American Journal of Medical Quality

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Improving Health Care Experiences of Persons Who Are Blind or Have Low Vision: Suggestions From Focus Groups

Bonnie L. O'Day, PhD, Mary Killeen, MA, and Lisa I. Iezzoni, MD, MSc

Persons who are blind or have low vision face special challenges in obtaining care that is safe, effective, timely, and patient centered. To explore perceptions of care and recommendations for improvements, we conducted 8 interviews with experts and 2 focus groups with 19 persons, all of whom are blind or have low vision. Interviewees perceived that they confront special barriers to care because of being blind or having low vision. Barriers fell into 4 broad categories: basic respect, including concerns about physicians thinking they cannot participate fully in their own care; communication barriers, including difficulties interacting with physicians and office staff; physical access barriers, including difficulties getting to and around physicians' offices; and information barriers, including receiving written materials in inaccessible formats (eg, not in Braille, large print, or audiotape). Using common courtesy and individualized communication techniques, physicians and office staff could improve health care experiences of blind and low-vision patients.

Key words: Barriers to health care, blind, low vision, primary care.

Providing safe, effective, timely, patient-centered care is central to ensuring high-quality health care for every patient (1, 2). Achieving these goals for some populations, however, may require careful thought, planning, and advice from patients themselves. In particular, ensuring high-quality care for persons who are blind or have low vision can raise special challenges not only within health care settings but also once patients return home. Although persons who are blind or have low vision know how to live, work, and travel daily throughout their homes and communities, health care providers rarely ask their advice about how to organize care settings, communication approaches, and routine clinical practices to maximize their quality of care and experiences as patients. The purpose of this study was to interview persons who are blind or have low vision to explore their experiences with health care and suggestions for improving its quality.

BACKGROUND

Approximately 9.7 million US residents are blind or have low vision, including individuals who cannot see at all and those who have difficulty seeing even with corrective lenses. About 1.3 million, roughly 5 in 1000 persons, are legally blind (central visual acuity of $\leq 20/200$ in the better eye with correction or a field of vision of ≤ 20 degrees), although about 80% of them have some useful vision (3). The majority of people with severe vision loss are older than 65 years, and their numbers are increasing with the rising prevalence of diabetes and diabetic retinopathy (4).

Evidence suggests that people with low vision have relatively higher rates of health problems and high-risk health-related behaviors than do others. About 30% of adults with visual limitations describe their overall health status as "fair" or "poor," compared with 8% of the general population (4). People with severe vision loss consistently report higher rates of depression and anxiety than do other people (4). Among adults with severe vision loss, 26.4% are obese (body mass index [BMI] ≥ 30 kg/m^2), compared with 15% of other adults (5). Approximately 33% of adults with severe vision loss smoke, compared with 26.3% of other adults (5).

Simultaneously, people with severe vision loss ap-

Dr O'Day and M. Killeen are from Cherry Engineering Support Services Inc, McLean, Va; and Dr Iezzoni is from Division of General Medicine and Primary Care, Department of Medicine, Harvard Medical School, Beth Israel Deaconess Medical Center, the Charles A. Dana Research Institute, and the Harvard-Thorndike Laboratory, Boston, Mass.

Corresponding author: Lisa I. Iezzoni, MD, MSc, Division of General Medicine and Primary Care, Department of Medicine, Beth Israel Deaconess Medical Center East Campus RO-137, 330 Brookline Avenue, Boston, MA 02215 (e-mail: liezzoni@bidmc.harvard.edu).

pear less satisfied with their health care than others (6–8). According to a nationwide survey of elderly and disabled Medicare beneficiaries, 8.1% of persons with very low vision report dissatisfaction with their overall quality of care compared with 4.0% of others. In particular, 11.1% of persons with low vision feel that they get inadequate information about their conditions, compared with 6.0% of persons without low vision; 9.9% of beneficiaries with low vision report that physicians are more concerned with isolated symptoms or diseases than with their overall health, compared with 5.1% of others (all P values < .0001) (6).

The growing prevalence of vision problems and the higher rates of health risks and dissatisfaction with care highlight the importance of improving primary care for persons who are blind or have low vision. In *Crossing the Quality Chasm,* the Institute of Medicine proposed organizing health care improvements around patients' values, goals, and preferences (1, 2). Furthermore, Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 require that physicians provide "effective communication" during clinical encounters unless doing so would cause significant difficulty or expense. Under both laws, patients' preferences should receive primary consideration, but physicians or other providers determine what constitutes effective communication. ADA regulations suggest various options, such as "qualified readers, taped texts, audio recordings, Brailled materials, large print materials, or other effective methods of making visually delivered materials available to individuals with visual impairments" (28 CFR Part 36. Subpart C. Sec. 36.303).

Studies of persons who are blind or have low vision generally highlight their health problems (3, 4) while providing little insight into patients' experiences or preferences for improving their care. We are unaware of published studies that asked persons who are blind or have low vision about their health care experiences or suggestions for improvements.

METHODS

This study was part of a larger project that examined the health care experiences of people with various disabling conditions (vision loss, hearing impairments, lower extremity mobility problems, and serious psychiatric conditions) (5–9). For this study, we adopted the approach of the World Health Organization, which views disability from a sociopolitical perspective as a product of the interaction between individuals and their surroundings (10). From this perspective, dis-

ability is not characterized by impairments of individual persons but by socially mediated barriers that can be addressed by altering public attitudes and making environmental modifications (11). In our larger study, we used quantitative (5–9) and qualitative (8) research techniques to describe and understand the experiences of persons with various disabling conditions. For our purpose here—eliciting information and advice from persons with vision loss—we used qualitative methods, specifically focus group interviews (12–16).

Researchers increasingly use interviews and focus groups to understand patients' perspectives on health care topics (16). These interviews typically involve 7–10 selected individuals who share certain characteristics; because of small nonrepresentative samples, the results do not broadly generalize. Nevertheless, focus groups yield important insight into participants' experiences from an insider's viewpoint and thus frame basic dimensions of research topics (13). Trained moderators encourage interaction among participants, stimulating ideas and assuring coverage of relevant points. Focus group interviews are generally semi-structured; moderators follow a guide that delineates broad topics and specifies open-ended questions.

Designing the Moderator's Guide

For our larger project, we developed a core moderator's guide based on literature reviews and interviews with selected experts in each of our target disabling conditions (8). This core guide contained 8 broad topics: overall views of health care quality; access to primary care doctors; communication; access to specialized services; accessibility within doctors' offices; training doctors; designing doctors' offices; and communicating our findings to other persons with disabilities. We then refined this core moderator guide, adding specific subsidiary questions relating to particular disabling conditions.

For refinements relating to vision loss, our literature search found few pertinent articles, which offered limited insight into patients' perceptions (17, 18). To get this guidance, 1 investigator (Dr O'Day), therefore, conducted in-depth telephone interviews with a convenience sample of key informants (15). These 8 individuals, 4 men and 4 women who reside throughout the United States, have different levels of vision loss, but are all legally or totally blind. They included a physician; an occupational therapist; 2 directors of agencies serving blind and low-vision persons; 2 service providers for elderly blind persons; a cancer survivor; and a health care advocate. The interviews, which were au-

diotaped and transcribed, asked about specific issues pertinent to blind or low-vision patients within each of the 8 core topic areas. After reviewing the transcripts, we developed specific subsidiary questions for the blind/low vision focus groups. Our moderator's guide is available on request.

Conducting the Focus Groups

Our expert interviews suggested that vision-specific health care experiences of blind and low-vision patients are sufficiently similar that we need not divide focus group participants by degree of vision loss or type of diagnoses. This approach conforms to the sociopolitical model of disability described above (10, 11). We planned separate focus groups for men and women because of gender-related sensitivities of some topics (eg, screening services).

To constitute 2 focus groups, we sought individuals in metropolitan Washington, DC, who met the definition of legal blindness and who spoke English. We recruited participants who were 30 years of age or older with significant experiences with the health care system and specifically with primary care. To recruit participants, we worked with agencies that provide services to people who are blind or have low vision (eg, the Washington, DC, Center for Independent Living, the Lighthouse for the Blind) and membership organizations of blind or low-vision people. Using these organizations as recruiting sources allowed us to recruit persons with knowledge about and experiences with health care. We asked recruiters to enroll diverse participants in terms of race, income, type of health insurance, and employment—factors that plausibly affect health care experiences and perceptions (19). The recruiters telephoned potential focus group participants and explained the purpose and conduct of focus groups and our provisions for protecting confidentiality.

The Beth Israel Deaconess Medical Center Institutional Review Board approved this project and required written informed consent. We provided consent forms to participants in large print and Braille and read the consent form out loud before requesting participants' signatures. We offered a $75 honorarium plus transportation expenses for participating in the focus groups.

An investigator (Dr O'Day) who has considerable experience moderating focus groups conducted both focus groups. Each focus group began with distributing the broad focus group topics in Braille or large-print versions. Although the moderator used the interview guide to ensure that she addressed all 8 broad topics (including the vision-specific questions), she followed the leads of participants to explore issues they raised. Focus groups lasted approximately 2 hours and were audiotaped. A professional transcription service transcribed the audiotapes verbatim, and the moderator reviewed the transcripts to ensure that speakers' names were accurately assigned. She removed actual names from the transcripts and substituted pseudonyms.

Analysis

After reviewing transcripts from these and other focus groups conducted for this study, 2 researchers (Dr O'Day and Dr Iezzoni) generated a coding scheme to facilitate analysis (available on request). Using this scheme, 1 author (Dr Killeen) sorted the texts with NVivo software (20). Using a grounded theory approach outlined by Miles and Huberman (21), each of the 3 researchers independently reviewed the sorted transcripts to identify common themes. We compared the themes raised by the 19 focus group participants with those of the 8 key informants, finding few differences in substance. The investigators discussed their findings during conference calls and reached consensus about the main messages.

Our primary goal here was to use information directly from persons who are blind or have low vision to inform improvements in health care delivery. To provide this insight in the interviewees' own words, this presentation uses statements that make the important points in the most compelling fashion, drawing on both the key informant and focus group interviews.

RESULTS

The focus groups involved 19 individuals, 11 men, and 8 women. Ten had no vision, whereas 9 had some vision. Their mean age was 49 years; 11 were African-American, and 8 were white. Twelve were employed. All participants except 2 had a primary care physician. Five participants had managed care insurance; the rest had fee-for-service, either through Medicare or through an employer. Eight had annual incomes under $20,000, whereas only 2 had incomes exceeding $60,000.

The overarching theme to emerge was participants' perceptions that they confront special barriers to care because of being blind or having low vision. Given our purpose here, we focus on these barriers and participants' suggestions for overcoming or circumventing these barriers. Barriers fell into 4 broad categories ad-

Table 1

Interviewees' Suggestions for Improving Communication

Training for all clinical and office personnel about:
Need to ensure patient-centered care, respecting patients' worth, values, preferences, and privacy
Professional, ethical, and legal obligations to ensure effective communication
Introducing all persons who enter rooms
Looking directly at the patient rather than at the sighted companion
Appropriate approaches for assisting persons who are blind or have low vision to move around facility and office
Appropriate methods to attract patients' attention during all encounters, especially physical examination and procedures
Verbalizing visual information during physical examination and procedures
Recognizing and eliminating physical environmental barriers:
Maintain specific information on local public transportation routes to facility
Be aware of patients using paratransit services and pick-up times; stay on schedule so that patients do not miss rides
Install Braille or raised-letter signage at appropriate height where written signs appear
Understand legal right for patients to bring service dogs, like guide dogs, into facility
Ask patients how they would like to be assisted in moving around facility and office
Communicating effectively:
Be aware of patients' communication preferences, especially about written materials (eg, Braille, large print) and communication between appointments (eg, telephone, e-mail)
Ensure privacy when assisting patients to complete forms (eg, paperwork at front desk)
Allow patients to audiotape encounters, especially medication instructions
Find alternatives to standard written materials, including audiotape, Braille, large-print versions
Learn about local resources, especially pharmacies that provide Braille or large-print labels or assist low-vision patients to organize medications
Learn about Internet resources for low-vision patients
Provide appointment cards in large print
Telephone or e-mail patient to remind them about medical appointments

dressing basic respect, communication, physical access, and inaccessible information formats. Table 1 summarizes suggestions for eliminating or reducing these barriers.

Basic Respect

At the outset, patients want physicians to respect them as human beings, not just feel pity for their blindness. As Dwight said:

I think that what doctors have to be told, first and foremost, is to ask blind persons [what they want.] But even before that, accept the blind person as another human being. We are not accepted as another human being, over and over again. We have got to be seen as persons of worth and people who actually can contribute to our own care and recovery. We can make a contribution, and we should be treated as individuals with intelligence.

Interviewees hoped that their physicians would get to know them as individuals and take an interest in their lives. They felt that communication barriers, such as those described below, often disappear once physicians and patients get to know each other. "If you've gone there for a while," said Trudy, "you form a rapport with your doctor. I guess from interacting with you, they become more sensitive." Samantha appreciates that her "doctor does try to get to know a little bit about me

and understand why I'm having some health problem or why I'm dealing with some stress situations. Trying to understand my day-to-day lifestyle or what I'm going through by being visually impaired—that means a lot."

Communication

Interviewees identified good communication between physicians and patients as the most important determinant of high-quality care. Respect forms the foundation of good communication, as described above, but in the clinical context other dimensions involve explaining complex medical problems and verbalizing visual information. The interviewees suggested that some clinicians feel uncomfortable communicating with someone who is blind, perhaps because blind persons do not maintain eye contact.

Interviewees reported that physicians sometimes address a sighted companion rather than the blind person, erroneously viewing the companion as in charge. "When you're with somebody," Howard explained, "doctors don't talk to you. They talk to the person that's with you, and they talk about you in the third person: 'What's his name?' 'What's his Social Security number'"? Jerry noted that he:

. . . even switched doctors because of something like that.

A doctor said, "I have some prescriptions I'm going to write for you. Is your wife or your secretary or someone out in the lobby"? I said, "Whatever you've got to say, say it to me, and we'll go from there." I consider it a lack of respect when someone won't talk directly to me.

Some participants stated that physicians focus on the blindness rather than the patients' presenting complaints. Martin explained:

When they see a blind person, no matter what you're coming there for, the first questions they ask you are, "What caused your blindness"? and "How long have you been blind"? Recently I fell and went to the emergency room because I hit my nose pretty badly. It turns out my nose was broken. Next thing I know, [I'm being asked] "how long have you been blind"? I said, "Would you tell me what that has to do with my nose being broken"?

Martin's blindness may or may not have contributed to his fall, but being questioned about the history of his blindness in the emergency room seemed inappropriate to him.

Interviewees suggested that basic courtesies and common sense foster good communication. They explained that introducing oneself upon entering a room is essential when patients cannot visually ascertain who has entered. Forewarning patients of physical actions, such as inserting a thermometer or drawing blood, is essential.

However, interviewees strongly stated that blind or low-vision people must take equal responsibility for fostering positive interactions with their physicians. Some interviewees admitted that being preoccupied with other stresses may divert their attention from communicating with their physicians. "Many things create a lot of anxiety for me," confessed John, "such as using public transportation and finding the right office. That affects my side of the communication equation. There's a lot of potential for missed signals, information not passing effectively between the patient and the professional." Jim observed, "I don't want to aggravate the doctor. I need him to give me the best attention and his most favorable thought. If I can get him interested in me as a person—as a nice person— it will be a whole different situation."

Some interviewees stated that patients should research their medical conditions (eg, through reading or searching the Internet) and prepare questions for their physicians. Carl suggested that blind people should "talk to our doctors and educate them on our needs. A lot of times, we see things going wrong, and we don't say anything about it. We just sweep it under the rug. But if we don't stop it, they're going to continue because they don't know."

Physical Access

Traveling to and from physicians' offices is the first barrier faced by people with low vision. Because they do not drive, they must be driven by someone else or use regular bus, subway, rail, taxi, or paratransit services (door-to-door, low-cost, advance reservation transportation for persons who meet medical disability requirements). Interviewees noted that lack of available transportation severely limits access, particularly to the newer suburban clinics. People without readily available, willing drivers (eg, family or friends) often select their physician based on the location of established bus, subway, or rail routes, as does Noreen: "I'm going to a doctor in DC that's accessible to a Metro [subway] station, period! I'm not going to get myself into a situation of having to go out to the suburbs to go to the doctor."

Using a taxi can obviate these concerns, but can prove too costly, as for Danielle:

There's the cost of the taxi, which adds to the cost to see [the physician]. You know, my throat's really sore, but maybe I should wait 3 or 4 days because it's going to cost me 25 dollars just to get there and back.

Interviewees recommended that office staff who answer the telephones know about nearby bus or subway stops, including the name or number of the bus or subway and give accurate directions from the stop to the office.

Requirements that paratransit services be scheduled in advance often become problematic. Pick-up and drop-off schedules are fairly rigid and do not accommodate such common problems as physicians being behind schedule. Sometimes the paratransit vehicle is late, making patients miss appointments. Interviewees recounted stories of the paratransit vehicle arriving for the return trip before the appointment is finished; when the vehicle leaves, the patient is stranded. Interviewees suggested that, if a physician is running late, the office should telephone the patient as soon as possible, noting the new estimated appointment time. Patients can then try to reschedule the return trip with the paratransit service.

Once inside the physician's office, people who are blind or have low vision use different methods to move around within the facility. People have strongly held individual preferences and abilities. Some use a long white cane or a dog guide, whereas others have sufficient vision to travel without these aides. Some people prefer to follow a few steps behind another person inside the office, some like verbal directions, and some people prefer a "sighted guide" (ie, the blind person

takes the elbow of a sighted person who walks one step ahead).

Interviewees suggested that physician office staff need more training about the different methods blind or low-vision people use to travel. Judith observed:

They don't really know how to deal with a blind person. They don't know how to treat you. As opposed to coming up and saying, "I'm so-and-so. I'm going to take you in the room now," they grab you. They snatch you. They push you. They'll grab you around the shoulders and push you along!

Rachel added, "It's a little embarrassing. [The receptionist] sees your condition, but she's not taking the time to show you the way, left, right, or whatever you're supposed to do." Focus group members agreed that medical staff should ask the patient how he or she would like to be assisted and follow the patient's requests. Interviewees found Braille and raised letter signage helpful to mark room numbers, bathrooms, elevators, and office doors. As Jerry explained:

When I step off the elevator onto a floor of long hallways with lots and lots of doors and no signage, I'm either opening doors and sticking my head into offices and saying, "Where is whatever?" Or I'm snagging someone in a hallway and asking where a particular place is. Proper signage on office doors would eliminate that problem.

Giving and Receiving Information

Typically, the first act on entering a physician's office is filling out forms. Persons who are blind or have low vision generally request assistance completing these forms. Interviewees reported that office personnel willingly provide assistance but generally in the waiting room with other patients nearby. This compromises privacy. Interviewees recommend that physicians' offices establish procedures to ensure that paperwork assistance is both available and private. Staff could even offer assistance to complete paperwork over the phone, at a mutually convenient time.

Physicians now routinely provide information about medications, not only actual paper prescriptions but also printed educational materials. Interviewees worried about obtaining accurate information about prescription drugs because these materials are rarely provided in accessible formats (eg, large print, Braille, and audiotape). Vernon suggested:

I've seen some doctors where their standard practice is writing out the prescription, and they'll rely on the pharmacist to type the correct instructions on the bottle. They may not bother to tell you whether to take it with food or not. It may not occur to you to get someone to read the

bottle to you while you're at the pharmacy. It would be particularly useful if they made sure they explain in detail how to take your prescriptions.

Interviewees recommended that physicians let patients audiotape their instructions if so desired.

Interviewees who take many prescription drugs face special difficulties in differentiating their medications. This could potentially result in serious medication errors. Noreen, who takes numerous medications, created her own strategy: "I stick rubber bands over some bottles. Then there are different shaped bottles. I just remember what's what."

Some participants mentioned problems obtaining accessible information on preventive medicine, general health, or certain medical conditions typically distributed in standard printed formats. Increasing numbers of blind and low-vision people, especially those of working age, have access to and are adept at using computers with voice or Braille output capability. Being informed of relevant Internet information resources would help interviewees who make use of these technologies.

The final step in physicians' office visits is frequently being handed a tiny slip of paper containing the date and time of the next appointment. Most blind and low-vision persons cannot read these slips. Although interviewees recognized their responsibility to keep track of scheduled appointments, they recommended a telephone call or e-mail a few days beforehand, as a useful reminder.

DISCUSSION

Physicians, especially those practicing primary care, encounter increasing numbers of people with varying degrees of visual loss. Because many blind and low-vision patients have significant health care needs, good communication between these patients and physicians and office staff becomes paramount. Unless patients have accessible information, they also may not know enough about their medical regimens when they return home, such as side effects to anticipate with prescription medications. The blind and low-vision interviewees suggested that physicians and office staff who use common courtesy and individualized communication techniques can effectively work with patients with vision loss.

Many recommendations (eg, introducing oneself on entering the room) generalize beyond blind and low-vision patients to all patients (22–26). The interviewees hoped that physicians would view vision loss as an important but not the primary aspect of the person's

health and well-being. Nevertheless, interviewees wanted physicians to recognize the special barriers raised by vision loss, not just for communicating effectively but also for the most fundamental needs, like finding transportation to and from medical visits. Sometimes these problems pose financial hurdles not covered by health insurance. For example, although Medicaid sometimes covers taxi costs for recipients to visit physicians' offices and clinics, other insurers rarely reimburse transportation expenses.

Many of the suggestions for improving the experiences of persons with low vision build on basic common sense, such as offering paperwork assistance in private locations, training office staff on respecting patients' preferences for navigating offices, installing Braille and raised-print signage, having information on public transportation routes readily available, and telephoning patients about future appointments. Although implementing these strategies may incur some costs, expenses will generally be modest. Braille and large-print signs are inexpensive and can be obtained from most sign manufacturers. The Internal Revenue Service provides tax credits, in certain situations, for costs incurred to improve access for people with disabilities; under ADA regulations, providers cannot charge patients directly for costs relating to improving access. Many informational brochures are produced by governmental agencies that must, by law, provide them in alternative formats, such as Braille or large print (27). However, some agencies have lagged behind in meeting this requirement. Physicians could advocate for their patients by requesting accessible materials, thereby increasing their availability.

The Internet has significantly increased access to health information for blind and low-vision computer users, who are able to access the Internet with screen magnification or speech and Braille output. Approximately 53% of people with low vision and no other health condition have access to a computer and use the Internet; this figure drops to 21% for people with an additional health condition (28). Although this solution will not work for all low-vision patients, physicians could advise some patients on how to locate relevant health-related information and could also communicate with patients through e-mail.

Importantly, if patients do not have complete information about their prescription drugs, they may not be able to adhere to their drug regimen, risking either dangerous side effects or ineffective treatments. Therefore, physicians must make special efforts to ensure that blind and low-vision patients know about pharmaceutical dosages and side effects. Physicians should carefully review all information about prescribed medications, allowing patients to take notes or tape-record the directions. Talking prescription devices are now available (29) that give patients verbal instructions when they insert pill bottles into an apparatus. However, most patients are unaware of or do not have access to such technology.

Our study has important limitations, and our results must, therefore, be viewed as preliminary. We did not interview a generalizable sample of persons who are blind or have low vision. Instead, we interviewed 8 experts and conducted focus groups with 19 individuals recruited by agencies and organizations for the blind. We conducted this study in greater Washington, DC; findings may not extend to rural residents or to people living in other geographic regions with other health care delivery systems. We could have enhanced our study by conducting more focus groups in diverse regions. But performing focus groups with persons who are blind or have low vision presents logistical challenges that increase the costs of this type of research. Other investigators will have to confirm our findings.

Nevertheless, the suggestions of the interviewees for improving their health care experiences have good "face validity"—they make sense, giving common understanding of the functional implications of vision loss and the way health care is currently delivered. Physicians can learn from asking patients about ways to improve their health care experiences. With almost 10 million Americans having vision loss and these numbers growing with the prevalence of diabetes and the aging population, clinicians will need to consider ways to ensure high-quality care for this important population.

ACKNOWLEDGMENT

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