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Talking to Latinos About Diabetes, Using Words They Understand

In 1997, the Robert Wood Johnson Foundation (RWJF) named Aracely Rosales a Community Health Leader in recognition of her work to create a culturally sensitive diabetes education program for Latinos in her largely immigrant community in Pennsylvania.

February 03, 2009

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The Problem: Latinos with diabetes often are labeled as "resistant to treatment" when the real problem may simply be that the majority of health information provided to the Latino community often lacks language and cultural sensitivity, making it hard to understand.

Background: In 1982, Aracely Rosales and her husband fled their native Guatemala with their two-year-old because of political unrest and violence. Settling in Philadelphia near relatives, Rosales began the difficult transition of learning English, finding work and making a new life for her family.

Using her expertise as a literacy teacher in Guatemala instructing adults how to read and write, Rosales applied these skills in Philadelphia to help fellow immigrants study for their high school equivalency exams through the Lighthouse Hispanic Women's Program where she worked first as a counselor, then as assistant program director. It was there Rosales discovered that many of her adult students had questions about health issues, but that most health information materials were not in Spanish and even if the information was in Spanish, it was written in a way few could understand.

From 1988 to 1991, Rosales educated, empowered and guided teens to prevent pregnancy through the use of family planning services, while serving as an advisor in the creation of the Latino Health Literacy Project, the first national effort to focus on both language and literacy barriers, for the Philadelphia Health Promotion Council.

Publication information

**Aracely Rosales**

Community Health Leader 1997

Publication Date:

February 03, 2009

Type of Publication:Grantee profiles
Stories and articles**Program Areas:**

Building Human Capital

Most e-mailed publications

In 1991, Rosales became director of a project where her first task was to translate health information into Spanish, using words that were easily understood—for example, "high blood pressure" instead of "hypertension" and "get well" rather than recuperate. She then started a diabetes education program for Latinos who, as a group, suffer disproportionately from the disease.

The eight-week class—which met for two-and-a-half hours weekly—had almost perfect attendance.

"It was one of the few programs at the time in diabetes education for Latinos that was producing good outcomes—statistically significant reduction of cholesterol, blood pressure, A1c [a blood test that measures average blood glucose over the past two to three months] and weight," says Rosales. The class was very interactive with a lot of visual aids and materials written at the 4th-grade reading level. One man never looked at the written materials—it turned out he could not read. "He relied completely on what we told him in class," says Rosales. "Yet, he dropped his sugar levels to the point where he could stop using insulin. He is a very good example of what can happen when you give information the right way."

Language was not the only barrier to her students' management of their disease. Many complained they did not like the foods typical of a diabetic diet. Plus, different Latino groups eat different foods, yet Spanish-language cookbooks and diabetes information about food were geared mostly for people from Mexico. There was nothing, for example, for Puerto Ricans, whose diet is typically rich in root vegetables such as sweet potatoes, which are high in carbohydrates.

"We had to create our own cookbooks, recipes and diabetes food lists with appropriate portions," Rosales recalls. Getting the foods right for the different national groups helped motivate her students to better manage their disease. "Meals are important to the culture," Rosales explains. "They are how people keep in touch and stay connected to their roots-eating foods they are accustomed to, cooked the way they have learned from their mothers and grandmothers. There had been nothing out there for them. Having these resources made the information and materials relevant and appropriate. And the fact that they were easy to read made it effective"

In 1997, the Robert Wood Johnson Foundation (RWJF) named Rosales a *Community Health Leader* in recognition of her work to create a culturally sensitive diabetes education program for Latinos in her largely immigrant community in Pennsylvania.

Results: The RWJF award not only helped to draw attention to the success rate of Rosales' diabetes education program—soon she was sought by hospitals, health departments, provider groups and professional associations—but also served as a call to action among health organizations for delivering appropriate health education to minorities. Knowing how well the program helped people control their diabetes, other professionals wanted to replicate the program and strategies. Some sought training and others wanted advice on health education, diabetes translation,

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simplification and education. Rosales had created a new trend, meeting an untapped need to help not only Latinos but diverse consumers who have low literacy skills.

Rosales was surprised at how often patients were labeled as "noncompliant" in managing their disease when, in fact, they lacked instructions they could understand.

"People would say, 'Patients don't come for regular checkups.' or 'Why have a program when people don't show up?'" she says. "I have proved that this is not true. When you modify your attitude and strategy—when you are the one who makes the changes to target these different populations—not only will they respond, but they will do well. The providers have the responsibility to make the changes to accommodate the patients. We cannot blame the patient. The change lies within us, to address the needs of our constituents."

Since the award, Rosales has taken her experience at the community level and has brought this approach to improve health communication at the systems level. She has worked with—among other groups—the U.S. Centers for Disease Control and Prevention, RWJF's Diabetes Initiative (a two-pronged effort to support partnerships among local health care providers and community organizations to address diabetes prevention and expand and test self-management programs that could be delivered in primary care settings), and the American Diabetes Association to create standards for culture and health literacy for diabetes education programs and materials. Recently, she also helped draft health literacy standards for the accreditation organization that sets standards for quality assurance for health plans.

Today, Rosales and her colleagues are looking at how to use technology to improve health communications in the health care industry. Her social entrepreneurship company, Health Literacy Innovations, created a software tool that organizations can use to find difficult medical terms in their materials and replace them with simpler words. A free resource guide on literacy and plain language provides tools needed to write and communicate in a way people can understand, no matter what health issue is being addressed, Rosales says.

Having started at the grassroots, Rosales now believes health literacy must be instituted in organizations from the top down. "We need to start with administrators who will actually look at their policies and institute new changes throughout systems," she says. "Once they're in place, the rest is easier."

RWJF Perspective: Since 1993, RWJF has recognized unsung and inspiring individuals who work in their communities—often among the most disenfranchised populations—to address some of the nation's most intractable health care problems. Formal recognition by the Foundation of these *Robert Wood Johnson Foundation Community Health Leaders* and their programs often launches them to greater levels of influence and extends their reach to serve more vulnerable populations.

RWJF provides a financial award to 10 individuals and their organizations each year, and connects the Community Health Leaders with one another so they can build their programs upon the wisdom and experience of their peers and previous award