

Stigma, lack of treatment hinder Alzheimer's battle among Chicago Latinos

Budding programs combat disease that often elicits shame, indifference

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Arturo Reyes sat quietly as family members talked about traveling to Mexico over the winter holidays.

Suddenly, the older man broke into the conversation. "We cannot do it; we are illegal," his daughter Angelica Reyes-Serving remembers him saying. "If we leave, we may never get back again."

The room fell silent with shock. Reyes and his family, who crossed the border from Mexico to Arizona three decades earlier, have been U.S. citizens for more than 20 years.

"It was then I realized my father is sick," Reyes-Servin said, recalling the experience of several years ago. "He's not himself anymore."

Reyes, 69, has Alzheimer's disease, a condition widely misunderstood in Latino communities, where there is little culturally appropriate information and a dearth of resources for caregivers.

A new effort in Chicago this week aims to address the problem. For the first time, specially trained professionals are offering free memory screenings in Spanish at the Mexican Consulate, Mount Sinai Hospital and several other locations. Educational materials and resource lists geared toward Latinos will be available.

If screening results are troubling, families will be referred to medical providers for more comprehensive examinations. Identifying Alzheimer's early is an important way for families to "learn what to expect," said Maria Marquine, a neuropsychologist at Rush University Medical Center.

Gaps in services are considerable in the Chicago area, home to 1.7 million residents of Mexican, Puerto Rican, or Central or South American descent. For instance, there is only one Spanish-language support group for families coping with Alzheimer's — on the Northwest Side, far from the Reyes' home in Lynwood.

Alzheimer's exacts a particularly heavy toll among Latinos, who tend to get the condition almost seven years earlier and live with it longer than white Americans, according to research from the University of Pennsylvania and the University of California at San Francisco.

Limited access to medical services and health insurance, low levels of education and income, and higher rates of high blood pressure and diabetes contribute to above-average risks for Alzheimer's among Latino seniors, experts said.

In Chicago, a push to respond is being led by Constantina Mizis, a Mexican immigrant who founded the Latino Alzheimer's & Memory Disorders Alliance, one of the few organizations of its kind in the country.

With a Mexican mother and a Greek father, Mizis says she has always lived between two cultures, aware of differences in people's traditions and beliefs. It's a lesson she's bringing to medical professionals who reach out to Latinos with memory problems.

Such efforts have to be undertaken with sensitivity, says Mizis, explaining that some Mexicans from rural areas believe Alzheimer's is inflicted as punishment for sins committed during one's youth. Others think of cognitive difficulties as "just part of age" — something that families have to accept without asking for assistance.

But cognitive lapses can occur because of treatable medical issues, including depression, thyroid problems and the side effects of medication, according to Freddy Ortiz, coordinator of the memory disorders clinic at Olive View- UCLA Medical Center in Los Angeles.

Although no medications can reverse Alzheimer's, some drugs can offer short-term relief of symptoms, and some services, such as adult day care, can ease caregivers' stress.

In many Latino families, however, adult day care is considered a type of warehouse. "They believe that if you leave someone there you have abandoned this person," Mizis said.

For Luisa Echevarria's Cuban mother, Nora, dementia was associated with mental illness and a source of shame.

"We had to be very careful not to use the words 'Alzheimer's' or 'dementia' around her," said Luisa Echevarria, community relations director for Univision and TeleFutura in Chicago. "If we did, she would scream and say, 'There's nothing wrong with me; it's you who are crazy.'"

Echevarria remembers going out to lunch with her parents years ago and being horrified when her mother suddenly started speaking in gibberish, her eyes dark with panic. Soon after, Nora began picking fights with her husband and becoming suspicious for no apparent reason.

Echevarria realized her mother needed medical help but felt torn. "You don't want to doubt your mother — the person you trust more than anybody, the person you go to for everything," she said. "It was a very hard time because I felt I was betraying her."

At Northwestern Memorial Hospital Nora flirted with the doctor while joking about tasks she could not complete, such as naming her age or drawing a box. "She was a queen at disguising her disabilities," Echevarria said.

Nora now lives in a small, Latino-oriented assisted-living facility in Miami, near her husband and a large circle of family members. "She is still my mother," Echevarria said. "Alzheimer's places you in a different reality, but it doesn't change who you are."

Education can be a complicating factor for those being tested for memory problems. People who have not had much education, including many Latino immigrants, tend to score lower on memory tests, and adjustments are needed to account for that, said Marquine of Rush's Alzheimer's Disease Center.

Also, language can be a concern even when tests are translated into Spanish. Consider that car is "carro" in some Latino groups but "auto" and "automovil" in others, Marquine said. If the translation used in a memory test is not familiar, that could affect a senior's score, she noted.

For Arturo Reyes' family, his Alzheimer's diagnosis in 2002 was an introduction to an entirely unfamiliar world of illness.

"We had never been around anybody who had Alzheimer's," said his daughter Laura, who lives with her parents. "We didn't know anything about it."

She remembers finding her father in the kitchen and opening all the drawers in search of silverware. Then came a call from his factory supervisor. Reyes had been standing in the middle of the factory floor, unsure where to turn or what to do next.

Now, Laura worries about their mother, who insists on doing everything for her husband by herself. She is not sure whether her father knows what has happened to him. Not long ago, her mother asked him if he realized he forgot things and the old man shook his head. "I don't know, I don't know," he repeated. "I don't know."