Differences in Perceived Barriers to Diabetic Eye Care

Although patients and physicians often have different perceptions of what barriers actually exist, all agreed that access to care is a problem.

REVIEWED BY M. ELIZABETH HARTNETT, MD

Researchers undertook a study to address inadequate retinopathy screening at a largely indigent clinic in New Orleans. They sought to explore perceived barriers to care using qualitative techniques.

M. Elizabeth Hartnett, MD, from the department of ophthalmology, The University of North Carolina at Chapel Hill, and colleagues at the department of ophthalmology, Louisiana State University Eye Center, wanted to address low diabetic eye examination rates specific to the Medical Center of Louisiana in New Orleans (MCLNO). Yearly eye examinations are recommended for all diabetic patients to prevent blindness, however, studies indicate that far fewer patients receive these exams. At the MCLNO, just 33% of diabetic patients received an eye exam in the 12 months before March 1, 2002.

STRUCTURED FOCUS GROUPS

Writing in the *Archives of Ophthalmology*, Dr. Hartnett said responses were analyzed from structured focus groups of patients and key informant interviews of primary diabetic physicians and ophthalmologists at MCLNO. "The MCLNO is the largest of nine facilities within the Louisiana State University Health Care Services division and provides mostly indigent health care for patients from greater New Orleans," Dr. Hartnett said. "The number of diabetic patients screened at the center from 2000 to 2002 was obtained by quantitative analysis of an administrative database."

Information for the analysis came from three sources: structured focus groups of diabetic patients; key informant interviews of primary diabetic physicians, including primary care physicians, internists and endocrinologists; and key informant interviews of ophthalmologists.

> Primary diabetes physicians listed education as the largest barrier to diabetic eye care.

Dr. Hartnett and colleagues found that approximately half of the patient participants knew the recommendations call for annual diabetic eye exams from their primary diabetic physicians or ophthalmologist. They generally lacked understanding of the rationale for the exams or knew what retinopathy was.

Patients cited cost and finances as the major barrier to care (Table 1). "The most common answer given when asked specifically what physicians could do to improve the participant's eye care was to provide money for insulin and other medications," the investigators wrote.

PATIENTS BELIEVE THEY ARE EDUCATED

The majority of participants said they believed they received adequate diabetes education, citing their primary diabetes physician and ophthalmologists as primary sources. The investigators reported that participants indicated an erroneous or limited understanding about diabetes. No participants knew that floaters or spots were an important symptom of severe retinopathy, and only one-third knew that diabetes could cause blindness.

Participants also cited the 1-year wait for an MCLNO eye clinic appointment as a barrier to care. The participants reported concern that multiple appointments scheduled at one time caused some patients to wait all day to see a physician. Some also expressed concern that their eye physician had so many patients to see.

OVERSHADOWED BY DIABETES BURDEN

Patients state that the burden of living with diabetes and its treatment, particularly insulin use, overshadowed concern about eye disease and the need for yearly examinations. "According to the study results, the burden was expressed as stress, fear, hopelessness, anger and reduced quality of life," Dr. Hartnett and colleagues said.

Ophthalmologists and primary diabetes physicians typically agreed about barriers to eye care. No physicians interviewed mentioned financial limitations as a barrier to diabetic eye care, Dr. Hartnett wrote. In contrast, the most cited barrier was a lack of patient education and knowledge about diabetes. "Both groups expressed a need to address the patients' complaints and to provide education regarding diabetic eye disease," they wrote. "In addition, both groups advocated the use of medical terms when providing patient education, as long as they were explained."

EDUCATION CLASSES NOT UTILIZED

Although patient education classes were open to all diabetic patients at the MCLNO, only one primary diabetes physician encouraged patients to attend.

Primary diabetes physicians cited personal issues such as child care concerns, transportation difficulty,

TABLE 1. EXAMPLES OF TYPICAL FOCUS GROUP RESPONSES

Cost/Finance

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."

Education/Insight into Disease

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 you retina becomes enlarged? I have heard the term before because I work in ophthalmology. I have never known what it was."

Access

Participant: "He [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 [doctor]. She has so many patients and I feel that I am not a priority to her. "

Burden of Diabetes Overshadows Burden of Eye Disease

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."

TABLE 2. RANK ORDER OF PERCEIVED IMPORTANCE OF BARRIERS TO DIABETIC EYE CARE FROM FOCUS GROUP PARTICIPANTS AND KEY IMFORMANTS

Barrier	Primary Diabetic Physicians	Ophthalmologists	Patients
Patient financial resources	Not mentioned	Not mentioned	1
Patient knowledge about diabetes	1	1	4*
Access to eye care	3	2	2
Doctor-patient communication	4	4	Not mentioned
Personal (work, child care, transportation, forgetting)	2	3	3

*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.

work and forgetting appointments second to education as a barrier to eye care. Ophthalmologists listed access to care next, saying that the long wait for appointments, scheduling problems, patients not having telephones or mechanisms for communication and long clinic wait times as important barriers. "Both groups cited the importance of physician compassion to patients," Dr. Hartnett added.

Both groups of physicians agreed that poor communication existed between primary diabetes physicians and ophthalmologists, for several reasons: medical records were not always available, resident staff changed every 4 to 6 weeks and patients did not remember their physicians' names.

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"There appeared to be a gap in the understanding of what each medical specialty needed from the other to maximize patient care," Dr. Hartnett and colleagues wrote. "When queried about how to improve communication, the most common recommendation from primary diabetes physicians and ophthalmologists was an electronic record or e-mail.

CONCLUSIONS

The perceptions of barriers to diabetic eye care differed among physicians and patients (Table 2). The perceptions of barriers differed in theme and ranking of importance, but all participants cited financial burdens as a major concern. Physicians cited patient knowledge as the most important barrier to appropriate diabetes care. It is clear that a gap exists between educational material provided to patients and what patients understand, Dr. Hartnett and the researchers found. Both groups recognized access to care as a barrier. A large unrecognized workload stresses the capacity of the current system.

The investigators came up with several suggestions that emerged from the study:

- addressing patient financial barriers, as these are important and compound stress associated with the burden of diabetes;
- developing a 1-page synopsis in electronic form to facilitate communication regarding patients' care between primary diabetes physicians and ophthalmologists to improve the effectiveness of patient education;
- scheduling and system changes at the MCLNO;
- testing the effectiveness of patient education, including the understanding that patients have after their appointments; and
- creating a glossary of commonly used terms by primary diabetes physicians and ophthalmologists that would be available to physicians, patients and staff to enhance communications. ■

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