



## **Health Literacy as a Contributor to Immigrant Health Disparities**

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### **Abstract**

The ability to obtain, understand and use the information needed to make wise health choices is known as health literacy. Low health literacy among members of populations with poor reading skills, limited mastery of the English language, members of ethnic or cultural minorities, and immigrants is likely a major contributor to health disparities in the US (Agency for Health Care Policy and Research 1997). A series of focus groups with East-Asian, African, Central and South American immigrants was conducted to better understand the perceptions of immigrants seeking health care services in an urban North Carolina county. Participants' responses are reported in terms of cultural competency, patient education, medication compliance, and communication. Implications for improving the health literacy of immigrant populations are discussed.

**Key Words:** health literacy, cultural competence, immigrant health, health communication

### **Introduction**

Health literacy is the ability to obtain, understand, and use the information needed to make wise health choices. According to *Healthy People 2010*, low health literacy—among older adults, people with poor reading skills, people with limited mastery of the English language, members of ethnic or cultural minorities, and immigrants—is likely a major contributor to health disparities in this country (Agency for Health Care Policy and Research 1997).

People with low health literacy often lack, not only the ability to read well, but also knowledge about the body, its functioning, and the nature and causes of different types of disease (Agency for Health Care Policy and Research 1997). Low health literacy skills impact health status in several ways and create barriers to access and comprehension

of diagnosis and treatment options. Patients with low health literacy often have greater difficulty understanding their conditions and making decisions related to treatment. Individuals' difficulties are exacerbated when their health care providers do not fully understand the degree to which they are lacking in understanding. Low health literacy costs the health system as much as \$58 billion a year and causes poor health outcomes, evident in intermediate disease markers, measures of morbidity, general health status, and use of health resources (Agency for Health Care Policy and Research 1997; Osborne 2005).

Broadly compatible with the narrow definition of health literacy above, basic or functional health literacy includes sufficient basic skills in reading and writing to be able to function effectively in everyday situations (Freebody & Luke 1990). Poor functional health literacy poses a major barrier to educating patients with chronic diseases, and may represent a major cost to the health care industry through inadequate or inappropriate use of medicines (Williams et al. 1998; National Academy on an Aging Society 1998). The consequences for immigrants are especially daunting. Immigrants make up a growing segment of the US population. Approximately 26.3 million immigrants now live in the US, the largest number recorded yet—a 33 percent increase since 1990 (Camarota 1999). In addition to language and cultural barriers, immigrants also must often contend with conditions of poverty. The foreign-born account for 10 percent of the US population, yet they make up 14 percent of the country's low-income population (Passel 2000). While only a small body of literature exists around immigrants and the healthcare system, the existing evidence suggests that immigrants find the system confusing, difficult to access, and bureaucratic (Searight 2003).

Many barriers—including poverty, limited education, low reading levels, and inadequate English-language skills—stand in the way of developing basic health literacy (Agency for Health Care Policy and Research 1997). Beyond gaps in education and reading skills, of immigrants and Americans alike, additional barriers arise because healthcare professionals often inadvertently make it difficult for lay people to understand what to do. Throughout their professional education and training, healthcare providers are taught to use precise technical language to discuss body parts and processes, disorders, and treatments—a habit that usually continues throughout their professional careers (Agency for Health Care Policy and Research 1997). Providers have begun to recognize the need for plain language communication, and some are attempting to advocate for improving patient-provider communication (Bass 2005). This need for change in communication

patterns is being further bolstered as the health care system begins to move away from a ‘doctor knows best’ model to one where patients must partner with providers to care for themselves (Scudder 2006). Alas, the routine challenges that accompany this system change further saddle low-literacy patients with the responsibility of recognizing and communicating their lack of understanding. Several studies have already illustrated how patients for whom English is a foreign language are less likely to understand medical instructions, and literacy has been singled out as a likely contributor to disparities (Scudder 2006). This knowledge provides a compelling and urgent reason for understanding issues around immigrant health literacy.

As a relatively new idea in theorizing causes of health disparities, few interventions have attempted to improve consumer health literacy. A search of the NIH CRISP database (June 2006, keywords “health literacy”) found multiple ongoing projects to understand the nature and correlation between health issues and health literacy in adults. Only four current and ongoing interventions were noted—two aimed at training health providers to increase competency in treating patients with low health literacy, and two interventions aimed at improving the health literacy of specific subgroups of the population (National Institutes of Health 2006). One project included non-native English speakers in the sample. The academic literature also contains little empirical data around health literacy intervention. Given the absence of evidence to better solve health literacy issues, a continued investigation into understanding the issues is essential. Therefore, the purpose of this study was to define the perceptions of immigrants when interacting with health care providers.

## Methods

Guilford County, North Carolina, has a total population of 443,519 and is home to a unique combination of approximately 65,000 recent immigrants. At the beginning of 2006, there were almost 100 languages and nearly 5,000 English for Speakers of Other Languages (ESOL) students in the school system, a little more than half of which were Spanish speakers. The next most common languages reported, in descending order, were Vietnamese, Arabic, Hindu/Urdu, Korean, French, Lao, Rade, Khmer, and Chinese (Center for New North Carolinians 2006). As an unusually diverse community, this context is ripe for the study of immigrant health issues.

Between February and April 2006, focus groups were held with immigrants and community lay health advisors working with

immigrants to better understand the health literacy issues facing non-native Americans. A total of 7 groups were held with 43 total participants. The focus groups were held in community college settings (with ESOL students) and a community center serving the needs of immigrants. Participants in the focus groups represented multiple East-Asian, African, Central and South American countries. Community lay health advisors were included as participants because of their expertise and intensive contact with immigrants, in expectation that they could provide additional depth to the study. These individuals were also immigrants themselves so they could speak to the issues both personally and as observers of other immigrants with whom they had contact.

For the groups held at the community college, participants self-selected from three course sections of adult education classes. At the community site, participants were invited to participate by community center staff, and again participants self-selected. Participation was completely voluntary and participants were fully advised of their rights as human subjects in research, as per the protocol approved by the IRB of the University of North Carolina at Greensboro. Each focus group lasted between one and two hours. Translators were available for participants, though their services were not needed during the study.

The goal of the focus groups was to understand what immigrant individuals perceived as their own needs around health education and health care. Participants were asked a series of questions for group discussion regarding barriers to receiving health care, procedures and practices in place to help patients with literacy needs, and suggestions about how providers could be helped to better communicate with patients. These questions were developed by the researcher in consultation with a group of community members with expertise in the areas of health care, immigrant issues, and literacy. (See Figure 1 for complete list of questions.) During the focus groups, the researcher used prompts to probe and better understand the meaning and intent of participants' stories. The questions were designed to provide descriptive information about immigrants' interactions with health care providers, as well as ideas about how to better serve immigrants through the health care system.

The focus groups were moderated by the researcher and a trained public health graduate student. The groups were audio-taped using Marantz recorders and multi-directional microphones. The tapes were subsequently transcribed and these transcriptions provided the basis for data analysis.

**Figure 1. Focus Group Questions**

- A. Think about the last time you were sick or needed care from a doctor. How did you decide how to get help? Prompts: Do you have a regular doctor? Who/where? Can you get help with health information over the telephone, from a friend or relative, or somewhere else? How do you feel about visiting the doctor? Do you feel respected? Understood?
- B. When you visit a doctor, they ask you to fill out forms about yourself and your insurance. Do most clinics offer to help you fill out the forms, if you need it? Prompts: Have you ever had trouble filling out the forms? What did you do?
- C. Sometimes, doctors use words that are hard to understand. It can be especially hard to remember what they are telling you if you are not feeling well or are upset. Can you think of a time when a doctor explained something to you which you later had a hard time remembering? Prompts: What was that like? How did you feel? Were you able to get the information you needed later?
- D. Sometimes, doctors give you written directions or information about what to do at home to take care of your health. Is this helpful to you? Are the directions easy to understand? If you don't understand, is there someone who can help you (a friend/relative or phone number to call a nurse at the clinic)?
- E. When a doctor tells you to take medicine, are you able to get the medicine that was prescribed? Does the drug store/pharmacy explain the directions clearly? If you have trouble with the directions, is there someone who can help you?
- F. Can you think of any ways that would help you get better information about how to take care of your health? Where would you like/prefer to get information? Prompts: churches, doctor's offices, grocery stores, drug stores, schools, internet, videos, other... Would you attend health education classes? Where?
- G. What could your doctor/clinic do to make it easier for you to understand directions for taking care of your health? Prompts: Do you prefer written directions, talking with a doctor or nurse, a telephone number to call with questions, all of these, something else ...
- H. Do you have any ideas for how to make it easier to take the medicines your doctor prescribes? Prompts: Color-coding, written directions, calendars, ...
- I. A lot of people have trouble following doctor's directions. Do you have any more ideas of how to help people take care of their health?

As a descriptive study, the researcher relied on open coding to identify emergent themes, categories, patterns and linkages across focus groups and participants. A holistic thematic approach was used to derive essential meaning from the statements of participants. These themes were organized into hierarchical categories to describe the stories of participants. Because themes were virtually the same across the community immigrant group and the lay health advisors, data were analyzed together as a single set, rather than comparatively.

**Results**

Strong themes emerged from analysis of the focus groups. The major issues can be summarized into four categories: cultural competence, medication compliance, patient education, and communication and translation. Both providers and patients have significant roles in each of these issues.

## Cultural Competence

Participants from all groups emphasized the need for enhanced cultural awareness among providers. They noted that issues of communication, respect, trust, and treatment compliance could all be addressed with improved cultural understanding between patients and providers. In particular, participants were concerned that providers generally do not attempt to understand the various cultures from which patients come. This is crucial because, as one participant noted, if providers do not understand patients' cultures, patients have a hard time trusting the diagnosis and following through on the instructions given to them.

Participants also noted the differences in health care systems and settings. Many immigrants come from small rural towns where they are not used to visiting doctors. Instead, family members might give them home remedies or herbs to treat health problems. As such, many people have no concept of what going to the doctor means, much less how to navigate the system for referrals, specialists, or medications. One participant noted, "People are not comfortable going to the doctor, in general, because back home they are not used to it because most are from very small towns where there are no doctors."

Nearly all participants stressed the importance of respecting patients and their cultures. Avoiding situations where patients feel intimidated or inferior is important, as many immigrants will then tune out, missing important instructions and potentially exacerbating their illnesses. One participant summarized the issue well: "I don't think [immigrants] feel safe or trusted because the doctor don't know about the culture and they [immigrants] don't know if the doctor is correctly right about all of his diagnosis."

## Medication Compliance

Understanding medication was noted as perhaps the biggest challenge for non-native English speakers. Focus group participants said they had difficulty understanding the instructions, the labels, and the basic idea that some medications must be taken on an ongoing basis. For example, antibiotics must be taken for the full course, not just until the patient feels better, and medications for chronic illnesses, such as high blood pressure, must be taken forever. These notions run counter to the traditions of many cultures, so understanding the concepts requires a significant amount of patient education, as well as cultural understanding on the part of the provider. Participants repeatedly recounted sharing prescription medications with friends or family

members who had similar symptoms, with no understanding about the potential dangers of this action.

Differences in language also were identified as critically important. One participant cited confusion stemming from similar words between languages: “It doesn’t matter if you give them their medicine in Spanish, because ‘once’ in English is ‘once’ (eleven) in Spanish. You have to literally show them how many pills to take.”

Pharmacists were highly regarded by ESOL students as approachable and easy to understand. They said that the pharmacists ‘explained very clearly’ the directions for taking their medicine. When questioned about how the pharmacists taught them about medicines, it was reported that the pharmacist used labels to help them take their medicine properly.

### **Patient Education**

Providing excellent patient education is key to helping immigrants maintain health and successfully treat illness. Aside from language constraints, several important concepts in health education arose from the focus groups.

Focus group participants favored methods of interaction that incorporated respectful questioning of the patients’ understanding. In their experience, they noted that pharmacists were typically better at this type of communication than physicians.

Asked if they preferred to receive health advice in person or over the telephone (in their native language), the overwhelming majority preferred face-to-face communication. None of the participants trusted the internet for health information. All preferred that providers instruct verbally first and then follow with written instructions. With written instructions from the provider, participants could then seek help from a friend or family member later if they had difficulty remembering or understanding the instructions.

Participants also agreed that many immigrants rely on health care providers for offers of education or referrals for more information. One lay health advisor participant pleaded, “Please let health providers know that they are the one to know better the patient. Because patient always sigh, they not say anything, they not ask anything. But please open the conversation and understand what soothes them.”

### **Communication and Translation**

Communication of symptoms was identified as a significant issue for immigrants. The lay health advisors noted that many individuals

say only that they feel sick, but cannot describe specific symptoms. They lack basic understandings of health, the body, and the language to try to describe the symptoms. Interpreter participants acknowledged this as a problem and as a significant barrier for health care providers trying to help the individual. One participant noted that immigrants sometimes expect too much from the physician. They believe that the doctor should be able to treat them immediately, based on a particular symptom, and do not understand why the doctor asks so many questions.

Translation was noted as a significant issue for non-native English speakers. When no bilingual providers or translators are available, children or other relatives are often required to translate. Participants reported that this can lead to disruption in the hierarchy of the family and can cause power struggles within the family.

Participants who act as interpreters lamented a lack of sufficiently trained interpreters in the community and expressed frustration in the limits of their role. Interpreters are not allowed to explain information, only to translate the words of the provider. They believed that miscommunication could be avoided if their role were broader, though they are extremely careful to follow the letter of the law and not overstep boundaries.

Finally, the participants noted that second-generation immigrants make many of the health care decisions. The children of immigrants are generally much more likely to understand and assimilate into American culture; therefore, they informally refer parents and other elder family members to community resources for health. They also tend to accompany older family members on health care visits to interpret and, as a result, assist in making decisions about treatment. They believed that if this group was more health literate, many more people would benefit from the investment.

Focus group participants were quick to accept responsibility for their side of the dialogue. They were cognizant of the widespread belief that immigrants should learn English and agreed with that idea. At the same time, they urged compassion and understanding that it takes time to learn the language and the culture.

## **Discussion**

Health literacy problems have grown as the health system has become more complex; diagnostic and treatment options have proliferated, and people are asked to assume more responsibility for self-care (Ratzan 2001). This idea is especially complicated for immigrants who may have difficulty understanding the language, not to mention



the health care system. Health literacy can be described as both a goal and an outcome, becoming the currency and capital needed to develop and sustain health (Nutbeam 2000). As a discipline, public health has recognized the issues of health literacy and has begun to define probable causes of low health literacy. However, little to nothing is known at this time about how to effectively intervene (Mika et al. 2005).

Many patients find that the majority of their time is spent with a nurse or nurse practitioner instead of an actual medical doctor. Therefore, it is vital that nursing staffs are trained on, and aware of, health literacy issues when interacting with patients. Literacy assessment is an important component of effective advanced practice nurse–patient communication, enabling a nurse practitioner or clinical nurse specialist to elicit better medical histories, explain treatment plans in understandable terms, assist patients with integrating treatment recommendations into their usual daily routines, be sensitive to patients' other psychosocial issues, and convey empathy (Artinian 2003). As nurses and other support staff become more attuned and attentive to the health literacy needs of patients, an opportunity exists for integrating health literacy teaching into routine visits. While time constraints are certainly a barrier to increasing the amount of patient education, innovative practitioners are already working to find effective and efficient means to increase patient understanding (Scudder 2006). The learning from these early attempts at improving health literacy will certainly have applicability to ongoing practice for all types of health care providers.

According to the Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) standards on patient and family health education, it is incumbent upon health professionals to identify learning and educational needs, use appropriate educational resources, and assess the patient's and family's ability to comprehend, use and apply information taught (Joint Commission for Accreditation of Health Care Organizations 2002). However, amid the demands of disease management—understanding complex clinical presentations, knowing multiple differential diagnoses, and interpreting laboratory and diagnostic tests—literacy assessment may pale in comparison (Artinian et al. 2003). This differential in priorities puts the onus on health care consumers to seek information and understanding. The role of health professionals then is to provide patients empowerment and an open setting for dialogue and questioning (Hemming & Langille 2006).

In attempting to understand the issues faced by US immigrants seeking health care, a number of striking and important issues were

uncovered. The immigrants who participated in focus groups clearly felt treated as outsiders when seeking care. They frequently felt misunderstood and that their culture was not respected by health care providers. This discomfort led to a variety of less-than-ideal outcomes, including leaving the clinic, never to return again. Though, ideally, all health care providers should try to deliver care in a warm and welcoming way, such care is especially important to immigrants, who typically must overcome their own cultural and other system barriers before they even think about approaching the health care system for help. Both providers and their entire staffs have an opportunity to make a difference in the lives and health of immigrant patients. By cultivating trust and respect, a health care environment which supports immigrants has the potential to lead to better outcomes in terms of treatment compliance and quality of life for the individual.

Immigrants also made evident the potential for various medication errors. Providers need to be extremely clear with medication instructions, ensuring the patient understands what the medication is for, how to take it, when to take it, and not to share the medication with others. Visual demonstrations as well as written directions may be necessary to communicate the information effectively. Pharmacists may be ahead of the curve in focusing on patient education around medications, particularly for immigrants. A recent prominent pharmacy journal (Mullins et al. 2005) led a call to action for pharmacists to work on patient health literacy by improving cultural sensitivity among pharmacists. "Because pharmacists are at the front line of patient care, their active participation in the health care system can improve health outcomes and reduce health disparities. Therefore, it is essential for pharmacists to be able to provide culturally competent care."

Finally, as with all human interactions, communication is critical. Immigrants face tremendous cultural and language barriers to understanding health problems. Participants acknowledged that they often do not fully understand information from their health care providers, and specifically requested written information for reinforcement. In addition, providers can help improve health education by engaging in teach-back techniques and by being open to questioning. Cultural differences are also important to note in health education. For example, participants discussed the humble nature of many Asian cultures and how this can cause communication difficulties. They wanted providers to know that Asian patients will not ask for or demand information or services, but will expect to be asked if a particular service is needed.

To competently address immigrant health care and health education, it is vitally important that providers and practitioners consider the context of each individual. There is no “one size fits all” solution to the problem. Rather, if immigrants are treated respectfully for the unique history and understanding they bring, care can be optimized and health outcomes may be improved.

Limitations of this study include the small sample size, a potential for selection bias (as participants self-selected to join the study), and the lack of quantitative data to describe participants. Larger studies to understand immigrant health literacy issues may be well-served to collect data describing length of US residency, age at immigration, quantitative assessment of health literacy status, or other factors that may differentiate degrees of health literacy among immigrant groups.

## Conclusion

Improving health outcomes will require increasing the health literacy of US residents so they can identify and report symptoms, communicate effectively with providers, and follow through with directions to prevent or treat health problems. Immigrants have to shoulder the additional burden of learning the language, culture, and health care system in order to interact with providers and act on health information. Potential solutions to this complex issue include:

- Recognizing health literacy as a global issue, affecting everyone in the community. Specifically, encouraging the universal use of teach-back techniques, active listening and questioning, visual teaching aids, clearly written instructions or other methods to ensure patient understanding may improve the general health literacy of the population, and will certainly aid in making sure those most likely to have difficulty understanding will be better served. As this study shows, immigrants in particular are at risk for misunderstanding instructions from their health care providers. Instituting multiple teaching formats along with routine checks for understanding could greatly improve outcomes and treatment compliance.
- Training health care providers on issues of cultural competency, health literacy, and patient education methods. Cultural competency occurs when individuals and organizations commit to understanding and valuing diversity and are willing and able to adapt policies, procedures and service delivery methods to meet the contextual needs of individuals. Multiple participants in this study cited occasions when they were disenfranchised

from the health care system, feeling devalued or disrespected. Not only do these instances result in immediate negative repercussions for the individual, but they also potentially discourage future help-seeking by both the individual and his/her family members. Health care providers (and their staffs) who are culturally competent are more likely to understand and attend to the particular needs of immigrant patients, potentially leading to improved communication, patient understanding, and higher-quality care.

- Ensuring that written health materials are distributed and widely available in low-literacy, multiple language formats. Study participants clearly sought help understanding instructions after a medical visit when they had access to written reference materials. Patients who have written materials to support what they have been taught verbally have the opportunity to review instructions post-visit with family members or seek additional advice from others in their community who may be more health literate. This process can assist with compliance issues, as well as increasing and reinforcing patient health literacy.
- Reaching out to communities through churches, schools, and community gathering sites to provide health literacy education. Ideally, health literacy education would involve open discussion about the nature of the local health care system(s) and culture, availability of services, how to navigate the available services and systems, resources for self-care, consumer rights and responsibilities, and referral to community organizations or health care providers for specific health needs. Immigrants, in particular, may face cultural barriers to seeking health information and traditional western health care services. Through intentional health literacy outreach activities, health care systems can help break down those barriers and draw immigrant community members into appropriate use of the system. Improving the general health literacy of the population can also potentially facilitate consumer empowerment in health care settings. Not only could this improve patient knowledge and understanding of health, but also compliance and health outcomes.

Each of these potential solutions will require considerable testing and evaluation to understand the impact among various immigrant groups. Clearly, though, immediate action is required to begin tackling this immense and important concern.

## Acknowledgments

This project was funded by grants from the Community Health Improvement Fund of the Moses Cone-Wesley Long Community Health Foundation and the Weaver Foundation. Special thanks to the Guilford County Health Literacy Forum and Reading Connections for supporting this work.

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