

Listening to Patients: Cultural and Linguistic Barriers to Health Care Access

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Background and Objectives: Full access to medical care includes cultural and linguistic access as well as financial access. We sought to identify cultural and linguistic characteristics of low-income, ethnic minority patients' recent encounters with health care organizations that impede, and those that increase, health care access. **Methods:** We conducted four focus groups with ethnically homogeneous African American, Latino, Native American, and Pacific Islander patients. Study participants were "walked" through the stages of a medical encounter and asked to identify physician and staff behaviors that made the patient feel more comfortable (a surrogate for increasing access) and behaviors that made the patient feel less comfortable (a surrogate for decreasing access). **Results:** African American and Native American patients in particular expressed overall satisfaction with their physicians' services. Patients from all groups saw nonphysician staff as frequently impeding access. Based on perceptions of negative stereotypes, Native American and Pacific Islander patients reported hostility toward physicians' efforts at prevention and patient education. **Conclusions:** For the ethnic minority patients in our study, most perceived that cultural impediments to access involved nonphysician staff. Closer collaborations between health care organizations and ethnic minority communities in the recruitment and training of staff may be needed to improve cultural and linguistic access to care.

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Increasing health care access is more complex than simply providing funding to pay for care. Access also requires that health care services be provided in a manner that is culturally and linguistically appropriate and that does not discriminate based on race or ethnicity. As described by the Office of Minority Health of the US Department of Health and Human Services (OMH), to provide full access to care, a system of care must ensure "that all persons entering the health care system, regardless of race or ethnicity, receive equal, fair, and quality treatment."¹ Such culturally and linguistically appropriate health care is a concern not only of policy makers and health care organization (HCO) administrators but also of physicians and the educators of future physicians.

OMH has published its "National Standards for Culturally and Linguistically Appropriate Services in Health Care," referred to as the CLAS standards.² While federal enforcement regulations specifically address the standards pertaining to linguistic access, the standards go considerably beyond linguistic criteria in defining

guidelines for full access to care. Full access requires that patients receive care ". . . that recognizes and responds to health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy."³ Table 1 presents the 14 CLAS standards in abbreviated form. All providers who receive federal funds as payment for health care services are required by law to adhere to the four CLAS standards that address linguistic access (Standards 4–7; see Table 1). Providers are requested to implement the remaining standards that address cultural access.

Efforts to implement the CLAS standards are complicated by documented differences in health status and health care access among American cultural/linguistic groups, even after insurance coverage is taken into account.⁵ Any consideration of increasing access to care for patient populations that include large numbers of minority ethnicity patients will of necessity include an examination of the causes and effects of these disparities. Full access includes the means to pay for care, care that is culturally appropriate, care that is linguistically available, and care that does not discriminate based on the ethnicity of the patient.

African Americans have historically been the principal minority group in which disparities in health care

Table 1

Standards for Culturally and Linguistically Appropriate Services (CLAS)*

1. All patients experience culturally and linguistically competent encounters with staff.
2. Health care organizations (HCOs) have implemented strategies to hire, keep, and promote diverse staff and leaders.
3. All staff receive ongoing education in culturally and linguistically appropriate services.
4. HCOs provide language assistance services (eg, bilingual staff, interpreter services).
5. Patients receive oral and written notice of their right to language assistance services.
6. HCOs assure the language competence of their interpreters and bilingual staff.
7. HCOs provide informational materials and signs in the languages of their patients.
8. HCOs follow a written plan to provide culturally and linguistically appropriate services.
9. HCOs conduct organizational assessments relating to cultural and linguistic access.
10. HCOs include data on patient race, ethnicity, and language in health records and management information systems.
11. HCOs maintain a current demographic, cultural, and epidemiological profile of the community.
12. HCOs have collaborative partnerships with the community to address barriers to access.
13. HCOs have culturally and linguistically sensitive conflict and grievance resolution processes.
14. HCOs publicly report their progress in overcoming cultural and linguistic barriers to access.

* in abbreviated form⁴

access and quality have been identified. The question arises as to whether other ethnic minorities face the same disadvantages as African Americans in obtaining full and equal access to care. Fewer studies, for example, have been done looking at Hispanics/Latinos, Native Americans/American Indians, Asian/Pacific Islanders, and other ethnic groups. For Latino patients in particular, many of whom may have limited English-speaking ability, expanding access requires a number of protections beyond expanding insurance coverage.

This research's goal was to develop a better understanding of low-income, minority patients' perceptions of the culturally and linguistically related characteristics of their recent encounters with local health care organizations (HCOs). Based on the experiences and perspectives reported by these patients, we attempted to identify specific cultural and linguistic characteristics of their encounters that either impede access to health care or increase access to health care.

Methods

The patient population in our research was low-income patients drawn from the African American, Latino, Native American/American Indian, and Pacific Islander communities of the San Francisco Bay Area.

We created a research team that included members of the subjects' racial and ethnic groups to increase the likelihood that the project's information elicitation procedures would be sensitive to the experiences and perspectives of members of those groups. The research team used a focus group format for eliciting information that "walks" study participants through various stages of their health care encounter, starting at the point when they contacted an HCO to make an appointment to be seen for a health problem. We obtained Institutional Review Board approval for this research, and informed consent was obtained from all study participants.

Sample Selection

We recruited 41 adults to participate in ethnically homogeneous focus groups composed of members of the four target groups. All were low income, and all typically used local community-based clinics for their medical care. A researcher belonging to that same group facilitated each focus group.

We recruited these patients with the assistance of three different agencies in the San Francisco Bay Area that provide health and/or social services to low-income populations. Two of the organizations provide a broad range of social and support services for low-income clients, including referrals to local nonprofit or government-funded HCOs that treat low-income patients. These agencies provide services to large numbers of African Americans, Pacific Islanders, and Hispanic/Latinos. To reach a substantial number of Native American/American Indian patients, we also recruited study subjects at a federally qualified health clinic that serves the Native American/American Indian population in the area.

Focus group research typically includes self-selection in the recruitment of study subjects. Subjects generally respond to advertisement of the research by volunteering for focus group participation. Such was the case with this research. At each of the three facilities collaborating with the study, we posted a sign inviting clients to participate in the focus groups. In addition, we spoke with staff at the facilities and asked them to mention the focus group recruitment to clients they work with. Each participant was offered a small cash stipend for participation, paid at the conclusion of the focus group. All clients who volunteered were included in the study. We conducted one focus group (Hispanic/Latino) in Spanish; the others were conducted in English. Consent forms and the focus group "script" (questions and associated directions) were translated into Spanish for use in that focus group.

Study Instrument

We developed a focus group script of 11 question sets that elicited information about study participants' experiences and perceptions regarding: (1) physicians,

(2) different categories of nonphysician staff, (3) HCOs' physical environment, (4) different types of services provided by physicians, and (5) different types of services provided by nonphysician staff. After introducing focus group participants to the general issue of cultural and linguistic access to care, we asked these questions to probe for specific features of their recent encounter that made them either more or less comfortable (Table 2). To elicit information that was clear and concrete, the questions directed study participants to focus on the specifics of what might be said and done by HCO physicians and staff at different stages of the patient-HCO encounter.

Focus Group Format

Each focus group was scheduled for a 2-hour time span. The moderators introduced themselves and the project staff providing assistance and invited study participants to briefly introduce themselves. The moderator then introduced the study by reading the brief descriptive information contained in the consent form and distributed copies of the consent forms for participants

Table 2

Sample Questions From Focus Group Script Asked of Study Participants

(Text in brackets was for focus group moderator's information and is not read to study participants. Full script includes 11 question sets)

[Question Set #1—Initial contact with the clinic for a particular episode of illness]

Think about times when you have called for an appointment to see a doctor or when you have come into the waiting room without an appointment because you needed to see a doctor.

- [1.1] Please describe anything that the person who answered the phone, or the receptionist when you came in, said or did that made you feel MORE comfortable about coming in to the clinic. [Try to get responses from around five different participants, and end up with a total of around five different responses. *Note: This reminder to the focus group moderator/facilitator appears after each question.*]
- [1.2] Please describe anything that the person who answered the phone, or the receptionist when you came in, said or did that made you feel LESS comfortable about coming in to the clinic.

[Question Set #2—Physical environment of the clinic]

- [2.1] Is there anything about the rooms in the clinics you have gone to, or the materials in the rooms, that made you feel MORE comfortable about going to those clinics?
- [2.2] Is there anything about the rooms in the clinics you have gone to, or the materials in the rooms, that made you feel LESS comfortable about going to those clinics?

[Question Set #3—Doctor comes into exam room]

Think about times you have been in the examination room of clinics you have gone to, and the doctor came into the examination room.

- [3.1] Please describe anything the doctor said or did when the doctor walked into the examination room that made you feel MORE comfortable.
- [3.2] Please describe anything the doctor said or did when the doctor walked into the examination room that made you feel LESS comfortable.

to read and sign. Each focus group session was videotaped, with an additional audiotape made as backup. A project staff member took extensive notes of what participants said while each focus group took place. The videotapes were subsequently played back to allow additions and corrections to be made to the notes.

Data Analysis

Using standard qualitative data analysis procedures,⁶⁻⁸ we developing a “map of the terrain” of respondents' experiences and perceptions relating to characteristics of patient-HCO encounters that impede and those that increase access to health care. This process involves reviewing transcripts and notes from the focus group session to identify frequent or common issues and themes raised during the discussion. Consistent with this type of qualitative methodology, we made no attempt to quantify the number of participants who reported a specific perception or experience. Rather, we identified and report below those perceptions and experiences that were shared by many, if not most, of the group's participants.

An inter-coder reliability check indicated that the project's data analysis procedures yielded consistent results across coders, with inter-coder agreement greater than 95%. This check was conducted by having two project team members independently code and analyze samples of interview transcripts. The resulting analyses were compared, and a percent agreement was calculated by having as a denominator the total of unique observations made by both coder/analysts. The numerator was the total number of agreements.

Results

African American Study Participants' Responses (Table 3)

Overall, African American study participants expressed great satisfaction with their doctors but also expressed concern that doctors and HCO staff lacked knowledge of, and sensitivity to, the broader life challenges facing African Americans. These study participants shared strong concerns about pervasive discrimination (not specific to the health care setting) against African Americans.

Table 3

Comments From African American Study Participants

- They [the doctors at this patient's clinic] always greet me with open arms. They care about their patients.
- They [her doctors] get to know you on an ongoing basis.
- They don't have a good understanding of what African Americans go through.
- They don't know about what our life challenges are like.

African American study participants also expressed strong concerns that the growth of the Latino population in the San Francisco Bay Area will negatively influence health resources for African Americans. Their principal concern was that the growth of the Latino population will lead to a division of available health care resources among a larger number of users, with decreased resources for African Americans as a result. They also expressed concern that the growth of the Latino population will lead to increased political power for Latinos over the allocation of health care resources, which would also lead to decreased health care resources for African Americans.

African American study participants further expressed concerns about time pressures in doctor-patient encounters; a lack of culturally appropriate informational materials at HCOs; rude, unhelpful nonphysician staff, especially when making appointments; and unsanitary or dirty physical facilities at the HCO from which they receive their care.

Native American/American Indian Study Participants' Responses (Table 4)

Overall, Native American/American Indian study participants expressed great satisfaction with their doctors. They also expressed great appreciation for the presence of Native American/American Indian staff members at the clinic from which they obtain their care.

Native American/American Indian study participants expressed strong concerns about perceived negative stereotyping of members of the Native American/American Indian community by doctors and HCO staff. Participants in this study group said that they were offended by, and therefore often ignored, physicians' prevention and early intervention efforts targeting such issues as obesity, diet, alcohol, and drug use. These patients viewed such activities as the result of negative stereotypes about members of their cultural community that were not applicable to them.

Native American/American Indian study participants also expressed concerns about time pressures in doctor-patient encounters and an associated unwillingness on the part of doctors to take the time to listen to patients' descriptions of their symptoms. Of particular concern was a pattern of doctors' cutting off elderly patients when the patients wished to provide information or ask questions. Participants indicated that such disrespect to the elderly is particularly troubling in Native American/American Indian culture. Participants also expressed concern regarding doctors' unclear or incomplete explanations of patients' condition or treatment plan.

Latino Study Participants' Responses (Table 5)

Discrimination was a pervasive theme in Latino study participants' comments about encounters with HCO staff. This included discrimination by non-Latinos against Latino patients, discrimination by Latino staff who "feel superior" to Latino patients, and discrimination by other "minority" staff against Latino patients who don't "look minority."

Latino study participants reported major language barriers to accessing health care services in their HCOs, including unavailability of Spanish-speaking staff, incompetent interpreters, lack of informational materials in Spanish, physicians' intolerance toward patients with limited English proficiency, and physicians' failure to access interpreter services when physicians have trouble communicating with patients.

Latino study participants expressed additional concerns about staff members being rude and not giving patients a sense of privacy. There was also concern regarding staff members not washing their hands and not wearing gloves or not putting on new gloves before touching patients. Additionally, a number of Latino study participants expressed the belief that generic drugs they received from their clinic are inferior to "real medicines" and are given only to impoverished patients. None of the other groups brought up this issue.

Table 4

Comments From Native American/ American Indian Study Participants

- I felt really quite at home [at the clinic].
 - I am not only a client, but a friend [of the clinic].
 - I like [the clinic she goes to]. The people there know me and my culture.
 - My doctor was wearing a [Native American] medallion—that made me feel great.
 - I went to see a doctor for a back problem, and he stereotyped me as an Indian who was overweight and likely to get diabetes.
 - The doctor asked first thing about drinking and smoking, assuming I am likely to have these problems because I am Indian.
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Table 5

Comments from Latino Study Participants

- They [staff] treat you based on your looks; if you look Mexican, you are discriminated against.
 - They [Latino staff] don't want to help Latinos [ie, Latino patients], even though we are of the same race.
 - Some of the doctors, you can't understand them. How can you tell them, 'I don't understand you'?
 - I heard the doctor say, 'Why don't these Mexicans learn English?' When the interpreters translate, they don't do their job [correctly].
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Pacific Islander Study Participants' Responses (Table 6)

Physicians' efforts to provide prevention and early intervention services targeting such issues as obesity, diet, and alcohol use were perceived negatively, because they were seen as stemming from negative stereotypes about Pacific Islander patients.

Pacific Islander study participants expressed concerns about long waits to see the doctor, followed by rushed encounters. As part of feeling rushed, participants identified difficulty in understanding physician-patient communication. Contributing to this problem was a perception that HCOs use incompetent interpreters for their Pacific Islander patients who are not comfortable in English. Pacific Islander participants also voiced concern about rude, unfriendly, and impatient staff who were not respectful of patients' privacy. Of particular concern was the "inappropriate" touching of female patients' "private parts" by physicians and other staff members. Participants also voiced concern about unsanitary HCO environments in which staff don't wash their hands or wear gloves and in which there is patient-to-patient and staff-to-patient transmission of communicable diseases.

Discussion

Stereotypes

In comparing the responses of the four different focus groups, we are able to identify two consistent themes with direct clinical as well as policy relevance. Several of the groups identified negative stereotypes applied to the health behaviors common to their group. They perceived these stereotypes as inappropriate and unhelpful.

Issues of obesity, diet, and alcohol consumption, even when raised by physicians in what is intended to be a positive and constructive light, can easily be perceived as invoking negative ethnic stereotypes that both don't apply to the patient (in the patient's perception) and are offensive. Physicians and HCO staff may often have epidemiologic data to indicate that these types of problems need to be addressed in members of the subject ethnic group. It seems important for HCOs with substantial numbers of patients from particular ethnic com-

munities to make every effort to have on staff a trained health educator from that community.

Satisfaction

The patients in these groups were by and large satisfied with the manner in which the physician interacted with them. Principal concerns about inappropriate treatment had mostly to do with the manner in which the nonphysician staff treated them.

While there were common complaints about specific aspects of the physician-patient interaction (eg, too hurried, not enough information provided, inappropriate methods of genital examination), none of the ethnic groups expressed a strong perception that their physicians approach them in a biased or discriminatory manner. On the other hand, many of the groups expressed strong, negative perceptions about the manner in which the nonphysician staff treated patients from their ethnic group.

It was interesting to note that many study participants expressed concerns with aspects of the primary care process that are typical of more generally held concerns about health care changes resulting from the "managed care revolution." Perceptions that physicians are hurried and don't have the time to stop and talk with or listen to patients echo a common theme in discussions of contemporary health care quality.⁹ Providers and administrators should be aware that low-income, minority patients express the same preference for an unhurried, humanistic physician-patient interaction that more affluent, and often more vocal, patients do.

Limitations

This study has several limitations that diminish our ability to generalize from it for policy purposes. As mentioned above, focus groups of the type we report involve selection bias and ought not to be considered a representative population sample in the statistical sense. In addition, by limiting our study to low-income participants, we cannot determine with certainty the extent to which participants' responses reflect socioeconomic issues in addition to cultural/linguistic issues. Finally, since study participants obtain their medical care from a variety of community-based sources, we cannot be sure of the extent to which characteristics of the individual HCO affect participants' responses. Nonetheless, we believe the insights and perspectives expressed by study participants suggest certain policy directions that bear on health care access for low-income patients from these racial/ethnic minority groups.

Policy Implications

From the results of this study, it is clear that the presence on the staff of an HCO of members of the patient's cultural community, trained in providing culturally sensitive care, will have the greatest potential of address-

Table 6

Comments From Pacific Islander Study Participants

- The doctor looks at you like you are fat.
 - The doctor blames you for what is wrong [with your health].
 - Doctors make choices of their own, like the types of food to eat, and they try to force them on you.
-

ing these patients' major concerns. These staff members will be more able to identify and to discuss culturally related barriers to access with HCO administrators, physicians, and other appropriate staff members. This finding coincides with the federal government's CLAS standards #2 and #3 (Table 1) and suggests that these two standards should receive heightened regulatory scrutiny.

Closer collaboration between the HCO and the patient community also seems crucial in light of the cultural barriers perceived by many of our participants in the area of disease prevention and patient education. The strong negative (and sometimes hostile) responses of Native Americans/American Indians and Pacific Islanders study participants to physicians' prevention, early intervention, and patient education efforts point to the existence of serious misunderstanding, miscommunication, and insufficient communication between HCOs and patients.

Recent reports have documented both the shortage in numbers and the need for increased racial and ethnic diversity among nurses and medical assistants, two of the most common type of staff members of community-based HCOs. One of the strategies available to address these issues is closer collaboration between educational institutions, such as community colleges, and HCOs to recruit entry-level staff from the patient communities served by the HCO. The increased availability of staff representing diverse cultural backgrounds will enhance HCOs' ability to meet the CLAS expectations of staff diversity.

In addition, participation by physicians in training in such collaborations between HCOs and ethnic minority patient groups would be important learning opportunities for these physicians. In such collaboration, they could develop their knowledge of culturally related barriers to health care for minority patients and of patients' perspectives on how to overcome such barriers. Nearly 90% of all US medical schools include training in cultural competence as part of their curriculum.¹¹ Participation by physicians in training in collaborative efforts to strengthen health prevention programs would enable these physicians to learn from patients how to overcome serious patient misunderstandings involving perceived negative stereotypes.

Patients' resistance to prevention and early intervention services and patient education also needs to be directly and systematically addressed through culturally

appropriate education and outreach efforts, including patient education materials and campaigns. Such materials could be developed by a central resource, with initial screening to avoid the perception of negative stereotypes.

Finally, it is apparent that HCOs need to implement or enhance training of current staff and improve their monitoring of performance regarding respect for patients' cultural/linguistic characteristics. They also need to provide effective training and performance monitoring regarding adherence to basic guidelines for respecting patients' privacy and for appropriate hygiene, such as washing hands and using clean gloves.

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REFERENCES

1. Office of Minority Health, US Public Health Service. Closing the gap. Washington, DC: US Department of Health and Human Services, 2001.
2. Office of Minority Health, US Public Health Service. Assuring cultural competence in health care: recommendations for national standards and an outcomes-focused research agenda. 2001. www.omhrc.gov/clas/indexfinal.htm. Accessed April 8, 2004.
3. Lavizzo-Mourey R, Mackenzie ER. Cultural competence: essential measurements of quality for managed care organizations. *Ann Intern Med* 1996;124(10):919-21.
4. Office of Minority Health, US Public Health Service. National standards for culturally and linguistically appropriate services in health care. Executive summary. Washington, DC: US Department of Health and Human Services, 2001.
5. Institute of Medicine, National Academy of Sciences. Smedley BD, Stith AY, Nelson AR, eds. Unequal treatment: confronting racial and ethnic disparities in health care. Washington, DC: National Academies Press, 2003.
6. Maxwell JA. Qualitative research design. An interactive approach. Thousand Oaks, Calif: Sage Publications, 1996.
7. Merriam SB. Qualitative research and case study applications in education. San Francisco: Jossey-Bass, 1998.
8. Strauss A, Corbin J. Basics of qualitative research, second edition. Thousand Oaks, Calif: Sage Publications, 1998.
9. Barr DA. A time to listen. *Ann Intern Med* 2004;140:144.
10. Taché S, Chapman S. Medical assistants in California. San Francisco: UCSF Center for the Health Professions, 2004.
11. Grumbach K, Coffman J, Muñoz C, Rosenoff E. Strategies for improving the diversity of the health professions. San Francisco: UCSF Center for the Health Professions, 2002.
12. Association of American Medical Colleges. A century of reform—medical education's quiet revolution to meet America's health care needs. www.aamc.org/newsroom/speeches/reform.htm. Accessed August 4, 2004.