	10.2 (5)
Doctor's office	75.5 (37)
Pharmacy	24.5 (12)
Internet	22.4 (11)
Television	36.7 (18)
Community center or senior citizen center	38.8 (19)
Church	28.6 (14)
Other	4.1 (2)
Home	2.0 (1)
School	2.0 (1)
If we developed a program to help glaucoma patients learn more about glaucoma and glaucoma medications, who should offer the program?	
Doctor	89.8 (44)
Nurse	10.2 (5)
Pharmacist	16.3 (8)

	Percent (N)
Ophthalmic technician	24.5 (12)
Patient with glaucoma	10.2 (5)
Other	2.0(1)
No response/blank	2.0 (1)
If we developed a program to help glaucoma patients learn more about glaucoma and glaucoma medications, what information should be included?	
How to use eye drops	77.6 (38)
What is glaucoma and what it means to have it	87.8 (43)
What is intraocular pressure (IOP)	65.3 (32)
Glaucoma medications and other treatment	87.8 (43)
Other	8.2 (4)
Informal setting where any question can be asked	2.0 (1)
What can be done to prevent glaucoma	2.0 (1)
New findings on glaucoma	2.0 (1)
Resources available to patients	2.0 (1)
How to deal with losing eyesight	2.0 (1)