The Challenge of Health Promotion & Health Literacy in North Carolina's Latino Population

INTRODUCTION

As the NC IOM Latino Health Task Force worked to define the nature and extent of health problems and health care access issues facing the state's growing Latino population, its members confronted the fact that Latinos do not experience (and therefore do not interpret) the symptoms of ill health in ways similar to the majority white or African-American populations. Moreover, when Latinos (especially recent immigrants) seek formal medical care from US health care providers, their expectations are different, and therefore the satisfaction they take away from such encounters is likely to be different as well. The Task Force came away from this analysis with the clear notion that a major impediment to health and health care among this population is that recent Latino immigrants are relatively unfamiliar with the methods of how health care is provided in the United States and may not interact effectively with health care providers when seeking care in this country. Ineffective communication and interaction in such circumstances can lead to reduced access to needed services. the ineffectiveness of diagnostic and therapeutic interventions, lower satisfaction and adherence to prescribed medical regimen, and ultimately to the detriment of the health of North Carolina's Latino population.

These communication barriers are only partly related to language differences or to the cultural competency of health care providers. The larger rubric under which much of this problem was discussed is that of health literacy, a term gaining more attention within the professional health and medical care community in reference to the specific skills necessary for communication between health care providers and their patients. Health literacy assumes a basic understanding of medical terms, techniques and technologies, which is essential to assure that the patient can be a full participant in managing his or her medical care in conjunction with a physician or other health care provider.

NC Latino Health 2003

Innovative Practice **Expecting the Best**

Expecting the Best is a collaborative effort between the North Carolina Community College System, the Division of Public Health in the North Carolina Department of Health and Human Services, Coastal AHEC, and the North Carolina March of Dimes. The program is designed to teach adults about health and wellness through English as a Second Language (ESL) classes administered by the Community College. Classes focus on health care, nutrition, and exercise and fitness, and are intended to improve health literacy, functional literacy, and communication skills. The program was piloted at Cape Fear Community College and Centro Latino in Wilmington in the fall, 2002. The Community College System plans to offer this curriculum statewide by 2004.

THE GENERAL PROBLEM OF HEALTH LITERACY IN AMERICA

The problem of health literacy is not confined to the Latino population. Low reading levels are a major concern for the larger US population as a whole. The National Adult Literacy Survey, which provides the best national portrait of the literacy capacity of the population, estimates that 22% of the total population score at the lowest level (Level 1) and are unable to perform such tasks as to identify the expiration date on their personal driver's license or to read and understand the front page of a major newspaper. Thirty-two percent have difficulty distinguishing between the price of two items on the grocery store shelf. Forty percent of Americans are unable to understand the information and warnings contained on a common prescription bottle label. The consequences of low literacy in relation to health and health care can mean that, despite the availability of personal health care services, both the awareness of such availability and the effectiveness of services received can be significantly reduced (if not eliminated).¹

The increasing complexity of health care information and the shift of a greater responsibility onto the patient to participate in health care decision making and manage their own diseases has meant that these health literacy problems have become much more daunting. Parker has shown how the situation has changed in 25 years with regard to the seemingly straightforward management of a patient with asthma.

"Consider the task we set for a newly diagnosed asthmatic today, and compare that situation to the same situation 25 years ago. In 1975, a newly diagnosed asthmatic would see the doctor, get a prescription for theoplylline, be told how to take the pills, and be instructed to comply with follow-up. Today, in a clinical encounter likely to be much shorter than a 1975 encounter, the patient would be instructed in the use of multiple meters and inhalers that function differently, and the taking of different dosages of medication. The patient would be shown how to monitor his or her asthma, and how to keep records. Patients are shown how to take different doses of steroids for flares, how to avoid mental triggers, how to use - but not to overuse - the emergency room, their primary care physician, and their subspecialist. Altogether, asthma management today is much more complex, much more technologically sophisticated and has become very challenging to be a patient."²

The complexity of today's health care system is compounded for Latinos who cannot speak English well, or who may not have access to health care providers who speak Spanish. This is a prescription for system failure, and ultimately a situation of extremely high health risk.

THE SERIOUSNESS OF THE HEALTH LITERACY PROBLEM AMONG LATINOS

Even ignoring the problem of language and cultural differences that may increase the seriousness of these problems for Latinos, we are becoming aware of the fact that as many as 50 percent of our US population (of any race or ethnic group) simply cannot participate at an effective level in the communication process involved in obtaining formal health care in this country. By any standard, this is a "public health disaster!"³ This means that in spite of well-recognized global leadership in medical science and health care technology in this country, there are large segments of the population for whom these benefits are out of reach, irrespective of their economic circumstances. For all our talk of giving patients the opportunity to express their preferences and to make their own decisions about health care, the fact that more than half of the people in the US, when offered this opportunity to participate in such decisions, simply lack the basic understanding of their diseases or health conditions or the range of treatment options available to them. "Shared decision making" with regard to these matters is without meaning, hence it is without any added value or benefit. We need to find ways of addressing this problem through a number of avenues, involving health care, educational, occupational and community development initiatives. But, first, we must find ways of at least talking about this huge and growing problem with American health care.

The problem may be growing more severe for Latinos as North Carolina has a higher proportion of Latino teenagers who have quit school - or bypassed it - than any other state, according to a new report from the US Bureau of the Census. Nearly 47 percent of Latino youth in North Carolina between the ages of 16 and 19 are not enrolled in school and lack a high school diploma.⁴

The NC IOM Latino Health Task Force has identified this as a problem of such proportions as to require substantial public and private sector intervention in the interest of ensuring the full participation of this growing segment of our state's population, a population on whom the very economy and vitality of our state depend.

THE CHALLENGE OF ADDRESSING THE HEALTH LITERACY PROBLEM

What is it about health literacy that makes this problem so difficult to address through sensible programs and planned interventions? First of all, we have to face the fact that basic literacy is not a problem limited only to health issues and concerns. The health care system cannot solve this problem alone.⁵ Many of those who immigrate to our country in search of employment and a better way of life arrive with only limited literacy in their native languages. Many have only limited formal educational backgrounds. Most are accustomed to working for less than the US standard minimum wage in their own countries and are willing to work for only the minimum wage rates here in the US.

It is in the interest of employers, nationally and here in North Carolina, to help solve this problem, for it has much to do with the health and productivity of their work force. Similarly, the schools can do much about this problem, not only for the students who are their primary targets, but also for their families (parents, grandparents, aunts and uncles, etc.). Students taught the basics of health, or chronic disease management, can help a parent or grandparent who suffers from those diseases manage their conditions. Many of us have had the experience of learning how to do something on our computers, or with our VCRs, from our children. Hence, the power of intergenerational teaching and learning can potentially be harnessed for public health benefit.⁶

Second, we have to remember that illiteracy is a problem shrouded in secrecy, guilt and embarrassment. No one with a problem of illiteracy is anxious to have this problem revealed. Adults who are illiterate devise novel ways of disguising this inability to read or understand printed material. Because the inability to read, in any language, leads to insufficient understanding of complex information, the consequences of concealment and deception can confound problems of communication between the health care professional and client. Further, health care encounters can serve to increase the anxiety that many with low literacy skills feel day to day. As Frank McArdle has pointed out,

"(low levels of health literacy) makes it harder for the patient and the medical professional to fully participate in the process of two-way communication. Commonly held expectations that patients read adequately and the implicit social stigma of not doing so, conspire to silence patients, inhibit them from disclosing their situation, and discourage patients from seeking information and asking for help."⁷

The fact that large numbers of enrollees in health care plans simply do not understand basic physician instructions, means that our efforts to target major health conditions in these populations is equivalent to "shooting blanks." Resources are being wasted and results are not achievable.

THE IMPORTANCE OF LATINO CULTURAL BELIEFS AND HEALTH CARE PRACTICES

The Latino Health Task Force had to recognize and deal with a phenomenon not normally so important in other areas of health policy development in our state. This is the matter of Latino culture and belief systems with regard to health and health practices. These would not be major concerns were we talking about meeting the health and health care needs of the Latino population in their native countries, where both patients and their health care providers were from the same culture and spoke a common language. Even if language barriers could be reduced through the acquisition of Spanish language skills by US health care professionals and clerical personnel, there would still be differences in cultural beliefs that could lessen the potential effectiveness of health care services and interventions offered by health professionals to their Latino clients and patients.

As noted previously, it is important to recognize the there is considerable diversity within the Latino community; there are many Latino cultures, each with its own traditions and beliefs. Many Latinos in the US have never lived anywhere other than the United States and may not speak Spanish at all. Moreover, Latinos are racially and ethnically heterogeneous as well, while Latinos will often self-identify by their country of origin and not a particular racial or ethnic group.

Since health promotion efforts often have as their primary goal the changing of personal behaviors and attitudes, it is important to consider the culture-bound belief systems that may influence the health behaviors targeted by such intervention programs. It is clear that many Latinos are suffering from diseases and dying from causes that can be prevented; many of these are associated with

risky behaviors or environmental exposures. Many of the self-care strategies employed by Latinos in response to symptoms are not based on any scientific evidence and are supported only by cultural beliefs and folk remedies from other parts of the world. Some are based on very different causal frameworks used to explain the nature of human disease and the prospects for cure. US health care professionals who attempt to treat Latinos in times of ill health may or may not know about the countervailing influence of these cultural phenomena. This can lead to additional health risks or treatment ineffectiveness.

As noted previously (Chapter 3), Latinos may rely on traditional and folk healers, may not understand how to access or use the US health system, and may have different cultural expectations about the provision of health services. The Task Force has concluded that any attempt to intervene within the Latino community in the interest of population-based health improvement or increasing health care access should start from an understanding of these social and cultural factors pertinent to the Latino community.⁸ Any meaningful and effective approach should therefore seek to build upon the strong family values and connections within the Latino community, recognize the cultural beliefs associated with health and illness within this community, seek to identify and work with indigenous persons and informal networks within the Latino community who are trusted and readily available sources of health advice, and address the problems of communication and understanding that may arise in conventional health care encounters between Latino immigrant populations and US health care providers.

Among the strategies for addressing these issues considered by the Task Force was the use of trained Lay Health Advisors, indigenous community members who are trusted sources of health and health care information and who can facilitate both access to care and understanding of health and illness symptoms and medical care advice received from professional health care providers. Lay Health Advisors work directly with individuals to provide health education, inform them about the peculiarities of the US health care system and how to access needed health services, and help link individuals to community resources. Lay Health Advisors can also help strengthen the capacity of Latino families to manage the consequences of illness and take positive steps to promote personal health status within the Latino community.

RECOMMENDATIONS

In its consideration of these social and cultural factors influencing the health behaviors and attitudes of Latinos, the NC IOM Latino Health Task Force offers the following recommendations intended to promote the positive health outcomes of Latinos now resident in North Carolina. The Task Force recommended that:

29. The NC Community College system (Adult Literacy) take positive steps to address the problem of low literacy, including health literacy, among its Latino population. There is a need for a statewide initiative to address this problem across all population groups (not limited to Latinos).

NC Latino Health 2003

This initiative should include the participation of all human services sectors (health, behavioral health, dental and social services), law enforcement, public utilities, education community as well as non-profits, philanthropies, faithbased organizations, private business and industry.

30. A statewide campaign be mounted, under the leadership of the North Carolina Area Health Education Centers, involving all types of health care professional membership organizations and health-related trade associations to elevate a concern for health literacy among those professions serving the needs of NC's population. This should include skill training for health professionals in methods of measuring and identifying low literacy problems in patients as well as interventional skills for overcoming the negative effects of low literacy in encounters with health and medical care providers.

Model programs such as those developed by the American Medical Association, and programs like those piloted here in North Carolina and mentioned elsewhere in this report, should be used as models for such an initiative.

31. The NC Department of Health and Human Services take the lead in convening a group of organizations who have developed and implemented lay health advisor programs. This group will help coordinate and strengthen lay health advisor programs, including developing training for lay health advisors and providing technical assistance to other organizations seeking to implement similar programs. The group should help identify possible funding sources from North Carolina and national philanthropies, with a priority given to communities and counties with large concentrations of Latino residents.

The group should include, but not be limited to, the NC Primary Health Care Association, Cooperative Extension Services, and the Department of Health Behavior and Health Education within the UNC School of Public Health.

32. The University of North Carolina System coordinate efforts to establish a Minority Health Research and Policy Center dedicated to advancing new and innovative public policy solutions toward more equitable and available health care. The center should seek to collaborate with such organizations as the Inter-University Program for Latino Research (IUPLR)⁹ and the UNC-Chapel Hill Program on Ethnicity, Culture, and Health Outcomes (ECHO).¹⁰

The mission of ECHO, the UNC Program on Ethnicity, Culture, and Health Outcomes, is to eliminate health status and health outcomes disparities through translatable, evidence-based research, multidisciplinary training and education, and culturally sensitive services to North Carolina communities.

33. El Pueblo, the NC Institute of Medicine, and the NC DHHS create a health care consumer guide for Latinos modeled after NC Programs Serving Young Children and Their Families published in Spanish and in English for the benefit of Latino families and individuals, as well as health and social services organizations serving the Latino community in the state.¹¹

NC Latino Health 2003

Some agencies throughout the state have already taken steps to educate Latino family members about services available throughout the community; however, more work in this area is needed.

NOTES

- Tuckson RV. Keynote Address. Proceedings of Conference on Health Literacy: Advancing Public Policy (2000). January 18-19. Washington, DC: Pfizer (www.pfizer.com/hml/literacy/hl2), pp. 4-6.
- Parker RM. Update on health literacy. Proceedings of Conference on Health Literacy: Advancing Public Policy. January 18-19. Washington, DC: Pfizer (www.pfizer.com/hml/literacy/hl2), pp. 6-8.
- 3. Tuckson RV, op.cit.
- 4. Raleigh News & Observer, November 4, 2002: 5B.
- Lurie N. Opportunities for setting a health literacy agenda. Proceedings of Conference on Health Literacy: Advancing Public Policy (2000). January 18-19. Washington, DC: Pfizer (www.pfizer.com/hml/literacy/hl2), pp. 8-12.
- 6. Ibid.
- 7. McArdle F. (2000) Proceedings of Conference on Health Literacy: Advancing Public Policy. January 18-19. Washington, DC: Pfizer (www.pfizer.com/hml/literacy/hl2), pp. 13-17.
- Some useful resources include: Karliner S, Crewe SE, Pacheco H, and Gonzalez YC. Latino 8. Health Beliefs: A Guide for Health Care Professionals. National Council of La Raza. Washington DC: Sept. 1998. National Alliance for Hispanic Health. 2001. (Designed to help providers in clinical, prevention and social service settings to better understand and more effectively respond to the service delivery needs of the growing Latino population). Guidelines for the Care of Migrant Farmworkers' Children. American Academy of Pediatrics Committee on Community Health Services and the Migrant Clinicians Network. 2000. (The guidelines describe the unique characteristics of migrant farmworkers' children and when used appropriately, assist clinicians with the provision of care that is of high quality and tailored to the context in which children of migrant farmworkers live). Doty MM, Ives BL. Quality Health Care for Hispanic Populations: The Cultural Competency Component. Bureau of Primary Health Care, Health Resources and Services Administration, US Department of Health and Human Services (2002). Technical assistance is also available from the NC Primary Health Care Association and the NC Farmworker Health Program within the Office of Research, Demonstrations and Rural Health Development for North Carolina agencies interested in adapting their services to better address the unique health care needs of migrant and seasonal farmworkers.
- 9. Inter-University Program for Latino Research (IUPLR). Information available at: http://www.nd.edu/~iuplr/
- 10. The UNC-Chapel Hill Program on Ethnicity, Culture and Health Outcomes. Information available at: http://echo.unc.edu/index.cfm
- Another example of this is: The Complete Guide to Immigration and Successful Living in the United States, Access USA, Inc. (1994). Millington, NJ, on sale for \$60. The book is divided into 12 sections covering a variety of topics such as Immigration Law, Employment, Insurance, Health, and Education.