

Knowledge, Attitudes, and Beliefs about Dilated Eye Examinations among African-Americans

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PURPOSE. To understand factors that influence African-Americans' attitude toward eye examinations.

METHODS. Ten focus groups were conducted with 86 African-Americans. Four focus groups were conducted with people 65 years of age and older who had not received a dilated fundus examination (DFE) in the past 2 years, two groups were held with people 65 years of age and older who had had a recent DFE, and two groups each were held with people 40 to 64 years of age, with and without recent DFEs. Focus group interviews were conducted by using a moderator guide to address perceived benefits of and barriers to getting an eye examination; motivators for getting DFEs; and knowledge of eye examinations, glaucoma, and diabetic retinopathy. Participants also completed a questionnaire that provided demographic information. Quantitative and qualitative analyses were conducted.

RESULTS. Cost or lack of sufficient insurance was identified as the most important barrier to getting a DFE. Also frequently mentioned was not having any symptoms and being too busy. The most frequently cited benefit of getting a DFE was to help prevent eye disease, whereas the most frequently reported motivating factor was experiencing a vision problem. Regarding knowledge, many people did not know the risk factors for glaucoma, but seemed to have a better understanding of how to reduce the effects of diabetes on their eyes.

CONCLUSIONS. Study findings identified important links between financial resources and experiencing a vision problem and the adoption of preventive eye care in an urban African-American population. (*Invest Ophthalmol Vis Sci.* 2007;48:1989-1994) DOI:10.1167/iovs.06-0934

As the population of the United States continues to age, the public health impact of vision loss due to eye disease will continue to grow. Projections for the year 2020 are that 3.4 million people will be affected by glaucoma¹ and between 6.1 and 7.2 million people in the United States will have diabetic retinopathy.² African-Americans are at increased risk of glaucoma, with an estimated prevalence rate of 3.5% among Afri-

can-Americans compared with 1.6% in whites.³ African-Americans are also at increased risk of diabetes, with a prevalence rate of 13.3% in African-American adults compared with 8.7% in adult whites,⁴ which puts them at increased risk of diabetic retinopathy.

Although early detection and subsequent earlier treatment can prevent or delay eye disease,⁵⁻⁷ several studies have shown that people are not getting dilated fundus examinations (DFEs) according to recommended guidelines.⁸⁻¹² More than half the participants in a glaucoma screening program in Baltimore city reported not having an eye examination in the past 2 years.⁸ Studies have consistently shown that approximately one third of people with diabetes have not had an eye examination in the previous 2 years.⁸⁻¹⁰ In addition, African-Americans have fewer eye examinations than do whites,¹⁰⁻¹² despite African-Americans' increased prevalence of glaucoma^{1,3} and diabetes.^{2,4}

Increasing the proportion of people who have a dilated eye examination, which is one of the vision goals in Healthy People 2010,¹³ can have a major impact on the prevalence of eye disease, as well as people's quality of life. To achieve this goal, we need to develop, implement, and evaluate interventions to change people's attitudes toward DFEs. The first step in this process is to understand the factors that influence people's knowledge, attitudes, and beliefs about eye care.

To date there has been limited research into the factors that are associated with African-Americans obtaining dilated eye examinations,¹⁴⁻¹⁷ or the information needed by this population to promote informed decisions about preventive eye care.¹⁸ There has been a limited use of qualitative methodology in ophthalmology for understanding these issues from the patients' perspective, in particular patients' knowledge, attitudes, and beliefs about eye care.¹⁹⁻²² Qualitative research is well-suited to providing understanding and insight into how perception, experience and culture shape medical decision-making among the research population, and can provide in-depth explorations of multifaceted issues. As such, qualitative methodologies are complementary to the use of quantitative methods, such as large-scale surveys that can less readily capture complex issues of context and subjective meaning which inform decision-making.²³⁻²⁵ Focus groups, in particular, are a time-efficient method to collect rich qualitative data through a "process of disciplined inquiry that is systematic and verifiable."²⁶

To address the gap in understanding the factors associated with getting dilated eye examinations, we conducted focus group interviews with African-Americans 40 years of age and older. The study was designed to elucidate knowledge, attitudes, and beliefs regarding dilated fundus examinations in this population. We were particularly interested in the barriers that keep people from getting DFEs and the perceived benefits that may serve as motivators for getting DFEs. In addition, because of the increased prevalence of glaucoma and diabetes among African-Americans, a secondary objective was to assess people's knowledge about glaucoma, diabetes, and diabetic retinopathy.

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METHODS

Between October 2004 and May 2005, we conducted 10 focus groups with African-American participants. To explore the range of perceptions regarding DFEs, and to preserve homogeneity within the groups and reduce possible response effects, participants were grouped by age and DFE status. We were particularly interested in the opinions of older African-Americans who had not had a recent DFE. Therefore, four focus groups were conducted with people 65 years of age and older who had not undergone a DFE in the past 2 years. Two focus groups were held with people 65 and older but who reported having had a DFE in the past 2 years. Two focus groups were held with African-Americans 40 to 64 years of age who had not received a DFE in the past 2 years and two groups were conducted with those 40 to 64 years of age but who reported having had a DFE in the past 2 years. Focus groups ranged in size from 5 to 11 participants. This research adhered to the tenets of the Declaration of Helsinki. We obtained Institutional Review Board approval for the study, and informed consent was obtained from all participants.

We recruited participants for the focus groups through print advertisements, radio announcements, flyers, and word of mouth. Interested people were screened for eligibility before assignment to the appropriate focus group. Potential participants were asked whether they were African-American and when they had their last dilated eye examination, with an explanation of a DFE provided. The focus group interviews were conducted at community sites that were easily accessible by the participants. Each focus group lasted from 1.5 to 2 hours, depending on the amount of participant discussion. Participants were paid \$25 to compensate them for their time.

Two trained experienced moderators, one of whom was African-American, facilitated the sessions. To ensure comparability between sessions, the moderators used the same guide, the wording of which differed based on whether or not the people within the group had undergone a DFE within the past 2 years. The moderator guide included opening remarks about the focus group process, introductions by the participants, and information about eye exams. Topics addressed in the focus group discussions were rates of DFEs and reported eye problems, perceived barriers and benefits of getting an eye examination, motivators for getting DFEs, knowledge of eye examinations, glaucoma, and diabetic retinopathy, and physician communication.

Focus group sessions were tape recorded and a note taker served as a backup recorder for each session. Once data from focus groups was fully transcribed, two types of analysis were undertaken. Initially, basic categorical answers to specific inquiries were subjected to descriptive analysis. The second type of qualitative data analysis involved both areas of inquiry driven by specific research questions and those themes that emerged from participants' own perspectives and conclusions. A codebook was constructed and the data were coded by thematic area and area of inquiry (Ethnograph data analysis software; Qualis Research Associates, Colorado Springs, CO).²⁶ At several points in the process, the data and codes were checked for consistency and to maintain objectivity. An audit trail was also carefully maintained throughout the analysis, to maximize reliability.²⁴

Data reduction was accomplished through a coded sort in the software, which identified key concepts within thematic and inquiry categories. These key concepts, which were derived from participant statements, were further reduced to form hypotheses that were then tested against rival hypotheses and through a search for disagreement.^{27,28} Minimal disagreement was indicative of consensus among participants. Key concepts were finally presented in the reporting format through narrative and the use of participants' statements. We examined focus group data by age groups and eye examination status, but use examples from the group as a whole to illustrate key concepts.

A brief questionnaire was completed by focus group participants before the start of the focus group discussions. Information about participant characteristics was collected, including age, gender, educational level, type of insurance, and income. Demographic variables were compared by eye examination status and age groups, using the

Fisher exact test for the categorical variables and the *t*-test for mean age. Missing and "don't know" responses were excluded from the analysis.

RESULTS

The demographic questionnaire was used to analyze participant characteristics. All other analysis is based on focus group discussions.

Participant Characteristics

A total of 223 people contacted us about the study. Eighteen people could not be reached or did not return our calls, 9 were younger than 40 years, 23 were not interested in the study, and 6 were not available at the time of the focus groups. We therefore had a pool of 167 people, from which a purposeful sample was selected.

Of the 86 participants in the focus groups, 33 were 40 to 64 years of age and the remaining 53 were 65 years of age or older. Fifty-eight participated in the groups without recent DFEs and 28 participated in the DFE groups. As shown in Table 1, our study population was more than 70% female, compared with 54% of the African-American population in Baltimore City.²⁹ Our population was more educated than the general population, with 54% of the participants having a post-high school education compared with 40% of the Baltimore city African-American population.²⁹ Overall, 74% of the participants reported a yearly income of less than \$35,000, compared with 57% of the Baltimore city African-American population.²⁹ Participants most often went to an eye doctor for their eye care, with 7% reporting that they did not go to anyone for their eye care. Six (7%) participants reported that they had glaucoma, and 19% reported that they had diabetes. Of these 16 individuals, 7 (44%) reported that diabetes had affected their eyes. Thirteen (81%) of the diabetics had not had a dilated eye examination in the past 2 years, including five of the participants who reported that they had diabetic retinopathy.

The mean age of the participants in the dilated eye examination group was 63.9 years compared with 63.5 years in the group that had not had a recent eye examination. As shown in Table 1, there were no statistically significant differences by eye examination status for any of the variables. We also compared these variables by assigned age group, and found a statistically significant difference in income and insurance status (Table 1). As might be expected, people in the ≥ 65 -year age group had a lower income than the younger group, with 66% of the seniors having an income of less than \$20,000 compared with 28% in the 40- to 64-year age group ($P = 0.005$). As a result of Medicare coverage, 98% of those in the ≥ 65 group reported having insurance compared with 72% in the 40- to 64-year age group ($P = 0.0006$).

Focus Group Analysis

Knowledge of Eye Examinations, Glaucoma, and Diabetic Retinopathy. Among the participants who expressed an opinion about the recommended frequency of DFEs, 42% thought yearly examinations were needed and 38% reported the recommended frequency as every 2 years. A misconception among approximately 60% of the participants was that all vision changes are a normal part of the aging process.

Regarding glaucoma risk factors, participants mentioned family history, other illnesses, and diet as risk factors for glaucoma, although not many participants offered an opinion. Participants recognized race as a risk factor only when specifically asked about it. A few participants mentioned hearing about the increased risk of glaucoma among African-Americans, but were not sure about the credibility of this informa-

TABLE 1. Distribution of Demographic Variables by Dilated Eye Examination Status and Age Groups

	Eye Exam Status			Age Groups		P
	DFE (n = 28) n (%)	No DFE (n = 58) n (%)	P	40–64 (n = 33) n (%)	65+ (n = 50) n (%)	
Gender (female)	17 (63.0)	44 (81.5)	0.10	23 (71.9)	38 (77.6)	0.60
Education						
Less than high school	4 (14.3)	11 (20.0)	0.56	2 (6.2)	13 (25.5)	0.10
High sch. grad/trade school	7 (25.0)	16 (29.1)		8 (25.0)	15 (29.4)	
Some college	11 (39.0)	13 (23.6)		12 (37.5)	12 (23.5)	
College grad/postcollege	6 (21.4)	15 (27.3)		10 (31.2)	11 (21.6)	
Income						
<\$20,000	11 (40.7)	28 (57.1)	0.11	8 (27.6)	31 (66.0)	0.005
\$20,000–\$34,999	5 (18.5)	12 (24.5)		10 (34.5)	7 (14.9)	
≥\$35,000	11 (40.7)	9 (18.4)		11 (37.9)	9 (19.1)	
Insurance status						
Yes	22 (78.6)	51 (92.7)	0.08	23 (71.9)	50 (98.0)	0.0006
No	6 (21.4)	4 (7.3)		9 (28.1)	1 (2.0)	
Eye care						
Eye doctor	20 (71.4)	26 (49.0)	0.15	17 (53.1)	29 (59.2)	0.80
Vision center/optical shop	6 (21.4)	16 (30.2)		10 (31.2)	12 (24.5)	
Hospital/clinic/family Dr.	2 (7.2)	5 (9.4)		2 (6.2)	5 (10.2)	
No one	0 (0.0)	6 (11.3)		3 (9.4)	3 (6.1)	
Diabetes						
Yes	3 (10.7)	13 (23.2)	0.24	6 (18.8)	10 (19.2)	1.00
No	25 (89.3)	43 (76.8)		26 (81.2)	42 (80.8)	

tion. There was more discussion among the participants regarding how to reduce the effects of diabetes on their eyes. Participants mentioned diet, exercise, regular doctor visits, and medications as factors to control diabetes.

Rates of DFEs and Reported Eye Problems. Most of the participants in the “no DFE” groups reported that they had had a DFE sometime in the past. We estimate that 24% of our participants had never had a DFE.

Many of the participants reported that they were currently experiencing some eye problem, with the younger age group describing more problems than their older counterparts. The problems conveyed by the younger group may be considered normal problems related to aging, such as difficulty reading. The older group reported problems such as cataracts, floaters, and blurred vision. Those who had had a recent DFE were slightly more likely to state that they were currently experiencing an eye problem than were those without a recent DFE.

Perceived Barriers to DFEs. Overall, cost and lack of sufficient insurance were considered the most important barriers to getting a DFE. Participants noted that eye examinations were not a high priority when compared with the cost of food and other necessities. There was a perception that even those with insurance may not be able to afford a DFE because of co-pays or the cost of glasses. Other frequently mentioned barriers were not having any symptoms, being too busy, and the inconvenience of the examinations. However, the ranking of these barriers was somewhat different between the younger and older groups. Whereas the most common barrier expressed by the younger group was cost or lack of insurance, older participants most frequently mentioned being too busy or the inconvenience of the examinations. To illustrate this discussion further, Table 2 provides specific participant quotes that were selected to exemplify key concepts.

A few participants noted the fear of pain associated with eye examinations, including the discomfort of eye drops and the fear of finding out something is wrong. Less frequently cited barriers were being lazy or neglectful, or just putting it off. In both groups the possibility of transportation as a barrier to DFEs was rejected, since it was noted that in the city transportation is readily available.

When the discussion turned to why other people fail to get eye examinations, some additional barriers were mentioned. Participants, particularly in the younger group, perceived cultural factors as playing a significant role in keeping others from having DFEs, particularly in terms of how some might prioritize the need for eye examinations. They explained that African-Americans are less likely to seek medical attention and have regular examinations because of denial that there is a problem. Similarly, pride was also reported as a barrier in the African-American community, with some participants mentioning that a lack of self-respect is based on the belief that suffering in silence is their fate. A few participants noted that the easy availability of reading glasses at the drug store allows people to self-diagnose their problems and find a quick solution without seeing a doctor.

Perceived Benefits of DFEs. The most frequently mentioned benefit of DFEs was to help prevent eye disease through early detection, which was cited by almost three quarters of the respondents. The only other benefit expressed by this group was for the ongoing monitoring of existing conditions, such as diabetes. There was little difference in perceived benefits by age group or eye examination status. Table 2 provides participant quotes to illustrate these findings.

Perceived Motivators for Getting DFEs. For all respondents, the most frequently noted reason for making an appointment was experiencing a vision problem. For the older participants, additional motivators for making an appointment were “as a matter of routine” or for general prevention of illness. There was little difference in responses by eye examination status.

Physician recommendation, having an existing medical problem, and having a family history of glaucoma may also be motivating factors. Although less than one third of the participants indicated that they had ever been told to get a DFE, more people in the DFE group reported this, with several participants noting that they were advised to have a DFE due to an existing medical problem. We also found that those who had a recent DFE were somewhat more likely to report a family history of glaucoma than those without a recent DFE.

TABLE 2. Examples of Focus Group Responses about Barriers, Benefits, and Motivators for Getting Eye Examinations

Examples of Responses	
Barriers	
Cost/lack of insurance	As you get to be a senior citizen, it is hard when you go into an office and they turn you down because you don't have any money. That's embarrassing, especially if you work your whole life if a visit is \$75 and you gotta choose between the \$75 and buying groceries, or paying a bill, then you're gonna do that. So, that's the only reason why I haven't been.
Lack of symptoms/no need	Unless they have an eye problem or recommended by a doctor that you have that done, but for no reason at all? No. I think the fact that a lot of eye diseases don't hurt and just like she said, if it doesn't bother you, you don't bother it.
Too busy/inconvenient	The other thing is after you get older, you now keeping up with your appointments and everything. You have to have some kind of schedule or system, and sometimes the 2 year period when you are supposed to return to get your new eye glasses, that kind of just floats right by you. You know, until something happens and you start to experience something and it reminds you to go back in.
Denial/pride	You know what amazes me is that people, especially the Afro-American community. They have relatives who have a history or have died from diabetes and they just dismiss it. "It's not going to happen to me." A lot of times black folks will not seek medical care for things because we accept it as our lot. We don't, you know, we haven't had this and we haven't had that and we've suffered and so on and so forth. We've suffered in silence, but we made it over. That mentality is involved in a lot of things, a lot of decisions we make. I've noticed a lot of people, especially men . . . seem like they're in denial. I agree . . . as far as African American men are concerned. It's the whole macho thing. It's the "I gotta be strong" and I could be falling apart, but we have this mentality that that's a sensitive issue that we'd rather put on the back burners and deal with it when it's catastrophic and we should be dealing with the problem as a preventive . . .
Benefits	
Early detection	Preventative. It gives you an opportunity to tackle the problem early on, before it gets progressive. There's a lot of conditions that they can catch when you get your eyes dilated that they can't catch without it.
Monitor existing problem	With glaucoma they check you periodically to see how that pressure is being stabilized, or if it is getting worse, because the higher the pressure gets . . . that is what takes your eyesight. So they really keep a check on that.
Motivators	
Experiencing eye problems	Because I knew it was time. My vision was starting to get more blurry, especially at night. I knew it was time to get an eye exam because it had been a couple of years.
As a matter of routine	Well, I've been doing it for years. Every two years I just do it . . . as a maintenance, health maintenance.

Physician Communication. Participants were divided in their feelings of satisfaction with the information provided by their doctors. Many expressed the opinion that they must rely on themselves for medical information rather than their doctors, particularly those in the DFE groups. A few respondents noted that they distrust doctors.

Only six participants said they had felt confused about their medical care because the doctor did not explain things well, with most specifically mentioning confusion related to medication. A few additional participants noted that it was the patients' responsibility to understand their diagnosis and treatment and did not blame their doctors for what they perceived as their own lack of knowledge. Other participants implied that their responsibility for understanding their medical information was empowering and a way to gain control over their own health.

Participants were divided in their assessment of whether their doctors were respectful and treated them as equal partners in making health decisions. Participants who were unhappy with their doctors felt that the doctors withheld information and did not consider them as individuals, while participants who were happy with their doctors noted that establishing a relationship of trust and friendship was a necessary precursor to respect. Participants in particular valued a doctor who listened to them. A few participants noted that having a doctor with a background similar to theirs helped them form bonds.

Throughout the course of discussions, focus group participants made many statements about doctors including perceptions regarding their "nature" and motivations. These observa-

tions, although not made in direct response to the questions analyzed herein, illustrate important themes in how participants perceived their doctors. One theme that was mentioned repeatedly was that doctors are not interested in making personal connections with their patients. Participants suggested that one reason for this lack of personal care is that doctors are involved in a "business" and are driven by a desire for profit, not the well-being of their patients. Others suggested that doctors are most concerned with maintaining power over patients. Finally, some participants did not blame individual doctors, but rather the medical system. Table 3 presents responses regarding physician communication.

DISCUSSION

Findings in this study identified a range of opinions about eye examinations, and the factors that influence eye examination behavior in African-American adults. Knowledge about the risk factors for glaucoma and differentiating between normal age-related vision changes and vision loss related to eye disorders, was limited in our sample. Although increased knowledge about eye disease has been associated with higher education, studies differ regarding the association of ophthalmic knowledge and race.^{30,31} Despite efforts by major organizations, such as the National Eye Health Education Program,^{32,33} to target educational information and communications to specific population groups, including African-Americans, our study suggests that these health messages may not be reaching their intended audience.

TABLE 3. Examples of Focus Group Responses about Physician Communication

Physician Communication Issues	Examples of Responses
Gets enough information about health problems	One of the things you gotta consider is that you're proactive in your healthcare. Many people go to the doctor and the doctor said, "So and so and so and so. Okay." And you ask them, "Well, what did the doctor say?" . . . Or they don't ask any questions because they're so intimidated. You know, I feel as though everyone's responsible for their own health. So, whatever diagnosis comes up, it's up to you to research.
Confused about their medical care	I used to [be confused] until I started asking questions. You know, for a long time I never asked about what was the process or procedures, but now I ask about everything. . . . 'cause I'm getting older now and I want to live a little longer.
Doctor respectful and treats as equal partner	I think the doctor and I should be together and come to the decision. You know, even though I know he might know, but I also . . . it's my body so; therefore, I think we should do it together. I believe it's because I think doctors don't want to give you too much information, like you can't handle it, like you're not intelligent. A lot of them have that attitude. Not necessarily talking down. They just withhold, I think, a lot of things that they could share with you.
Not interested in making personal connections	I think overall, there's no personal care or concern with doctors no more. Some of them are all business now. It's a numbers game and insurance . . . What we need to realize is that the medical profession is a big business. Big business.

Other studies have reported barriers similar to those reported in our study. For both African-Americans and whites with diabetes, factors related to not getting a regular eye examination included cost, not having health insurance, not experiencing an eye problem, lack of time, and not being told they needed one.^{13,15,19,24} In two studies of older African-Americans, one that was population based and the other in which people with glaucoma or suspected glaucoma were recruited, cost was a barrier to eye care,^{14,22} as was not being told to come back for an examination.¹⁴ Our focus group discussions provided some insight into cost as a barrier to getting dilated eye examinations. Having insurance does not eliminate the cost barrier, since the cost of co-pays and the cost of glasses adversely affected getting a dilated eye examination. An important difference to note relates to transportation, the most frequently cited barrier in the study by Owsley et al.²² In our population, transportation was dismissed as a barrier, even after we specifically asked about it when it was not brought up in the discussions. This difference may be explained by easier access to public transportation for our urban population.

Our focus group participants described cultural factors they felt were specific to the African-American community that helped explain attitudes toward eye examinations. They argued that African-Americans are less likely to seek medical attention and have regular examinations because of denial of a problem and pride, particularly among African-American men. As in our study, issues of trust, empathy, and communication with their doctors have been cited as affecting attitudes toward eye examinations.^{18,22}

There was little discussion about the benefits of eye examinations in our focus groups. In contrast, two studies that presented a list of benefits, rather than asking open-ended questions, found that >80% of the participants agreed with each of the benefits statements.^{17,31} Although participants most frequently cited preventing eye disease as a benefit, only older participants reported making an eye appointment for general prevention of illness. In fact, experiencing a vision problem was the most frequently mentioned motivator. Physician recommendation was also reported in this study as well as in other studies.^{15,17,34}

Low health literacy rates in this population may be a contributing factor to avoidance of preventive eye care. Other studies have demonstrated that African-American ethnicity, older age, and fewer years of education are associated with low health literacy rates.^{35,36} Low health literacy is associated with

less health knowledge, less preventive care, and poorer health outcomes,^{37,38} including a higher rate of retinopathy among a group with type 2 diabetes.³⁹

Several limitations in our study design warrant mention. Although we recruited participants from various community sites, the people who agreed to participate in our focus groups were predominantly female and better educated than the African-American population of Baltimore city. In addition, our urban population of seniors may have different perceptions of the barriers and benefits of getting DFEs than do rural residents. Because people who choose to participate in studies may be more aware of their health issues and more compliant with health recommendations, we specifically recruited participants who had not had recent eye examinations. Although we attempted to keep the focus groups homogenous regarding age, there were three people who participated in the focus groups who were not in the correct age group.

Our focus group findings highlight that there is still much work to be done to promote knowledge of preventive eye care. Such an effort will facilitate the process of making informed decisions about preventive eye care and obtaining dilated eye examinations according to schedules that take into account personal levels of risk. Health messages should let people know that they should not wait until they have a vision problem before getting an eye examination, that glaucoma and diabetic retinopathy are asymptomatic in the early stages, and that early detection and treatment can stop the progression of these diseases. We need to find ways to provide this information at a sixth to eighth grade reading level so that people with low health literacy can benefit as well. This information will now be used to develop interventions to change eye examination behavior.

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