Patient Expectations Regarding Eye Care

Focus Group Results

Aerlyn G. Dawn, BA; Cecilia Santiago-Turla, MD; Paul P. Lee, MD, JD

Background: Increasing emphasis on patient-centered care and other recent developments should make patient expectations increasingly important in ophthalmology. Motivated by the pivotal role of patient expectations in quality-of-care assessments and by the limited knowledge about patients’ expectations regarding eye care, we initiated a pilot study using focus groups to determine a relevant set of concerns that patients express as expectations.

Methods: A total of 6 focus groups were conducted with patients at Duke University Eye Center (Durham, NC). Focus groups ranged in size from 4 to 10 people. The average group size was 6.

Results: Content analysis of transcripts from the 6 focus groups yielded 22 areas of expectations for eye care, which were classified into 5 categories: communication, interpersonal manner, physician’s skill, logistics, and other. The 6 areas that appeared to be of greatest importance to focus group participants were the following: (1) honesty, (2) information about diagnosis and prognosis, (3) explanation in clear language, (4) ophthalmologist’s experience and reputation, (5) empathy, and (6) listening and addressing concerns.

Conclusions: In general, ophthalmology patients in the focus groups emphasized expectations related to communication and interpersonal manner. In contrast to previous studies with primary care patients, however, ophthalmology patients expressed few expectations for technical interventions, such as medication prescriptions, physical examination, or diagnostic testing.

Arch Ophthalmol. 2003;121:762-768

Historically, medicine has been primarily physician centered; however, to an increasing extent, physicians and health administrators have begun to incorporate patients’ perspectives into health care.1 Patient-centered care, at its core, is health care that is responsive to patients’ wants, needs, and preferences.2 Moreover, the rise of consumerism and dramatic increases in patients’ level of education have contributed to greater patient demand for information and involvement and rising expectations.3 The patient-centered care movement can also be linked to related major trends in medicine during the past decade. The shift toward continuous quality improvement, which gained momentum in the 1990s, places meeting patient expectations at the core of medicine’s mission.4 Furthermore, the growing integrative medicine movement insists on patients being active participants in their health care.5

As such, there has been a growing body of literature regarding patient expectations during the past 2 decades. However, most of this research has been conducted in primary care settings. Little is known about patient expectations of ophthalmologists and eye care. The ophthalmology literature that does exist has focused primarily on expectations regarding surgical outcomes, such as patients’ expectations for cataract surgery.6 However, recent developments should make patient expectations increasingly important in ophthalmology. First, the dramatic rise in the number of refractive surgeries performed in the United States has drawn increasing numbers of patients to the field of ophthalmology for elective procedures for non–sight-threatening conditions.7 Second, increased competition in the eye care market has led to a greater appreciation for the need to understand patient desires.8,9 To learn more about patients’ expectations for eye care, we initiated a pilot study using focus groups to determine a relevant set of concerns that patients express as expectations. Motivated by the pivotal role of patient expectations in quality-of-care assessments and by the limited knowledge about patients’ expectations for eye care, we conducted a pilot study using focus groups to determine a relevant set of concerns that patients express as expectations.
care, we have undertaken a study designed to answer several fundamental questions:

- What do patients look for when choosing an eye doctor?
- What do patients expect their eye doctor to do during an eye appointment?
- What kinds of information do patients expect to receive during an eye appointment?
- What kinds of things make patients want to change eye doctors?

**METHODS**

We first reviewed the literature on patient expectations between 1966 and 2002. The initial MEDLINE search terms were the following: (title words: expectations or desires or requests) and (Medical Subject Headings: consumer satisfaction or patient satisfaction or physician-patient relations). We also examined review article reference lists for potentially relevant studies. We then reviewed and analyzed the existing literature.

In general, value expectations, which refer to patients’ desires, hopes, or wishes concerning clinical events, are the dominant model. However, the existing literature contains substantial discrepancies in the ways that expectations are measured, and no standardized assessment instrument currently exists for measuring patients’ expectations. Disagreements over the most appropriate methods for measuring patient expectations have been a barrier to more refined understanding.

Throughout the literature on expectations, mostly conducted in primary care settings, the 10 most commonly addressed areas of patient expectations and requests are as follows:

- Medical information
- Medication/prescription
- Counseling/psychosocial support
- Diagnostic testing
- Referral
- Physical examination
- Health advice
- Outcome of surgery or treatment
- Therapeutic listening
- Waiting time

We then used these areas as initial starting points for our qualitative study to create the script for our focus groups.

After the study was approved by the institutional review board, focus group participants were recruited from among patients waiting for eye appointments at the Duke University Eye Center (Durham, NC). Patients were identified by means of daily appointment schedules. Researchers approached patients in the eye center waiting areas and requested their participation in future focus groups. If patients expressed willingness to participate, we obtained their contact information as well as their primary diagnosis and level of education. Participants were then classified into 1 of 4 categories based on their primary diagnosis and level of education. We contacted interested participants by telephone to schedule them for a focus group.

For this study, patients were classified as having either potentially irreversible blinding or nonblinding eye conditions and as either lower or higher socioeconomic status, using education as a proxy. Blinding eye diseases included diagnoses such as glaucoma, age-related macular degeneration, and diabetic retinopathy, among others. Patients classified as having nonblinding eye disease included patients with well eyes, refractive errors, and cataract, among others. Individuals who had pursued any post-secondary education were classified as higher socioeconomic status, and those who did not pursue education beyond high school were classified as lower socioeconomic status.

A total of 6 focus groups were conducted at Duke University Eye Center. We conducted 1 group with patients with lower socioeconomic status and nonblinding eye disease, 1 group with patients with higher socioeconomic status and nonblinding eye disease, 2 groups with patients with lower socioeconomic status and blinding eye disease, and 2 groups with patients with higher socioeconomic status and blinding eye disease. We obtained informed consent from all focus group participants before the start of each group.

The script for the groups was based on the review of the literature and the results of initial patient interviews. However, participants were given ample opportunity to deviate from the script to explore other issues related to their expectations regarding eye care. In addition, at the end of each group session, participants were presented with a copy of the Patient Concerns Form and asked to identify items that they thought were important when they visited their ophthalmologist.

Focus groups ranged in size from 4 to 10 people. The average group size was 6. A total of 38 patients participated in the focus groups. Of these 38 patients, 25 were women and 13 were men. Twenty-eight of the 38 patients lived locally in the Research Triangle area of North Carolina, but 10 patients lived remotely and traveled a substantial distance, up to 160 km in some cases, to visit their ophthalmologist at Duke. A variety of diagnoses were represented in the groups. Patients’ primary diagnoses included the following: 14 patients had some form of glaucoma, 4 had a cataract or had previously had cataract surgery, 4 had well eyes and visited the eye center only for routine eye examinations, 3 had refractive errors, 2 had suspected glaucoma, 2 had diabetic retinopathy, and 1 had age-related macular degeneration. In addition, 8 patients had less common eye diseases, which included complete lacrimal duct obstruction, choroidal melanoma, thyroid ophthalmopathy, posttraumatic retinal detachment, squamous cell cancer of the eyelid, optic neuropathy, Fuchs dystrophy after corneal transplantation, and corneal dystrophy.

All 6 focus groups were moderated by one of the authors (A.G.D.). All focus groups were recorded by means of 2 microcassette tape recorders to ensure clarity and accuracy of transcriptions. The interviews were subsequently transcribed into word-processing software. Focus group participants were compensated $20 for their time and transportation expenses.

Two of the authors (A.G.D. and P.P.L.) reviewed the transcripts of the focus groups and analyzed them for content and key concepts. The results presented are based on consistent patterns of responses obtained from 6 focus groups representing a variety of ophthalmology patients. The results are based around findings that had the strongest, broadest-based support from participants in our groups, as well as unique areas, even if mentioned by only 1 person. The primary purpose of the research was to help provide the range of issues that might be explored in subsequent quantitative research.

**RESULTS**

One hundred twenty-two single-spaced pages of original data transcribed from the 6 focus groups yielded 22 areas of expectations for eye care expressed by focus group participants. These areas were not mutually exclusive, and many patient comments could be classified in multiple ways. We classified the 22 areas of patients’ expectations into 5 categories: communication, interpersonal manner, physician’s skill, logistics, and other (Table 1). We used content analysis of the groups to evaluate the number of separate instances in which focus group participants cited individual areas of expectations. On the
This pilot study used focus groups with ophthalmology patients at Duke University Eye Center to build an understanding of patient expectations regarding eye care. Focus groups capitalize on communication between participants to generate data. Open-ended questions encourage focus group participants to explore issues of importance to them, in their own vocabulary, pursuing their own priorities. Because of these unique characteristics, focus group interviews served as a robust method of gathering information on patients’ expectations for eye care. Focus groups are not meant to be representative of the entire population of interest; rather, focus groups are intended to provide insights about the psychological and sociologic characteristics of population subgroups.

This pilot study has produced a total of 22 areas of patient expectations for eye care, classified into 5 categories. The majority of expectations expressed fell into the communication and interpersonal manner categories. In contrast, there were few expectations expressed for tangible actions on the part of the ophthalmologist. Focus group participants most commonly cited expectations related to communication. Interestingly, the expectation cited most frequently throughout the focus groups was a desire for honesty from the ophthalmologist. Honesty was not only the most frequently cited expectation among focus group participants as a whole but also the most frequently expressed expectation area among all subgroups as well. Content analysis of focus group transcripts demonstrated that men and women, participants with lower and higher socioeconomic status, and patients with nonblinding and potentially blinding eye diseases all rated honesty more frequently than any other area of expectations. Patients also placed particular emphasis on receiving information regarding diagnosis and prognosis and receiving explanations in clear language. All subgroups rated information regarding diagnosis and prognosis among the top 5 areas of expectations, and all subgroups, except for male participants, rated explanation in clear language among the top 5 as well.

Focus group participants’ emphasis on communication is consistent with the shift in medicine toward patient-centered care and with previous studies demonstrating that patients have high expectations for medical information. Ophthalmology patients in the study appeared to expect a fairly high level of involvement in their eye care. In general, medical information enables patients to participate in medical decision making; hence, patients have high expectations for information. Individual patients may differ with respect to the amount of detail they wish to receive, their ability to comprehend medical information, and their desired degree of involvement in medical decisions; however, focus group participants expressed a nearly universal expectation for honest communication regarding diagnosis, prognosis, risks of procedures, treatment options, and other elements of care. These findings are supported by a previous study of ophthalmology patients, which found that communication of medical information regarding diagnosis, prognosis, and treatment was a significant determinant of patient satisfaction. There is also growing evidence that physician-patient communication and higher levels of patient involvement in care are linked to better clinical outcomes.

### Table 1. Categories and Areas of Patients’ Expectations for Eye Care

<table>
<thead>
<tr>
<th>Category</th>
<th>Areas of Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Communication</td>
<td>Honesty (1)</td>
</tr>
<tr>
<td></td>
<td>Information about diagnosis and prognosis (2)</td>
</tr>
<tr>
<td></td>
<td>Explanation in clear language (3)</td>
</tr>
<tr>
<td></td>
<td>Listening/addressing concerns (6)</td>
</tr>
<tr>
<td></td>
<td>Information about medications (10)</td>
</tr>
<tr>
<td></td>
<td>Information about holistic medicine (12)</td>
</tr>
<tr>
<td></td>
<td>Discussion of family history (18)</td>
</tr>
<tr>
<td>B. Interpersonal manner</td>
<td>Empathy (5)</td>
</tr>
<tr>
<td></td>
<td>Personal connection (7)</td>
</tr>
<tr>
<td></td>
<td>Courtesy (11)</td>
</tr>
<tr>
<td></td>
<td>Professionalism (13)</td>
</tr>
<tr>
<td></td>
<td>Encouragement/reassurance (19)</td>
</tr>
<tr>
<td></td>
<td>Patience (21)</td>
</tr>
<tr>
<td>C. Physician’s skill</td>
<td>Experience/reputation (4)</td>
</tr>
<tr>
<td></td>
<td>Outcomes (14)</td>
</tr>
<tr>
<td></td>
<td>Competence (15)</td>
</tr>
<tr>
<td></td>
<td>Access to advances in eye care (20)</td>
</tr>
<tr>
<td>D. Logistics</td>
<td>Waiting time (9)</td>
</tr>
<tr>
<td></td>
<td>Coordination of care (17)</td>
</tr>
<tr>
<td></td>
<td>Appointment access (22)</td>
</tr>
<tr>
<td>E. Other</td>
<td>Time with physician (8)</td>
</tr>
<tr>
<td></td>
<td>Referral (16)</td>
</tr>
</tbody>
</table>

*The overall ranking of each expectation area based on frequency is noted in parentheses.

basis of this content analysis, the 6 areas of expectations that appeared to be of greatest importance to focus group participants were the following: (1) honesty, (2) information about diagnosis and prognosis, (3) explanation in clear language, (4) experience or reputation, (5) empathy, and (6) listening and addressing concerns. Examples of participant comments in each of these 6 areas are given in Table 2. Focus group participants also raised 16 additional areas of expectations regarding eye care. Examples of participant comments in each of these 16 additional expectations areas are given in Table 3.

At the end of each focus group session, patients were presented with copies of the Patient Concerns Form19 and asked to verbally identify items of particular importance to them when they visit their ophthalmologist. The 3 items most frequently identified as important were a desire to know more about the problem (identified by all 6 groups), a desire to discuss medications (identified by 5 groups), and a desire to do tests to find out what is wrong (identified by 5 groups). Other items that were identified by multiple groups included a desire for relief of physical discomfort or symptoms (identified by 3 groups), a desire to receive test results (identified by 2 groups), a desire to tell the eye doctor ideas or concerns about the problem (identified by 2 groups), and a desire to be comforted (identified by 2 groups).
Focus group participants also emphasized the importance of an ophthalmologist's interpersonal manner, particularly a sense of empathy and personal connection. These findings are consistent with evidence that a physician's affect toward patients is closely correlated with patient satisfaction. A previous literature review found that one of the most strongly supported relationships in the literature is the connection between “personal” care and high levels of satisfaction. There is also some evidence that more personal care is associated with better communication and more patient involvement. In the focus groups, patients with blinding eye diseases rated empathy higher than those with nonblinding diseases. This is not surprising. Interestingly, personal connection ranked next to last among expectations of participants with lower socioeconomic status, but personal connection rated second among those with higher socioeconomic status. This may be related to the shared socioeconomic status between patients with higher socioeconomic status and their ophthalmologists, but it is, nevertheless, a surprising finding.

In general, participants expressed few expectations for specific actions to be taken by the ophthalmologist. Our results are compatible with previous research findings that clinic employees, physicians, and administrators underestimate patient expectations for empathy but consistently overestimate expectations for tangible actions. However, this observation conflicts with studies from the primary care literature in which patient expectations and requests frequently included elements of the physical examination, diagnostic tests, referral, and new medication or treatment. For example, one study found that one of the 3 most desired elements of care was “listen to my chest (lungs) with a stethoscope.” Although ophthalmology patients in the focus groups did express expectations for referral, they did not express any analogous expectations for specific elements of the eye examination, medication, or testing. The observation that ophthalmology patients place greater emphasis on communication and interpersonal manner than technical interventions is consistent with a previous study, which found that patient satisfaction is more closely linked to patients' perceptions about whether they received nontechnical interventions, such as education, than technical interventions, such as diagnostic tests.

Patients' inability to effectively assess the technical quality of the eye care they receive may be part of the reason that focus group participants expressed few expectations for technical interventions. However, it does not explain discrepancies between the expectations of ophthalmology patients and primary care patients. One possibility is that ophthalmic medications, the eye examination, and ophthalmic testing may be less familiar to patients than corresponding elements of care in a primary care setting; thus, patients may have fewer expectations for these less familiar elements. In addition, the discrepancy might be attributed in part to the nature of the focus group discussions, which centered primarily around expectations for eye care in general. In contrast, most primary care studies have assessed patients' expectations at the time of a visit. It is possible that ophthalmology patients might express greater expectations for technical interventions in the setting of an individual visit; however, there was no evidence of this in the focus groups.

Although study participants generally prioritized nontechnical expectations, content analysis of the expectations expressed in the focus groups showed some differences according to sex, socioeconomic status, and condition type (blinding or nonblinding eye disease). Overall, expectations were fairly consistent across subgroups; however, there are additional differences worth highlighting.

Content analysis showed that female participants cited expectations for appointment access, experience or reputation, and explanation in clear language far more frequently than men did. Honesty was the most frequently cited expectation for both men and women. However, women rated both experience or reputation and explanation in clear language among their top 3 expectations, whereas men raised these expectations infrequently. The reason for this discrepancy is unclear. Male participants rated information about diagnosis and prognosis and empathy among their top 3 expectations.

Similarly, there were differences in some areas of expectations by socioeconomic status as well. Although no

<table>
<thead>
<tr>
<th>Table 2. Examples of Most Frequently Identified Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expectation</strong></td>
</tr>
<tr>
<td>1. Honesty (communication category)</td>
</tr>
<tr>
<td>2. Information about diagnosis and prognosis (communication category)</td>
</tr>
<tr>
<td>3. Explanation in clear language (communication category)</td>
</tr>
<tr>
<td>4. Experience/reputation (physician’s skill category)</td>
</tr>
<tr>
<td>5. Empathy (interpersonal manner category)</td>
</tr>
<tr>
<td>6. Listening/addressing concerns (communication category)</td>
</tr>
</tbody>
</table>
patients with lower socioeconomic status cited these expectations, patients with higher socioeconomic status expressed expectations in the following categories: access to advances in eye care, information about holistic medicine, and professionalism. Participants with lower socioeconomic status expressed expectations for referral, time with physician, and patience far more frequently than participants with higher socioeconomic status. The discrepancies in access to advances in eye care and holistic medicine are somewhat predictable. Participants with higher socioeconomic status were more likely to live outside of the immediate area and, as a result, may be more likely to expect cutting-edge diagnostic or therapeutic techniques when traveling to a tertiary care center. Interest in holistic medicine is also typically more common among higher-income populations. On the other hand, it is logical that patients with less education would place greater emphasis on patience on the part of the ophthalmologist. Differences between the groups in other areas of expectations, however, do not have clear explanations.

When the expectations expressed by patients with nonblinding and potentially blinding eye diseases were compared, differences were noted in 2 areas. Patients with potentially blinding diseases more frequently expressed expectations regarding appointment access and encour-
Ophthalmology patients’ expectations may vary among individuals. However, we have highlighted consistent areas of expectations for eye care expressed by focus group participants. Since one of the primary goals of studying patient expectations is to better meet these expectations, it is worth exploring what lessons we can take away from this investigation. We summarize patients’ expectations of their ophthalmologists in Table 4.

While most of the study results are relatively unsurprising, patients’ desire for honesty in communication was central. Patients have many expectations of their ophthalmologists, particularly in the areas of communication and interpersonal manner. While most patients are not equipped to measure the technical quality of eye care, patients are fully qualified to evaluate their ophthalmologists’ communication style and level of caring. In the environment of increasing emphasis on efficiency, it is important to remember the high priority that ophthalmology patients place on communication of medical information, explanation, listening, and personal connection.

### Table 4. Summary of Patients’ Expectations of Their Ophthalmologists

<table>
<thead>
<tr>
<th>Communication</th>
<th>Interpersonal manner</th>
<th>Logistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Be honest, even when there is bad news</td>
<td>• Demonstrate empathy</td>
<td>• Stay on time, whenever possible. When unavoidable delays occur, explain the reason to waiting patients and give them the option of rescheduling or waiting</td>
</tr>
<tr>
<td>• Provide explanations in clear, layperson language</td>
<td>• Show that you know patients as people and understand their unique situations</td>
<td>• When patients have urgent concerns, find a way to see them as soon as possible</td>
</tr>
<tr>
<td>• Provide patients with specific information regarding their diagnosis and prognosis whenever possible</td>
<td>• Be friendly and courteous at all times</td>
<td>• Communicate regularly with other providers caring for your patients</td>
</tr>
<tr>
<td>• Discuss rationale for and possible side effects of all medications</td>
<td>• Be encouraging when progress is made and reassure patients when appropriate</td>
<td>Other</td>
</tr>
<tr>
<td>• Discuss the possible benefits of diet and healthy living on a patient’s eye condition</td>
<td>• Be friendly and courteous, but always remain professional</td>
<td>• Try to avoid acting rushed when you are seeing a patient</td>
</tr>
<tr>
<td>• Listen carefully to patients’ concerns about their eyes</td>
<td>• Be patient, particularly with new patients who may be unfamiliar with elements of the eye examination</td>
<td>• Refer to an ophthalmologist with greater expertise if you are not confident in your ability to manage a patient’s eye condition</td>
</tr>
<tr>
<td>• Discuss patients’ family history of eye disease with them</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**CONCLUSIONS**

Ophthalmology patients’ expectations may vary among individuals. However, we have highlighted consistent areas of expectations for eye care expressed by focus group participants. Since one of the primary goals of studying patient expectations is to better meet these expectations, it is worth exploring what lessons we can take away from this investigation. We summarize patients’ expectations of their ophthalmologists in Table 4.

While most of the study results are relatively unsurprising, patients’ desire for honesty in communication was central. Patients have many expectations of their ophthalmologists, particularly in the areas of communication and interpersonal manner. While most patients are not equipped to measure the technical quality of eye care, patients are fully qualified to evaluate their ophthalmologists’ communication style and level of caring. In the environment of increasing emphasis on efficiency, it is important to remember the high priority that ophthalmology patients place on communication of medical information, explanation, listening, and personal connection.
Submitted for publication August 25, 2002; final revision received January 28, 2003; accepted February 5, 2003.

This study was supported in part by a grant from Research to Prevent Blindness Inc, New York, NY (Dr Lee is a recipient of the Lew Wasserman Merit Award) and by a gift from the Eberly family.

We thank the following physicians who permitted us to recruit their patients to participate in the study: Natalie Afshari, MD, R. Rand Allingham, MD, W. Banks Anderson, Jr, MD, Michael J. Cooney, MD, Leon W. Herndon, MD, Glenn J. Jaffe, MD, Terry Kim, MD, Calvin Mitchell, MD, Laurie K. Pollock, MD, Cynthia A. Toth, MD, Robin R. Vann, MD, and Julie A. Woodward, MD.

Corresponding author: Paul P. Lee, MD, JD, Box 3802, Duke University Medical Center, Durham, NC 27710 (e-mail: lee0106@mc.duke.edu).

REFERENCES