Perceived Barriers to Care and Attitudes about Vision and Eye Care: Focus Groups with Older African Americans and Eye Care Providers

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PURPOSE. To identify by using focus group methods the perceived barriers to eye care and attitudes about vision and eye care among older African Americans as well as among ophthalmologists and optometrists serving their communities.

METHODS. Seventeen focus groups of older African Americans residing in the Birmingham or Montgomery, Alabama, areas were led by an experienced facilitator. Discussion was stimulated by a semistructured script focused on their perceived barriers to eye care and attitudes about vision and eye care. Six focus groups of ophthalmologists and optometrists who practiced in this geographic region addressed the same topics. Discussion was audiotaped and transcribed. Comments were coded using a multistep content analysis protocol.

RESULTS. One hundred nineteen African Americans (age range, 59–97 years) and 35 eye care providers (51% ophthalmologists, 49% optometrists) participated. The barrier-to-care problem most frequently cited by both African Americans and eye care providers was transportation. The next most common problems mentioned by African Americans were trusting the doctor, communicating with the doctor, and the cost of eye care; and for eye care providers, the next most common problems were cost, trust, and insurance. With respect to older African Americans’ comments on their attitudes about vision and eye care, these comments were predominantly positive (69%), highlighting the importance of eye care and behavior in their lives and attitudes that facilitated care. However, when eye care providers relayed their impressions of African Americans’ attitudes about vision and eye care, their comments were largely negative (74%) centering on concerns and frustrations that older African Americans did not have attitudes or engage in behavior that facilitate eye care.

CONCLUSIONS. These results provide some guidance for the design of interventions to increase the use of routine eye care in this population. At a societal level, there is a need for affordable and accessible transportation services for older African Americans seeking eye care. For ophthalmologists, optometrists, and their staffs, there is a need for continuing education that imparts culturally sensitive and age-appropriate communication and trust-building skills for interactions with this population. In addition to reinforcing the generally positive attitudes of older African Americans toward the importance of eye care, community-based educational programs should be focused on strategies for overcoming the common barriers to care.

Vision impairment and eye disease rates among older African Americans are two times higher than those of older whites, especially uncorrected refractive error, cataract, glaucoma, and diabetic retinopathy. The public health challenge is that if these eye problems were detected early, much of this disease and vision impairment could be reversible and even preventable with currently available ophthalmic treatments. A factor underlying their higher eye disease and vision impairment rates may be that African Americans, including older adults, are less likely to receive routine comprehensive eye examinations, when newly emerging eye conditions could be detected and treated in a timely fashion. This may be due at least in part to some African Americans’ lower eye health literacy—that is, inadequate knowledge about basic symptoms, risk factors, and effective treatments available for common eye conditions. For example, although African Americans are more prone to development of glaucoma than are whites, Gasch et al reported that African Americans were less familiar with the disease. Other factors potentially contributing to reduced eye care utilization in this population are cost, transportation, social support, and other health problems competing for attention—especially acute medical conditions. Lower eye care utilization rates in older African Americans may also be related to attitudes and actions on the part of ophthalmologists and optometrists, including the understanding and sensitivity of ophthalmologists and optometrists about successful communication strategies and interpersonal approaches that are culturally and age appropriate.

The purpose of the present study was to use focus group methodology to learn about the perceived barriers to eye care among older African Americans, as well as their attitudes about vision and eye care. Focus groups are viewed as a gold standard for capturing patients’ perspectives and experiences, because this forum permits issues to be conceptualized and expressed in the target subjects’ own words. We also held focus groups with ophthalmologists and optometrists who serve the geographic areas where these older African Americans reside, to gather information on the providers’ perspectives on older African Americans’ barriers to care as well as their impressions about older African Americans’ attitudes about vision and eye care.
Methods

Our recruitment source for the older African-American focus groups was census tracts for ZIP code regions in the Birmingham and Montgomery, Alabama, areas where ≥50% of the population is African American. Potential participants were randomly identified from adults aged ≥60 years, as listed in driver licensing records for Alabama. Letters describing the study were mailed and were followed up by phone calls by the project coordinator inviting the recipients to participate and to confirm that each person self-described him- or herself as African American. The goal was to continue recruitment until we were able to organize between 15 and 20 focus groups.

Focus groups for older African Americans were held in hotel conference rooms or in community centers in Birmingham or Montgomery. We specifically avoided holding groups in ophthalmology or optometry clinics or in our university facilities, because we thought this might bias the types of comments made. Free taxi service was provided to the focus group location if transportation was needed. Before each focus group began, written informed consent was obtained from participants after the nature and possible consequences of the study were explained. This research was approved by the Institutional Review Board at the University of Alabama at Birmingham and the protocol was in accordance with the provisions of the Declaration of Helsinki. The discussion was led by a trained facilitator who was African American. No ophthalmologists or optometrists were present at older African-American focus groups. The discussion was audi-taped. The facilitator stated ground rules for the discussion (e.g., “all opinions are valued,” “it is okay to talk to each other as well as to me”). As an “ice-breaker” participants were asked to introduce themselves by first name and share in a few words their interests or hobbies.

A semistructured script was used by the facilitator to guide discussion. Topics for discussion were selected based on those identified by a review of the literature11,12,17–21 and those deemed relevant by informal telephone interviews with older African Americans from the same communities that were preliminary to the study. The two general topics for focus group discussion were attitudes (e.g., beliefs, knowledge, and values) about vision, eye conditions, and eye care and what participants viewed as barriers to seeking and receiving eye care. The script was pilot tested on several older African Americans, to ensure that the discussion topics were clear and viewed as relevant. In an effort to minimize the facilitator’s influence on the types of comments participants made, the script began with general, open-ended questions (e.g., How important is it to you that you have an eye doctor? How important is vision to you? Do you think you have some control over the health of your eyes? Do you have obstacles that keep you from receiving regular eye care?). As the discussion moved to specific topics (e.g., transportation and accessibility), follow-up probe questions were also posed on an as-needed basis to facilitate the depth of descriptions about (e.g., Do you have difficulty driving yourself to the doctor? Can someone give you a ride? How far away from the eye doctor do you live? Do you feel you have a choice of eye doctors in your area?) The focus group concluded by asking participants if they had any other issues related to accessing or receiving eye care or about vision and eye conditions in general that they had not discussed previously.

Another set of focus groups was performed with ophthalmologists and optometrists, since both types of provider work within the geographic areas targeted. Separate groups were formed for ophthalmologists and optometrists. The same facilitators who acted as moderators of the older African-American groups did so for the eye care–provider groups. Potential participants were identified through a listing of those practicing in the Birmingham, Montgomery, or Selma, Alabama, areas. The listing was based on the provider names and practice locations shown on the Web sites of the state professional organizations for ophthalmologists and optometrists and in the Yellow Pages. At the time of the study, there were 266 providers in these areas. All eye care providers had state licenses to practice and were board certified by their respective professions. The recruitment process began with a letter describing the project, with a follow-up telephone call by the principal investigator, and continued until a target goal of six groups was reached. Focus groups took place in the early evening at area restaurants having private meeting rooms. Written informed consent was obtained. The facilitator followed a semistructured protocol, using the same methodology and addressing the same topics as for the older African-American focus groups, but this time from the ophthalmologists’ and optometrists’ perspectives.

Audiocapes were transcribed word for word by a professional transcriptionist. Comments were identified and coded after a standard multistep content analysis protocol modeled after methods we used previously22–25 and as discussed by Holsti.26 The primary coder read through each transcript to get a general impression of the type of comments made by participants with respect to perceived barriers to care or factors that enable care. Next, barriers-to-care/enabling factor comments were highlighted and grouped into mutually exclusive and exhaustive categories according to the main theme of the comment. During a second pass through the data, these coded comments were categorized as positive, negative (“problem”), or neutral. A comment was coded as positive if it was beneficial to the person (i.e., enabled or facilitated seeking care). A comment was coded as negative if it was detrimental or caused a problem to the person. Neutral comments were defined as those that were neither positive nor negative.

For the older African-American focus groups, comments on attitudes with respect to vision and eye care were coded as follows: positive, if the comments highlighted the importance of eye care or behaviors and attitudes that facilitated care; negative, if they reflected concerns, fears, frustrations, or behaviors that contributed to not seeking care; and neutral, if they were neither positive nor negative. The same coding scheme was applied to the eye care–provider focus groups with respect to comments they made about their beliefs about older African Americans’ attitudes about vision and eye care.

Using the operational definitions and coding rules of the primary coder, the second coder read through all comments and categorized them as positive, negative, or neutral, according using the definitions just described. Cohen’s $k$ was calculated for interrater reliability and was 92%.

Results

Seventeen focus groups were conducted with older African Americans. Group size ranged from 3 to 11 persons (average group size, seven persons), and 119 persons participated. The average age of participants was 70 ± 8 years (SD; range, 59–97 years); 64% ($n = 76$) of participants were women and 36% ($n = 43$) men. The age and gender distributions for our focus group sample were not different from those of the source population of older African Americans living in the target ZIP codes.

Six focus groups were conducted with eye care providers. Group size ranged from 4 to 9 (average, 6 persons), and 35 persons participated, with 18 (51%) ophthalmologists and 17 (49%) optometrists. Thirty-four percent ($n = 12$) of eye care providers were women and 66% ($n = 23$) men; 68% ($n = 24$) were white of non-Hispanic origin, 26% ($n = 9$) were African American, and 6% ($n = 2$) were Asian. In terms of the extent of each provider’s patient base that he or she reported to be African American, 9 (25%) had a clientele that was less than one-third African American, 13 (37.5%) had a clientele one-third to two-thirds African American, and 13 (37.5%) had a clientele greater than two-thirds African American. Eye care providers had been in practice on average for 14 ± 9 years (SD).

With respect to perceived barriers to care, older African Americans made a total of 772 comments on the following topics (Table 1), from most common to least common comments: trust of eye care provider, communication, clinic accessibility, service at the doctor’s office, spiritual issues, social support, cost, insurance, and miscellaneous. Overall, approximately one half (49%) of the comments were positive, in that
the participants indicated that the issue at hand was being dealt with in a beneficial way that facilitated rather than interfered with eye care (e.g., “my family makes sure I receive my glasses,” “transportation to my eye clinic is available,” “my doctor lets me know what is going on”). About half the comments were negative in that they were viewed as problems or obstacles to receiving eye care (e.g., “I have to have someone take off work to take me to eye examination,” “doctors treat patients differently if they are of a different race or cannot afford to pay,” “the doctor leaves the room before I can ask questions,” “medications are too expensive to buy”). Figure 1 illustrates the topics most frequently identified as problems, from most frequent to least frequent. The top four most frequently mentioned barrier-to-care problems were clinic accessibility (transportation to the clinic and the location of the clinic), trust of the doctor, communication with the doctor, and cost of eye care, which together accounted for approximately three fourths (77%) of all problem comments made. Unlike the older African-American focus groups, there were no problem comments from eye care providers falling into the category of service in the clinic.

With respect to older African American’s comments on their attitudes about vision and eye care, the comments were predominantly positive (69%; Fig. 3), when they highlighted the importance of eye care or behaviors and attitudes that facilitated care (“I feel like you are supposed to see the eye doctor yearly,” “eyes are my most prized possession,” “education is the key to taking action,” and “having regular eye exams allows you to correct your vision problems”). In contrast, eye care providers’ comments relaying their impressions of older African American’s attitudes about vision and eye care were predominantly negative (74%), centering on concerns, fears, frustrations, or behaviors that do not facilitate routine eye care (“their other medical problems take priority,” “healthcare becomes a priority when the person is already impaired,” “fear of a bad diagnosis is a barrier,” “patients are resistant to accepting help if it’s not from an intimate source”).

**DISCUSSION**

Accessibility to the doctor’s office, particularly inadequate transportation resources, was the most frequently cited barrier

<table>
<thead>
<tr>
<th>Perceived Barrier to Care Category</th>
<th>Comment Type n (%)</th>
<th>Total Comments</th>
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<tbody>
<tr>
<td></td>
<td>Positive</td>
<td>Negative (Problem)</td>
</tr>
<tr>
<td>Trusting eye care provider</td>
<td>95 (56)</td>
<td>63 (37)</td>
</tr>
<tr>
<td>Communication</td>
<td>89 (72)</td>
<td>57 (19)</td>
</tr>
<tr>
<td>Clinic accessibility</td>
<td>45 (37)</td>
<td>75 (61)</td>
</tr>
<tr>
<td>Service at doctor’s office</td>
<td>64 (73)</td>
<td>20 (25)</td>
</tr>
<tr>
<td>Spiritual issues</td>
<td>15 (19)</td>
<td>8 (10)</td>
</tr>
<tr>
<td>Social support</td>
<td>47 (70)</td>
<td>12 (18)</td>
</tr>
<tr>
<td>Cost</td>
<td>0 (0)</td>
<td>57 (100)</td>
</tr>
<tr>
<td>Insurance</td>
<td>17 (32)</td>
<td>32 (60)</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>4 (36)</td>
<td>5 (46)</td>
</tr>
</tbody>
</table>

Data are frequency of positive, negative (“problem”), and neutral comments within perceived barrier/enabling factor category (772 comments in total).

**FIGURE 1.** Number of problem comments on barriers to eye care made in the older African-American focus groups, stratified by topic of comment.
to receiving routine eye care by both older African Americans and eye care providers in our focus groups. This finding is consistent with national data that accessible and affordable transportation options for older adults in the United States are greatly lacking and underscores the potential negative impact that inadequate transportation has on the health and well-being of the elderly.27,28

For older African Americans, problems with trusting and communicating with the doctor were the next most commonly mentioned obstacles to eye care. Previous research has shown that trust is a critical element in medical care, in that trust of the physician is related to the degree to which patients seek routine medical care and comply with prescribed treatments.29 With respect to communication, previous research has shown that eye clinic patients' greatest expectations and values in interactions with their ophthalmologists are successful communication of medical information, explanation, listening, and personal connection.30 That older African Americans in our focus groups expressed concerns about gaps in trust and communication implies that the quality of the doctor–patient relationship is important to them. Although problems with trust were among the most frequently cited barriers to care cited by older African Americans, it is important to point out that there were more positive comments made about trust than there were negative, suggesting that trusting relationships can be established in this dyad. It is interesting that from the eye care providers’ standpoint, communication was not identified as one of the most frequent barriers to care, implying that they may not be fully aware of communication problems and the potential inadequate communication has for contributing to lower eye care utilization rates in this population.

The cost of eye care was among the top four barriers mentioned by both older African Americans and eye care providers. Cost comments centered on issues such as the high cost of prescription drugs, copayments, deductibles, supplemental health insurance, and eyeglasses and their relationship to poor compliance with treatment plans and skipping follow-up care. Medicare is the primary insurance coverage for most older Americans, and it remains a concern that routine, preventative care is not wholly covered. One problem area mentioned by older African Americans but, interestingly, never raised in discussion by eye care providers was problems with service at the doctor’s office. These comments by older African Americans chiefly addressed two concerns: the clinic staff’s not showing respect and courtesy toward the elderly, and long waiting periods before seeing the doctor. On the contrary, although older African Americans mentioned problems in clinic service, they were three times more likely to make positive comments about service than problem-oriented comments.

Most of the older African Americans’ comments reflecting their attitudes about vision and eye care were positive, focusing on the high value that they place on good vision for their well-being and the importance of seeking eye care. These positive, constructive attitudes in one sense seem at odds with previous research suggesting their underutilization of eye care.

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</thead>
<tbody>
<tr>
<td></td>
<td>Positive</td>
</tr>
<tr>
<td>Clinic accessibility</td>
<td>4 (8)</td>
</tr>
<tr>
<td>Cost</td>
<td>1 (3)</td>
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<tr>
<td>Trusting eye care provider</td>
<td>12 (35)</td>
</tr>
<tr>
<td>Communication</td>
<td>13 (54)</td>
</tr>
<tr>
<td>Spiritual issues</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Insurance</td>
<td>0 (32)</td>
</tr>
<tr>
<td>Social support</td>
<td>6 (50)</td>
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<tr>
<td>Miscellaneous</td>
<td>2 (17)</td>
</tr>
<tr>
<td>Service at doctor’s office</td>
<td>6 (100)</td>
</tr>
</tbody>
</table>

Data are frequency of positive, negative ("problem"), and neutral comments within perceived barrier/enabling factor category (207 comments in total).

![Figure 2](http://iovs.arvojournals.org/pdfaccess.ashx?url=/data/journals/iovs/932939/ on 06/05/2017)
However, the perceived barriers to care discussed herein may be overwhelming for a substantial portion of this population, thus offsetting their generally positive attitudes about the importance of seeking routine eye care.

In contrast, eye care providers made predominantly negative comments about the attitudes of older African Americans with respect to vision and eye care, with the eye care providers expressing concerns that older African Americans do not make eye care a priority like other aspects of health and do not fully understand the importance of preventative strategies and available treatments. These focus group results make it clear that there is a mismatch between older African Americans’ perceptions of their knowledge and attitude base and how eye care providers view their knowledge and attitude base. This mismatch itself could contribute to the communication and trust gaps between the older African-American patient and the eye care provider.

Strengths of this study include the use of a research methodology to gather information about attitudes about vision, eye conditions, and eye care that allowed the population of interest to express concerns in their own words. Eye care providers, who constitute the other half of the dyadic eye care interaction, provided their perspectives in the same research context. Participating eye care providers worked within the same geographic areas where our older African-American participants resided, and approximately one fourth were African American. Weaknesses should also be addressed. The population studied consisted of persons with current driver’s licenses, and to what extent the findings generalize to persons without current licenses is unknown and is thus a study limitation. Compared with focus groups with older African Americans, there were fewer focus groups of eye care providers, and thus the findings for these groups are based on fewer comments. Bringing ophthalmologists and optometrists together into group settings was challenging, given the wide variety of workday and personal schedules. There was no information gathered in the study for about eye and general health status of African-American participants, their eye care utilization history, or insurance status nor was information gathered on these variables with respect to persons who declined participation, which may affect the ability to generalize findings. The generalizability of these findings outside Alabama is unknown.

The results of these focus groups are useful in that they provide some guidance about the kinds of intervention in need of development and evaluation if the goal is to increase the use of routine, comprehensive eye services among older African Americans. In terms of interventions at a societal level, affordable and accessible transportation services for seniors need to be broadly available. By the year 2010 there will be approximately 40 million adults aged 65 years and older in the United States, and 1 in 5 of them, or 8 million, will be nondrivers. Educational interventions directed at older African Americans, ophthalmologists, and optometrists could also be beneficial. With respect to eye care providers and their clinic personnel, continuing education modules could be designed to impart culturally sensitive and age-appropriate communication strategies and trust-building skills for interactions with older African Americans. Older African Americans in our focus groups had a frequently positive attitude toward the importance of eye care and the need for routine examinations. Thus, in addition to reinforcing these positive attitudes so that they are as widespread as possible, community-based educational programs should be focused on strategies for overcoming personal obstacles to care (e.g., how to plug into existing community transportation services, going to the doctor with a list of symptoms prepared ahead of time, feeling that it is acceptable to ask about potential ways to minimize cost). The results of our focus groups can also help inform the content of outcomes tools for assessing the effectiveness of these educational programs as they are evaluated.

References


