

Panel 2: Meeting the Health Literacy Needs of Special Populations

Topics covered in Panel 2:

- Language barriers, literacy, and communication in health care
- The role of health literacy in reducing health disparities
- Health literacy needs of older adults
- Health literacy needs of young children

Lost in Translation: Language Barriers, Literacy, Communication, and Quality in Health Care

*Glenn Flores, M.D., F.A.A.P.,
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Medical College of Wisconsin and the Children's Hospital of Wisconsin*

Dr. Glenn Flores, Director of the Center for the Advancement of Underserved Children at the Medical College of Wisconsin and the Children's Hospital of Wisconsin, began by emphasizing the rapid growth in the United States of those speaking a language other than English at home and those with limited English proficiency (LEP). Specifically, 52 million people in this country speak a language other than English at home, and 23 million have LEP.

Mismatch in Language between Provider and Patients: A Barrier to Health Care

Although Title VI of the Civil Rights Act of 1964 protects LEP individuals' rights to medical care, there continue to be barriers, particularly in the availability of medical interpreter services. At one inner-city primary care clinic, 26 percent of mothers of Latino children cited language problems as the single greatest barrier to health care (Flores, Abreu, Olivar, & Kastner, 1998). A study of patients seen in an urban emergency department revealed that no interpreters had been used for 46 percent of the LEP patients, and when interpreters were used, 39 percent had had no training in medical interpreting (Baker, Parker, Williams, Coates, & Pitkin, 1996). In a separate study by Flores and colleagues of 175 pharmacies, 47 percent never or only sometimes printed prescription labels in a language other than English and 64 percent never or only sometimes could orally communicate with LEP patients (Bradshaw, Tomany-Korman, & Flores, in press).

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Glenn Flores, M.D., F.A.A.P.

The Dangers of Using Ad Hoc Interpreters

Quality of care is compromised when LEP patients do not have interpreters or use untrained, ad hoc interpreters such as children. Language problems have an impact on many aspects of health care, including access, health status, use of services, patient-physician communication, satisfaction with care, and patient safety. There are many examples in the literature that cite interpreter problems, such as omissions or erroneous information, that demonstrate that lack of quality interpretation leads to poor health outcomes for LEP patients (David & Rhee, 1998; Flores, 2003; Launer, 1978).

The hazards of using ad hoc interpreters (e.g., family members, friends, strangers from the waiting room) are numerous. In these instances, interpretation errors are more likely to have potential clinical consequences than those caused by professional interpreters. Examples of interpreter error of clinical consequence include:

- Omitting questions about drug allergies
- Erroneously adding that hydrocortisone cream must be applied to a baby’s entire body, instead of solely to a rash on the arm
- Omitting instructions about antibiotic dose, frequency, and duration
- Instructing a mother not to answer personal questions about STDs and drug use (Flores, 2003).

One study found that family members of LEP patients misinterpret 23 to 52 percent of questions asked by physicians (Ebden, Bhatt, Carey, & Harrison, 1988).

Increasing Language Access in Health Care: Recommendations for Action

Based on his body of research, Dr. Flores outlined several areas where action is needed in order to increase language access in health care, including:

- Increasing the number of bilingual health care providers
- Increasing the level of foreign language study available to children in school
- Ensuring clinicians’ access to information regarding free or low-cost English classes in order to refer LEP patients
- Ensuring comprehensive language access from intake to discharge

- Enforcing Title VI requirements
- Creating centralized banks of trained interpreters
- Providing third-party payer reimbursement for medical interpreter services for all 50 states.

A Call to Action: The Role of Health Literacy in Reducing Health Disparities

*Harold P. Freeman, M.D.,
Medical Director,
Ralph Lauren Center for Cancer Care and Prevention, New York*

Dr. Harold Freeman, Medical Director at the Ralph Lauren Center for Cancer Care and Prevention, began by encouraging participants to marry efforts to improve health literacy with access to recommended health care. If patients can neither comprehend needed health information nor access the recommended care, attempts to improve the quality of care, increase survival, and reduce health disparities will inevitably fail. According to Dr. Freeman, this linkage must be achieved at the community level and must include not only patients, but also community health care providers and systems of care.

The Persistence of Health Disparities

It is well known, Dr. Freeman observed, that disparities exist in health care for the poor and medically underserved, especially in minority communities. The interaction of three major factors—low socioeconomic status, social injustice, and culture—causes disparities in health to persist in these communities. The current health system does not adequately address these disparities. Furthermore, there is a disconnect between scientific discovery and delivery. By developing strong alliances between literacy and access, Dr. Freeman proposed, we can have an impact on closing the delivery gap in this country, a key determinant, for example, in the unequal burden of cancer.

“We must marry efforts to improve health literacy with access to recommended health care.”

Dr. Harold Freeman, M.D.

When he was President of the American Cancer Society, Dr. Freeman conducted a series of hearings with testimony from poor Americans who had been diagnosed with cancer. He found the principal barriers to care for this group were related to:

- Cost
- Communication and information
- Medical system

- Fear and other emotional aspects
- Geographic concerns
- Cultural concerns
- Unequal treatment

The Patient Navigation Program

Based on his experience as President of the American Cancer Society, Dr. Freeman created the first "Patient Navigation" program, conceived and initiated in 1990 at the Harlem Hospital Center (Freeman, 2006). The program provided patients with a navigator to help them make their way through the complex health care delivery system and promoted access to timely cancer care, from diagnosis through treatment. Evidence of the program's success was observed in the early diagnosis and higher survival rates for women with breast cancer (Oluwole, et al., 2003).

As a result of the Harlem experience, patient navigation is being evaluated widely. The National Cancer Institute (NCI) has awarded nine grants to examine the effectiveness of patient navigation programs in various settings across the country, particularly in communities with an unequal burden of cancer.

By augmenting the role of patient navigators in developing health literacy, and by providing resources to train patient navigators in health literacy, Dr. Freeman hopes to be able to accelerate progress and expand the reach of health literacy efforts. Dr. Freeman emphasized that patient navigators could play a major role in promoting community-based health literacy efforts across all populations.

Recommendations for the Field

To ensure that improvements in health literacy effectively result in improved quality of life, increases in survival, and reductions in health disparities and costs, Dr. Freeman outlined several steps health professionals should take. These include:

- Marry the improvement of health literacy with access to recommended health care.
- Target geographic areas with excessive mortality with an intense approach to providing culturally relevant education, screening, diagnosis, treatment, and network of social support.
- Enhance patient navigation programs to improve health literacy and promote strong community involvement.

Meeting the Health Literacy Needs of Older Adults

*Denise C. Park, Ph.D.,
Director of the Center for Healthy Minds,
University of Illinois at Urbana-Champaign*

Dr. Denise Park, Director of the Center for Healthy Minds at the University of Illinois, began with three main points:

- Healthy older adults experience cognitive decline;
- This decline affects their ability to comprehend medical information and follow treatment regimens; and
- It is much more feasible to restructure materials and messages than it is to improve cognition to enhance health literacy in the elderly.

Old Age and Cognitive Decline

Older adults are vulnerable. Very old age (over age 80) is a particular risk factor for poor health literacy. Data suggest that this increased vulnerability is the result of decreased efficiency in information processing, declines in working memory function, and difficulty remembering context or learning, all of which can create confusion (Brown and Park, 2003). Older adults may have problems when facing new medical issues as they have to learn about a new disease or disorder and make complex decisions about treatments. These tasks may tax the capabilities of a declining cognitive system. In one study, lower literacy scores in a sample of older adults predicted increased hospitalization and poorer health, even in the well-educated, affluent population (Baker et al., 2002).

The Illusion of Truth

Given the changing cognitive systems of older adults, Dr. Park and her colleagues became interested in a memory effect called "the illusion of truth" which holds that familiar information, even when false, feels true, particularly to older adults who forget where they learned or heard something. The researchers asked older adults to study medical phrases, some of which were designated as false. They varied how often they presented the same statements as true or false. They found that the more often participants had been told a medical statement was false, the more likely they were later to believe that it was true (Skurnik, Yoon, Park, & Schwarz, 2005). Dr. Park noted that information presented as health "myths" also encourages the illusion of truth effect.

"Familiar information, even when untrue, feels true, particularly to older adults who forget where they learned or heard something."

Denise Park, Ph.D.

Recommendations for Action

She concluded that many health laws, programs, conditions, and consent forms exceed the cognitive capabilities of a significant proportion of older adults, even those who are well-educated. Dr. Park cited Medicare Part D as one example. Cognitive scientists can play an important role in engineering effective and memorable health materials and Web sites for older adults that will help them process medical information accurately and increase their ability to follow medical instructions. Policymakers can help by consulting with experts on designing elder-related government programs that are compatible with the cognitive systems of older adults.

Meeting the Health Literacy Needs of Young Children

*Frank C. Keil, Ph.D.,
Professor of Psychology and Linguistics,
Yale University*

Dr. Frank Keil, Professor of Psychology and Linguistics at Yale University, provided an overview of his research concerning the way children learn and how that learning relates to health literacy.

Children, along with most adults, have large gaps in their understanding of health-related issues (Eva, Cunningham, Reiter, Keane, & Norman, 2004; Hayes, Hulleat, & Keil, 2004; Kriz & Hegarty, 2004; Rozenblit & Keil, 2002; Simons & Keil, 1995). But it is also clear that children have surprisingly rich ways of making sense of the living world (Inagaki & Hatano, 2002). Taken together, the body of research strongly suggests that children of all ages have the potential to understand a great deal about health and about how to access health information. In particular, more attention should be paid to the ways in which children can grasp cause-effect relationships in the world around them and how they can use these relationships to reason in more powerful and effective ways, both about health and about providers of health information (Sigelman, Rinehart, Sorongon, Bridges, & Wirtz, 2004).

Illusions of Understanding

On one level it appears that children are severely limited in their ability to understand health and illness. In addition, there is substantial evidence that both children and adults have little understanding of just how limited their knowledge is (Eva, et al., 2004; Hayes, et al., 2004; Kriz & Hegarty, 2004; Rozenblit & Keil, 2002). In fact, people of all ages systematically mislead themselves into thinking they have far more mechanistic knowledge than they really do. Children show the same illusions of understanding. They also hold dramatic misconceptions about the biological world. In one study by Dr. Keil and colleagues, large numbers of kindergartners were unable to correctly choose bottles of bodily organs as the appropriate insides of animals in comparison to bottles of pebbles and bottles of gears (Simons & Keil, 1995).

Cause-effect explanations are powerful in maintaining knowledge about disease, thinking about new situations, and forming negative views of health risks.

Sigelman, et al., 2004

Very young children know a good deal in the way of abstract patterns, while being quite ignorant about concrete details—a notion contrary to classical views. For example, by the preschool years, children know that food gets transformed after it enters the body and that the transformed version is critical for helping the body grow—even though they may have incorrect knowledge about the specific details of digestion (Inagaki & Hatano, 2002).

Cause-Effect Explanations

Keil and his colleagues also found that children are interested in cause-effect explanations and these explanations are powerful in maintaining knowledge about disease, thinking about novel situations, and forming negative views of health risks. For example, teaching children about the effects of drug actions is much more effective in making them good judges about risk in novel situations than simply teaching them a list of behavioral dos and don'ts (Sigelman, et al., 2004).

Evaluating the Quality of Health Information

A second and more recent development concerns children's potential ability to seek out health-related information and evaluate its quality. Children appear to have a good basis for learning about appropriate domains of expertise. Studies by Dr. Keil and colleagues show that young children are inclined to doubt claims made by an adult who has previously been mistaken and are more inclined to doubt the truth of a message if it coincides with the speaker's self-interests (Mills & Keil, 2004). While this work has largely been done outside the health arena, there is reason to believe that similar results will occur with regard to health messages. This research suggests that providing children with information about the people making health-related claims will make them better able to evaluate those claims.

Dr. Keil argued that from preschool years onward, there are tremendous benefits to be gained from teaching health-related concepts in ways that connect that information to coherent causal biological accounts. However, a key challenge lies in pruning these explanatory messages down to a developmentally appropriate level.

Discussion: Panel 2

Much of the discussion that followed the second panel centered on the potential influence of language, ethnicity, culture, and belief systems on health literacy and health outcomes.

The Relationship between Culture, Language, and Health Literacy

Audience members offered a variety of examples illustrating the lack of adequate communication on the part of healthcare providers in response to differences in ethnicity, culture, and belief systems between providers and patients. They expressed interest in learning about the research on ethnicity, health perception, and culture, as well as cultural taboos and their role in health literacy. In response, panel members described a number of studies that demonstrate that either cultural or linguistic concordance leads to positive health outcomes. Moreover, panel members agreed that communication must be tailored and framed to take into account the patient's language, culture, and illness representation.

Two members of the audience highlighted the problem of false fluency errors created by physicians, i.e., physicians who believe that they can speak a second language, but who in fact make errors that may affect patient safety. Dr. Flores noted that there is not much research on this area and that the evidence is largely anecdotal. In response to this discussion, a representative from the Office of Minority Health stressed the need to increase the bilingual capability of health professionals, noting that there is a severe under-representation of minorities in the health professions. Dr. Flores agreed that to effectively bridge language barriers, efforts must be made to increase the number of health professionals from minority populations.

Trust and the Patient-Provider Relationship

Several speakers also commented on patient-provider communication. Dr. Baker expressed interest in the notion of probabilistic thinking highlighted during Dr. Keil's presentation, and asked whether current communication by physicians who follow the "don't do this, or this will happen" format might lead to a general distrust of the physician. Dr. Keil was not aware of any specific data on this topic, but agreed that physicians need to be sensitive about their presentation of health information.

Dr. Freeman commented on the issue of distrust of providers and the legacy of the Tuskegee experiment, particularly in poor Black communities. He noted that the trust barrier seems to disappear when programs that promote health literacy are developed with involvement from the people who will use them. One audience member asked whether there were data to support the use of *promotoras*, or community health workers, as a way of meeting the cultural and linguistic needs of patients. Dr. Flores explained that the research consists largely of case studies and anecdotal evidence that show the success of case managers, similar to *promotoras*, in reaching out to diverse communities.

Persons with Limited Literacy as a Special Population

One participant remarked on what she observed to be a general theme of the day—the need for additional research to document the extent and associations of limited health literacy. She commented that despite the recommendation in the 1999 IOM report *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved* to define low literacy groups as a special

population, large national studies typically do not measure or identify health literacy levels among their sample populations.

Defining the Problem: Limited Health Literacy or Poor Quality Health Care?

Panelists and participants had varying opinions on the role of the individual versus the system in improving health literacy. An adult education advocate in the audience questioned whether the problem is low health literacy on the part of the patient, or rather, poor quality health care. Dr. Flores commented that the issue is primarily about communication, though it is confounded by cultural, literacy, and language barriers.

Dr. Keil stated that the more health literate people are, the more likely they are to communicate effectively with their doctor; thus, communication and literacy go hand in hand. Dr. Freeman stressed that doctors cannot solve the problem of limited health literacy, given their time constraints, and that there needs to be systemic solutions such as the navigator concept. Finally, Dr. Park suggested that future research should explore technological solutions to limited health literacy.