THE DIABETES EPIDEMIC IN HISPANIC AMERICA: POLICY RECOMMENDATIONS

Diabetes in the U.S. Hispanic community has reached epidemic levels, and mainstream efforts to diminish the impact of this "silent killer" on the men, women, and young people of the nation's largest racial and ethnic group are not keeping pace. Because of a confluence of genetic, socioeconomic, and lifestyle factors, people of Mexican, Central American, South American, and Caribbean descent are fully twice as likely to suffer the onset, complications, and consequences of this costly and debilitating disease.

The most effective interventions are necessarily based on both science quantifiable medical and pharmaceutical knowledge and the less-tangible behavioral tendencies of the at-risk Latino community. However, programs reflecting advances in the former category are regularly undermined, even rendered ineffective, if certain factors in the latter category have not been taken into account. The best diagnosis and treatment advice are not going to save a patient who persists in eating the wrong foods, who drinks too much alcohol, who can't afford transportation to medical appointments, and who believes that his diabetes reflects the immutable will of God (with the trade-off, though, that his high blood sugar, he thinks, gives him extra energy to do his work) even though he recognizes on some level that mainstream health authorities have said he *should* try to control his diabetes. Unfortunately no one has yet convinced this patient, in Spanish and with arguments he understands and accepts, the reasons why.

Access to appropriate medications and high-quality, ongoing medical care is of course part of the solution to this and other public health crises. More than most other conditions, though, diabetes requires management not only making sure to see one's healthcare provider on a regular basis and take one's medications, but understanding and taking to heart some fundamental lifestyle changes. Persuasive, clear education is essential. Studies have confirmed, though, that mainstream efforts to translate diabetes-management information into Spanish and disseminate such materials throughout the Hispanic community are almost completely ineffectual.

There are deep-rooted cultural and religious reasons why various Hispanic subgroups are reluctant to comply with even the most clearly-stated diabetes-management instructions, and until those reasons are understood and addressed by healthcare providers the simple distribution of information is futile. In addition, lifestyle and economic barriers of which the U.S. mainstream healthcare community might be insufficiently aware can compound the basic reluctance of many Hispanic men and women, particularly those of limited education and English-language proficiency, to manage their diabetes appropriately.

Dr. Yanira Cruz and her colleagues at the National Hispanic Council on Aging have conducted comprehensive research into the barriers that keep Hispanic men and women from effective diabetes management, as well as the factors which some of the Latinos who are handling diabetes successfully identify as helpful. NHCOA's research has also focused on both Hispanic and non-Hispanic healthcare providers working with the Hispanic community doctors, community-based nurses and clinicians, lay health workers, and others to determine what works and what does not work in efforts to increase compliance rates.

I. Barriers to Effective Diabetes Management: Cultural Factors

Among the cultural factors that healthcare practitioners must understand and address if they wish to engage their Hispanic patients in effective diabetes management are: the role of religion and fatalism; the attractions of folk remedies; dietary traditions; the desirability of being heavy; the inappropriateness of exercise for older people; false beliefs about the dangers of insulin; misunderstandings about the causes of diabetes; and *machismo*.

Faith, fatalism, and the attractions of folk remedies. Many Hispanics regard matters of illness and health in the context of religious faith and spirituality. The National Institutes of Health (1994) has found that for some Latinos, the belief that good health is a reward from God and poor health a punishment for sin can limit a diabetic person's determination to seek medical care "que sea lo que Dios quiera" (what God wishes is what will be) remains a disincentive to action. A strong sense of fatalism *fatalismo* is characteristic, in fact, of most Hispanic subgroups. Those who realize that diabetes involves a strong hereditary component often find their culturally-reinforced *fatalismo* preventing them from seeking care. Besides, folk remedies for many disorders, including the symptoms associated with diabetes, may be more readily available and more comforting.

Food and weight. Another cultural factor involves diet. Communities tend to feel a strong bond to their traditional cuisines, and the psychological and social need to cling to familiar ways of cooking and eating are especially strong in immigrant communities particularly where limited finances and limited availability to a variety of healthy foods are also factors. In addition, many Hispanic families resist the idea that being overweight is unhealthy. For some groups, thinness is associated not only with poverty but with illness; being "chubby" is seen as desirable.

Older people do not need to exercise. In addition to obesity, a sedentary lifestyle aggravates one's risk of developing diabetes. In the hard-working Hispanic community, older adults are encouraged to relax, out of deference for their age and for all they've done in years past for their families. The idea that a stout grandmother should be out exercising would strike many families as inappropriate, even if a doctor has told the family that exercise will help her control her diabetes.

Fear of insulin, and the benefits of diabetes. A further cultural impediment to proper diabetes management is a fear of insulin. Many Latinos believe that taking insulin causes people to go blind or suffer other physical complications. Other widely-held (and profoundly unhelpful) beliefs have to do with the nature of diabetes itself that having too much "sugar" in the blood gives a person extra strength and stamina, so diabetes management will probably make one physically weak.

Causes of diabetes. Furthermore, a robust folk tradition regarding the causes of diabetes and other illnesses makes it difficult for many Hispanics to accept appropriate management instruction if you believe, for example, that your diabetes was caused by *susto* (a sudden traumatic shock), arguments that you need to take insulin or change your diet may seem less than compelling. Why should one make inconvenient or unwelcome lifestyle changes based on the advice of someone who thinks, wrongly, that diabetes is caused by unhealthy lifestyle choices, like too much fried food and lack of exercise? **Manliness.** Finally, *machismo* prevents many Hispanic men from seeking appropriate medical advice or from complying with even life-saving instructions and medication regimens. Bolstered by *fatalismo* and a belief that diabetes in fact makes one stronger, many Hispanic men will fail to seek help particularly when economic factors also make accessing healthcare services difficult.

II. Barriers to Effective Diabetes Management: Language Problems

There are still too few doctors and other healthcare providers who are fluent in Spanish, and even clinics with interpreters on staff have a diminished chance of successfully working with their diabetic Hispanic patients, particularly those who are elderly and/or of limited educational background. It is not simply a matter of language *per se*; older Spanish-speaking patients typically feel very inhibited in trying to communicate with English-speaking authority figures. They tend not to ask questions, feeling that to do so would be impolite; and many of them will try to appear to understand a doctor's explanations and instructions even when they do not. The result, all too often, is noncompliance and a failure to return for follow-up care. There are a great number of nuances subtle body language, tone of voice, eye contact, use of one's first name, briskness or slowness of address, and so on that tend to be part of how speakers of a particular language communicate; English-speaking practitioners, even when assisted by interpreters, can unintentionally inhibit their non-English-speaking patients from the depth of dialogue essential to good healthcare.

III. Barriers to Effective Diabetes Management: Economic Factors

Poverty. Many Hispanic families simply cannot afford good healthcare, and will spend what available healthcare funds they have on looking after children rather than adults particularly when the adult's condition is “silent,” even asymptomatic until it becomes critical. In addition, many low-income families, particularly those in which the adults are limited-English-proficient and of limited educational background, simply do not know how to access healthcare programs for which they might, in fact, be eligible.

problems. Transportation is an enormous problem for low-income Hispanic families. In many parts of the U.S., Spanish-speaking families live in comparatively remote areas, with only limited access to transportation to carry them to doctor appointments. Even Hispanics living in cities with public transportation may lack the funds for buses or subways, and the linguistic or social wherewithal to navigate complex public transportation systems. Older adults in particular rely on younger family members to take them places, and those younger relatives may be at work or otherwise unavailable during a doctor's appointment hours.

Expense of medications and food. Finances are also a problem, of course, in affording medication, and in affording healthful foods even when the foods that diabetics should be eating are readily available, which is often not the case.

Inadequate health coverage. And although Hispanics represent a large sector of the labor force, most work at jobs that do not carry health insurance benefits. Despite their having jobs, very few can afford private insurance coverage, even for their children; and yet many members of the "working poor" do not qualify for Medicaid. Finally, even older Hispanic adults who are Medicare beneficiaries do not always have access to physicians who accept Medicare patients, and these elderly patients cannot, typically, afford other care.

IV. Factors that Enhance Good Diabetes Management

NHCOA's research activities among Hispanic adults who *are* managing their diabetes successfully reveal several factors that increase significantly a Latino diabetic's likelihood of complying with a course of treatment. Prominent among these factors are the role of the family, the manner and behavior of the doctor and other healthcare workers, the cultural- and age-appropriateness of recommended exercise regimens, the linguistic, cultural, and age-related features of both printed and oral educational materials, and the degree to which community-level outreach workers are able to put low-income Hispanics in touch with healthcare programs for which they qualify.

Role of the family. *Familismo* a strong sense of family, and the active company and support of one's relatives is one of the biggest factors in determining whether or not an older Hispanic diabetic will manage his or her condition successfully. In Hispanic culture, all family members tend to be acutely aware of their responsibility to each other, including the duty younger people have to help older relatives with food, medication, transportation, and communications with the outside world. In addition to providing practical day-to-day help with grocery shopping, cooking, transportation to doctor appointments, translation assistance when necessary, and other tasks, the diabetic adult's family provides emotional support and plays a vital role in reminding the patient to avoid unhealthy eating, to exercise, to take his or her medications on schedule, and so on.

Cultural etiquette. *Personalismo* in a Hispanic diabetes patient's relations with his or her doctor/healthcare practitioner is another vital key to success. There are many ways a non-Hispanic doctor can enhance the sense of personal bond to which his or her Spanish-speaking patient will respond. Such techniques as establishing a formal but friendly relationship from the start, greeting a patient by name and inquiring briefly about the wellbeing of his or her family before getting down to the business of the visit, not rushing through the visit or displaying brusqueness or impatience, paying direct attention to the patient and not just to an English-speaking relative who has come along to help, or to the screen of a laptop computer these are all factors that make up a sense of *personalismo* and engender trust in a Hispanic patient. If the patient feels that a personal sense of affinity and mutual respect has been established, he or she will tend to regard the doctor as an important authority figure, perhaps on a par with the mayor or parish priest, and will tend to follow that doctor's recommendations.

Safe exercise venues. Hispanic adults who live in neighborhoods where it is safe to walk have an advantage in terms of diabetes control. Participation in activities at senior centers or community gathering-places particularly dancing is often cited as a benefit in controlling diabetes.

Appropriateness of materials. It is vital that community-level healthcare providers, including lay healthcare outreach workers called *promotores de salud*, receive training and support for their work among hard-to-reach Hispanic groups. A knowledge of Spanish is necessary, as well as an understanding of cultural factors that might impede a patient's understanding of, or compliance with, diabetes-management information. All printed and oral materials should be age-appropriate, as well as geared to the appropriate literacy level. Finally, outreach should include the family of the diabetic patient, as the family's role tends to be vital to the diabetic patient's outcomes.

V. Policy Recommendations

Public policy focused on appropriate outreach that takes into account the cultural and socioeconomic characteristics of the Hispanic community can have a tremendous impact of stemming the diabetes epidemic in America.

1. Primary attention should be given to **increasing the number of healthcare professionals who are culturally and linguistically competent to serve our growing Hispanic population.** Continued support should be given, for example, for the **Health Careers Opportunity Program (HCOP)**, which is dedicated to identifying, recruiting, and assisting students from educationally/economically disadvantaged backgrounds to prepare for entry into health professional schools and allied health and health sciences graduate programs. In addition, the Joint Commission on Accreditation of Health Care Organizations should modify their criteria to include cultural and linguistic competencies as part of their accreditation requirements when evaluating health care organizations.

2. Medicare reimbursement rates for healthcare providers serving Medicare beneficiaries should be reviewed and adjusted, to make universal access to good-quality, affordable diabetes treatment available to all who need it.

3. Increased funding for strategic federal programs like **the National Diabetes Education Program** is essential.

4. The dearth of **research into the epidemiology of diabetes among the various Hispanic subgroups in the United States** should be addressed. Particularly valuable would be further research into risk factors such as the characteristics of neighborhoods where Hispanics live, and the role of the Hispanic media.

5. The Federal and state governments should support **more programs helping community-based organizations educate older Hispanic adults and their families on the risk factors for diabetes and the importance of diabetes management.** These efforts should highlight the importance of offering information on a one-to-one basis which is linguistically-, culturally-, and age-appropriate.

6. **Outreach targeted to Hispanic older adults who live alone** should be designed, funded, and implemented on a grassroots basis through community-based Hispanic organizations.

7. Further support should be given to community-based organizations working to educate older Hispanic adults on the benefits **of Medicare Part D and assist them to enroll.**

8. There are not enough clinics or centers in the communities for helping Hispanics with diabetes. Support should be given to establishing **clinics where Hispanics can obtain all pertinent medical services, including screening, education, nutrition counseling, and treatment under one roof and in Spanish.** Support for safe exercise facilities should also be a priority.

9. Support for **programs that recruit and train community-level lay health workers and supply them with effective, culturally-appropriate materials** can make a significant difference. Home visits should be the objective, whenever possible, so that the whole family receives education on diabetes risks and treatment.

About the National Hispanic Council on Aging

The research upon which this policy paper is based was conducted in 2005-2007 by Dr. Yanira Cruz and her colleagues at the National Hispanic Council on Aging. The National Hispanic Council on Aging, a 501(c)3 organization, is the premier national organization in the field of Hispanic aging. NHCOA focuses its efforts on Hispanic families as a whole, recognizing that Hispanic older adults' quality of life is inextricably linked to that of their spouses, children, and grandchildren. NHCOA represents a network of 42 community-based organizations across the continental U.S., the District of Columbia, and Puerto Rico. NHCOA also maintains a broader network of 7,000 individuals and reaches 10 million Hispanics each year through its work and that of its affiliates.

The mission of the National Hispanic Council on Aging is to improve the quality of life for Hispanic older adults, their families, and their communities.
For over 25 years, NHCOA has supported the growing number of aging Hispanic adults through advocacy, research, the building of support networks, capacity-building assistance to support and strengthen Hispanic community-based organizations, and funding for community-based projects.

NHCOA recognizes that the health and wellbeing of the nation's padres y abuelitos is directed related to care and nurturing from their families and communities, so works hand-in-hand with local community organizations, government agencies, and private-sector entities nationwide to promote high-quality services for our aging Hispanic population.

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