Perceived Barriers to Diabetic Eye Care

Qualitative Study of Patients and Physicians

M. Elizabeth Hartnett, MD; Ira J. Key, CPHQ; Natalie M. Loyacano, COT, CSA; Ronald L. Horswell, PhD; Karen B. DeSalvo, MD, MPH, MSc

Objectives: To address inadequate retinopathy screening at a largely indigent clinic and to explore perceived barriers, using qualitative techniques.

Methods: Responses were analyzed from structured focus groups of patients and key informant interviews of primary diabetic physicians and ophthalmologists at the Medical Center of Louisiana in New Orleans. The number of diabetic patients screened at the center from 2000 to 2002 was obtained by quantitative analysis of an administrative database.

Results: Participants cited finances as the major barrier, while physicians cited inadequate patient education. Patients largely believed that diabetic education was adequate, yet there was a gap between patient education provided and their understanding. All sources agreed that poor access to care, particularly the 1-year wait for an appointment, was a barrier. No respondent mentioned constraints of the system to provide eye care to the number of diabetic patients as a possible barrier, despite the 1-year wait for an eye appointment and a 29% increase in eye examinations within 2 years.

Conclusions: Perceptions of barriers to diabetic eye care differed among physicians and patients, although both groups agreed that access to care was a barrier. A gap exists between educational material provided to patients and what patients understand. A large unrecognized workload stresses the capacity of the current system.


Early eye examinations are recommended for all diabetic patients to prevent blindness. However, studies indicate that far fewer diabetic patients receive annual eye examinations in the United States. At the Medical Center of Louisiana in New Orleans (MCLNO), 33% of diabetic patients received an eye examination in the 12 months before March 1, 2002.

To address low annual diabetic eye examination rates specific to the MCLNO, we used qualitative techniques that included patient focus groups and key informant interviews of ophthalmologists and primary diabetic physicians (PDPs). Qualitative approaches in systems research serve to understand root causes, reduce preconceived judgments, and permit insight into specific local or cultural stresses. They are a valuable adjunct to traditional quantitative research techniques by providing data unavailable through other approaches, and they help formulate hypotheses to forge detailed quantitative analyses. Few studies have used qualitative approaches of physicians and patients to probe into barriers to eye examinations, although some studies have been performed outside the United States or have used surveys of preconceived questions posed to physicians, patients, or both. The results of these studies have been inconsistent, in part because they have used different methods or have posed slightly different questions. Consistent, however, across several of these studies was the necessity for greater patient education about the need for annual diabetic eye examinations.

Analysis of the responses in our study provided a means to determine common perceived barriers to diabetic eye care. Some of these can be generalized to other indigent populations, whereas others are unique to the stresses of the MCLNO system and the patients served.

METHODS

The MCLNO is the largest of 9 facilities within the Louisiana State University Health Care Services Division and provides mostly
indigent health care for the greater New Orleans area. The eye clinic, staffed by 1 nursing director, 2 nurses, 4 to 5 technicians, and 4 to 6 resident physicians supervised by attending staff, works at its maximum efficiency in the current system to provide daily patient care. Approximately 120 patients are scheduled daily, not including emergencies. Newly diagnosed diabetic patients have dilated fundus images taken in the Diabetes Clinic 2 days per week that are interpreted by ophthalmologists.

QUANTITATIVE ANALYSIS

The number of diabetic patients receiving annual eye examinations at the MCLNO from 2000 to 2002 was determined from the administrative database of the Louisiana State University Health Care Services Division.

QUALITATIVE STUDIES

To increase the rigor of our qualitative analysis,13 we obtained information from 3 sources: (1) structured focus groups of diabetic patients; (2) key informant interviews of PDPs, including primary care physicians, internists, and endocrinologists; and (3) key informant interviews of ophthalmologists. All participants were patients or physicians who worked at or received care from the MCLNO. The focus group format was chosen for patients to reduce bias secondary to differences in literacy among participants. The key informant interview was used for physicians instead of a focus group format to increase the likelihood of responses from busy physicians across the MCLNO system and to maintain similarity to the focus group format. Examples of questions include the following: (1) What are the factors that encourage your diabetic patients to keep their eye appointments? (2) What could you specifically do to remove barriers to eye care that patients face in your practice?

CODING

Descriptive codes for textual data14 were taken from focus group transcripts or the written responses from key informant interviews. Three independent reviewers performed the coding to improve dependability and reliability. Two (M.E.H. and N.M.L.) were focus group comoderators, and 1 (K.B.D.) was not involved in the focus group sessions. If disagreement existed regarding the coding, a consensus was reached. Coding of the focus group transcripts was compared with summaries of field notes created promptly after each focus group session. Codes for focus groups and key informant interviews were grouped into patterns, and common themes were discerned and ranked ordered based on the central questions regarding barriers to eye examinations.

RESULTS

QUANTITATIVE ANALYSIS

Twenty-nine percent (2145/7395) of diabetic patients received an eye examination in 2000 at the MCLNO. In 2002, the rate rose only to 33%, but the 4–percentage point increase represented a 29% increase (621 examinations) in the number of eye examinations, because the number of diabetic patients at the MCLNO also increased. When we included only diabetic patients eligible for free care, 40% had an eye examination. Approximately 10% of screenings were performed with fundus imaging.

PATIENT FOCUS GROUPS

Four focus groups were held from February through June 2002 with 17 participants (4 men and 13 women). We were restricted by our institutional review board from obtaining actual ages; however, some participants volunteered this information, and we were able to get a reasonable estimate of the age of participants from the transcripts. Ages ranged from 30 to 60 years, and most participants were between 45 and 65 years of age. There were 2 white, 2 Hispanic, and 13 African American participants (about 82% of diabetic patients at the MCLNO are African American). About one third of the participants reported having diabetes for 5 or more years; two thirds reported 1 or more comorbidities.

PHYSICIAN KEY INFORMANT INTERVIEWS

A 12-question interview was sent by e-mail to 22 physicians (12 attending staff and 10 residents, comprising 9 ophthalmologists and 13 PDPs). Interview questions were open

©2005 American Medical Association. All rights reserved.
GENERAL UNDERSTANDING OF DIABETIC EYE RECOMMENDATIONS

Approximately half of the participants knew of the recommendation for annual diabetic eye examinations from their PDPs or ophthalmologists. Participants generally lacked understanding of the rationale for annual examinations or knew what retinopathy was. The fear of blindness sometimes was an incentive to keep annual appointments.

COST AND FINANCES

Cost and finances were the most commonly cited barriers to diabetic care expressed by all focus group participants (Table 1). When specifically asked what the medical profession could do to improve the participant’s diabetic eye care, the most common answer was to provide money for insulin and other medications.

EDUCATION AND INSIGHT INTO THE DISEASE

Most participants believed that they received adequate education about diabetes and cited their PDPs and ophthalmologists as the primary sources, with the drugstore and Internet cited as secondary. However, there was a common pattern observed from the transcript codes (patient insight, diabetic education, and knowledge of the disease) that indicated an erroneous or limited understanding about diabetes (Table 1). No participant knew that floaters or “spots” were an important symptom of severe retinopathy. Only one third knew that retinopathy could cause blindness. Few knew what retinopathy was, and almost none knew that retinopathy could cause blindness and be asymptomatic. There was confusion about presbyopia vs diabetes symptoms. The most preferred methods of education were group settings, their physicians, literature, videos, and the Internet.

ACCESS

Participants cited the 1-year wait for an MCLNO eye clinic appointment as a barrier (Table 1). Participants were concerned that multiple appointments scheduled at one time caused some patients to wait all day to see a physician. Some patients expressed concern that their eye physician had so many patients to see.

OVERSHADOWING OF EYE DISEASE BY DIABETES BURDEN

Patients stated that the burden of diabetes and its treatment, especially insulin use, overshadowed concern about eye disease and the need to have yearly eye examinations. The burden was expressed as stress, fear, hopelessness, anger, and reduced quality of life (Table 1).

PHYSICIAN KEY INFORMANT INTERVIEWS

Responses were received from 13 PDPs (6 internists, 1 diabetologist, and 6 ophthalmologists).

Table 1. Examples of Typical Focus Group Responses

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Typical Response</th>
</tr>
</thead>
</table>
| Cost and finances | Moderator: If we could do anything to help you with your diabetes, what would you like to ask for?  
Participant: “... free medication. As far as dieting and caloric intake and all, that has to be done on my own. But, the biggest problem is my medicine.”  
 Moderator: If we could do whatever we can do to help you with your diabetic eye care, what would you like us to do?  
Participant: “I would like for you to help with the medication.”  
 Participant: “I would like the same thing.”  
Participant: “What does diabetes in your eyes mean? Does that mean some kind of mold or something?”  
Moderator: Have any of you heard of retinopathy?  
Participant: “Is that when your retina detaches?”  
Participant: “Is that when your retina becomes enlarged? I have heard the term before because I work in ophthalmology. I have never known what it was.”  |
| Education and insight into the disease | Access  
Participant: “He [the physician] told me because you are a diabetic you need to have your eyes checked. ... They made me an appointment for a year later.”  
Participant: “The doctor tells us that we need an eye appointment. I don’t think we should wait a whole year.”  
Participant: “The problem is when I miss my eye appointment. ... I might get another appointment not until the next year.”  
Participant: “Charity Hospital ... I have to wait so long to see her [the physician]. She has so many patients and I feel that I am not a priority to her.”  |
| Overshadowing of eye disease by diabetes burden | Participant: “I know because of that stress my sugar rises.”  
Participant: “I know another way you can catch diabetes. Stress.”  
Participant: “With this sickness, you have so many things you have to worry about.”  
Participant: “I think the sugar has a lot to do with stress. Your whole life just changes.”  
Participant: “I am having to take the shots. I cannot do my arms. My family is afraid to give me shots in my shoulder because they are afraid of the needles.”  |

PERCEIVED BARRIERS TO DIABETIC EYE CARE

Ophthalmologists and PDPs mostly agreed about barriers to eye care (Table 2). In contrast to the patients’ focus group statements, no physician interviewed mentioned patients’ financial limitations as a barrier to diabetic eye care. The most cited barrier to diabetic eye care was lack of patient education and knowledge about diabetes mellitus. Physicians addressed educational needs using similar methods, including model eyes, drawings representing the eye and retinopathy, images of the patients’ retinas, and written literature. Both groups expressed the need to address the
Some of the terms used were patient education, as long as they were explained. In addition, both groups patients’ complaints and to provide education regarding diabetic eye disease. In addition, both groups advocated use of medical terms when providing patient education, as long as they were explained. Some of the terms used were neovascularization, retinal detachment, and retinopathy. Although diabetes education classes were open to all diabetic patients at the MCLNO, only 1 PDP encouraged patients to attend them.

The PDPs listed personal issues (child care concerns, transportation difficulty, work, and forgetting appointments) second to education as a barrier to diabetic eye care, whereas ophthalmologists listed access to care next (long wait for appointments, scheduling problems, patients not having telephones or mechanisms for communication, and long clinic wait times). Primary diabetic physicians and ophthalmologists described physician-patient communication as a barrier. Both groups cited the importance of physician compassion to patients.

### COMMUNICATION BETWEEN PDPS AND OPHTHALMOLOGISTS

Physicians agreed that poor communication regarding patients existed between PDPs and ophthalmologists for several reasons: (1) medical records were not always available, (2) resident staff changed every 4 to 6 weeks, and (3) patients did not remember their physicians’ names. When asked what information one physician would like from the other, PDPs listed diagnosis, prognosis, and treatment plan, whereas ophthalmologists requested glycosylated hemoglobin, level of diabetic control, comorbidities, and overall health status. Although not specifically probed, there appeared to be a gap in the understanding of what each medical specialty needed from the other to maximize patient care. When queried about how to improve communication, the most common recommendation from PDPs and ophthalmologists was an electronic medical record or e-mail.

### Table 2. Rank Order of Perceived Importance of Barriers to Diabetic Eye Care From Focus Group Participants and Key Informants

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Primary Diabetic Physicians</th>
<th>Ophthalmologists</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost and finances</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
<td>1</td>
</tr>
<tr>
<td>Education and insight into the disease</td>
<td>1</td>
<td>1</td>
<td>4*</td>
</tr>
<tr>
<td>Access</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Physician-patient communication</td>
<td>4</td>
<td>4</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>Personal (work, child care, transportation, and forgetting appointments)</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

* Adequate diabetic education was generally the perception of focus group participants, although there appeared to be a gap between education and understanding based on analysis of transcripts and interviews.

Patient and physician perceptions of barriers to diabetic eye care differed in theme and ranking of importance. The use of different methods (ie, focus groups and key informant interviews) may have influenced responses and therefore the trends noted. In both methods, we used broad nondirected questions that were similar and believe that our data have identified real differences in perceptions.

In our study, without prompting the participant with preconceived questions, financial burdens emerged as major barriers. When participants were questioned specifically about what health care providers could do to help with their diabetic eye care, respondents cited financial relief for diabetic medications, like insulin, as the single most important incentive. The financial burdens increased stress, which was believed to interfere with diabetes care and to outweigh concerns for eye care among some participants. However, physicians did not mention finances or the extent of their effect on patients as barriers to eye care. This supports the findings in a survey of health providers and administrators concerning barriers to overall diabetes care in which only 25% agreed that significant barriers included affording home blood glucose monitoring, special diets, and testing.

Physicians cited patient knowledge about diabetes as the most important barrier to eye care. Most patients believed that they had adequate education about diabetes, but focus group data indicated a gap between the perceived communication from physician to patient and what the patient understood. Although more than half of the patients knew that eye examinations were recommended, there was limited understanding of the rationale behind the recommendation and misunderstandings or little knowledge about retinopathy. Telephone interviews of a random sample of African Americans in New York and studies in Australia also revealed a limited understanding of retinopathy among diabetic patients and a need for improved education.

Ophthalmologists and PDPs acknowledged the importance of physician-physician and physician-patient communication and that significant barriers existed. It remains unknown whether patient compliance with eye examinations would be improved if patient-physician continuity of care were maintained. Improved communication between ophthalmologists and PDPs might also result from focusing the time spent on education provided to diabetic patients. For example, the PDP might provide eye education in general diabetic educational groups early before retinopathy develops, and the ophthalmologist might provide education later when retinopathy develops. This finding was also suggested after a study in Australia.

Physicians and patients agreed that there were systems problems at the MCLNO, particularly the long wait from when the appointment was requested to the actual date. Patients feared going blind before the next eye examination, were confused about a 1-year wait for an important appointment, and distrusted that the physician’s recommendation and the system’s response did not
match. However, no diabetic patient or key informant mentioned capacity constraints (number of patients per session needed to see >8000 diabetic patients per year) as a possible barrier, although several focus group participants commented that physicians seemed to have too many patients to see at one clinic.

Our results may be generalizable to other indigent groups that receive state-subsidized health care in which physicians have minimal input into the management and leadership. Our future studies will address the generalizability of our data to other populations. However, the present study raises unique differences based on local and cultural stresses within the MCLNO system and among the patients served. Our study highlights the need to use a process to determine the local stresses within a group to effectively and efficiently use health care resources.

Limitations exist when using qualitative approaches to research. Although efforts were made to include a balanced participation from both sexes, most of the participants were female. Those who participate in focus groups may be compliant with health recommendations, so we may have missed important information from diabetic patients who have not had eye examinations. Focus groups are not meant to replace surveys or larger quantitative analyses; rather, they provide unique information in cases in which quantitative approaches fail and can help formulate questions for later validation or to test future interventions. The key informants were chosen to broadly represent physicians directly involved in diabetic patient care at the MCLNO. Determinations of perceptual differences in barriers cited by key informants and the participants of the focus groups are representative of the MCLNO population and must not be overinterpreted.

Several suggestions emerged from this study. These include the following: (1) addressing patient financial barriers, as these are important and compound stress associated with the burden of diabetes; (2) developing a 1-page synopsis in electronic form to facilitate communication regarding patient care between PDPs and ophthalmologists and to improve the effectiveness of patient education; (3) scheduling and system changes at the MCLNO; (4) testing the effectiveness of patient education, including the understanding that patients have after their appointments; and (5) creating a glossary of commonly used terms by PDPs and ophthalmologists that would be available to physicians, patients, and staff to enhance communication.

Submitted for Publication: September 26, 2003; final revision received June 24, 2004; accepted June 24, 2004.

Correspondence: M. Elizabeth Hartnett, MD, Department of Ophthalmology, The University of North Carolina at Chapel Hill, 5109D Bioinformatics Bldg, 130 Mason Farm Rd, Campus Box 7040, Chapel Hill, NC 27599-7040 (hartnett@med.unc.edu).

Funding/Support: This study was supported by grant HS11834-02 from the Agency for Healthcare Research and Quality, Rockville, Md, through the Building Research Infrastructure and Capacity Program.

Previous Presentation: These results were presented in part as a poster at the 30th Annual Meeting of the North American Primary Care Research Group; November 18, 2002; New Orleans, La.

Acknowledgments: We acknowledge Shannon McNabb, MA, and the Louisiana State University Health Services Research Program for assistance and support, and SusanMasse, BS, CCRC, for her help in processing and maintaining anonymity of key informant interviews.

REFERENCES


