

Executive Summary

*Attitudes, Level of Stigma, and Level of Knowledge About Alzheimer's Disease Among
Hispanic Elderly Adults and Caregivers, and
Alzheimer's-Related Challenges for Caregivers*

Alzheimer's disease has a devastating impact on the lives of patients and caregivers.

It is an irreversible, progressive brain disease that slowly destroys memory, thinking skills, and eventually the ability to carry out the simple tasks of daily living. It is estimated that about five million Americans have Alzheimer's disease, making it the most common form of dementia (National Institute of Aging). According to the Centers for Disease Control and Prevention (CDC), Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death for people 65 years and over. Although there is currently no medical cure, early detection and medical management can improve the quality of life of patients and caregivers.

Alzheimer's disease is a particularly serious problem for Hispanic older adults and caregivers. Latinos are 1.5 times more likely to develop Alzheimer's disease than non-Hispanic whites; however, they are less likely to be diagnosed (Alzheimer's Association). As a result, data from the Alzheimer's Association estimates that between 200,000 and 365,000 Hispanic older adults have Alzheimer's disease or another form of dementia. There is a higher risk of Alzheimer's disease and other dementias in Hispanics because they have higher rates of cardiovascular risk factors (i.e. diabetes, high blood pressure and high cholesterol) and longer life expectancies than the general population.

The Alzheimer's Association reports rates of Alzheimer's and other dementias in 7.5% of Hispanics between 65 and 74; 27.9% between the ages of 75 and 84; and 62.9% over age 85. These numbers are substantially higher than the incidence of Alzheimer's among non-Hispanic whites, which the Alzheimer's Association reports as 2.9% among those between the ages of 65 and 74; 10.9% among those between 75 and 84; and 30.2% of those 85 and over.

In light of this, the National Hispanic Council on Aging (NHCOA) — the leading national organization working to improve the lives of Hispanic older adults, their families, and their caregivers — conducted a qualitative research project and produced a corresponding report of the findings. This project assessed Latino older adults' and Latino caregivers' attitudes and knowledge about Alzheimer's disease, as well as the challenges faced by the latter in caring for Latino persons with Alzheimer's. Offering their observations on the same topics was a group of healthcare providers whose patients included elderly Latinos with Alzheimer's disease. The focus of the research project was to identify the challenges to early detection of Alzheimer's disease within the Hispanic community. Alzheimer's research focused on the Hispanic community is of critical importance because 1.) Hispanic older adults are the fastest growing

older adult population in the U.S. (by race and ethnicity); 2.) Studies show that the incidence of Alzheimer's disease in the Hispanic community is about 1.5 times that of Alzheimer's disease among non-Hispanic whites; and 3.) Research indicates that Hispanics are showing signs of Alzheimer's at an earlier age than other racial/ethnic groups. The study's Principal Investigator was Dr. Jim Sherry of the Center for Global Health at The George Washington University. Dr. Yanira Cruz, President of NHCOA, was Co-Investigator.

Investigators used two qualitative research methods to conduct the study – focus groups and key-informant interviews. Latino elderly adults (over the age of 55) and Latino caregivers participated in focus groups. Healthcare providers (of any ethnicity) served as key informants. The focus groups were conducted in the communities of Alamo, Brownsville, and Pharr in Texas, and in Washington, DC. The healthcare providers who participated in the project practice in the same areas. Below is a summary of the findings.

Knowledge

The study found that there is lack of knowledge about Alzheimer's among Hispanic older adults and caregivers. Although they associate the disease with memory loss, they have no other information in terms of complications or treatment. The study also found that misperceptions exist among Hispanics about the reasons why a person develops the disease. For example, older adults stated that some people get Alzheimer's because they think too much, are stressed, or have personality issues. Caregivers stated that this happens because people do not take things seriously, or because they were just destined to develop the disease.

Healthcare providers participating in the study observed that elderly Latinos tend to know very little about Alzheimer's disease. That opinion is supported by the findings of the focus group discussions, in which many participants (both older adults and caregivers) described themselves as having little knowledge of the disease other than what little they may have read or heard; however, focus group participants did enumerate certain symptoms that they associated with Alzheimer's, including memory loss (especially short-term), disorientation and depression.

Some providers suggested that while some older adults are aware of the fact that memory loss can be a symptom of Alzheimer's, few considered their own memory loss in the context of Alzheimer's risk. Rather, they and their families tended to attribute most early symptoms of Alzheimer's, including memory loss, to old age.

Some providers stated that very few older adults will link the symptom of memory loss to Alzheimer's. Rather, older adults and their families tend to attribute it to symptoms of aging.

In addition, many healthcare providers indicated that older adults generally do not ask questions about Alzheimer's; while others said that patients and their caregivers do ask questions, but only under certain circumstances.

Attitudes

"I did know that you forget things, because of age. I didn't know that people could die from it." – Latino older adult in Washington, DC

This study found that although Latino older adults are likely to accept suggestions that they be evaluated for Alzheimer's risk, they would do it only if those suggestions are made by independent parties whom they trust and who are knowledgeable about the disease—usually their primary care physicians. Latino caregivers are likely to accept suggestions that can help the elderly

adults in their care obtain evaluations for Alzheimer's risk. Healthcare providers confirmed that Hispanic older adults are receptive to Alzheimer's screening when it is suggested by their healthcare provider.

While Latino older adults may be open to a provider's suggestion of being screened for Alzheimer's, their likelihood of agreeing to be screened is affected by such factors as fear, lack of knowledge, and denial of the disease. According to healthcare providers, the probability of agreeing to screening is also affected by such factors as poverty, lack of health insurance, language barriers, and lack of access to healthcare.

Perceptions

When asked to identify the names by which the disease is known in their native countries, some older adults confused Alzheimer's with different disorders (for example, Huntington's disease, epilepsy, arteriosclerosis, and amnesia), equated it with dementia generally, or indicated that it is called simply "craziness" or "mental illness."

*"What happens is that they call you crazy. He was alright and suddenly went nuts. Women drove him crazy; and if it's a woman, the man she was in love with drove her crazy."
– Latino older adult in Texas*

Older adult participants identified the role of the family in recognizing and responding to Alzheimer's symptoms as consisting in part of telling a family member that he or she needs an evaluation for the disease, and of giving sick family members "lots of love" and the help they need throughout the illness. Some older adults reported that their family members do not live in the United States, or they do not live with them. Some expressed

concern that elderly Latinos tend not to have supportive families; however, others responded that families want to help, but because of their work and responsibilities they do not have time and resources to do it.

Caregivers identified the role of the family in caring for relatives with Alzheimer's as, above all, giving them love, and providing them with a consistently loving and nurturing environment. They also indicated that, in addition to providing emotional support, and aiding with such activities as therapy and bathing, it is important for family members to remain strong and to avoid expressing sadness in the presence of the patient.

Healthcare providers described the family's role in helping to identify Alzheimer's symptoms as, among other responsibilities, educating themselves about the warning signs of the disease.

Older adults participating in this study had varying opinions with respect to the healthcare provider's role in identifying Alzheimer's symptoms. Some felt the provider had no such role, and that, if they themselves had questions about Alzheimer's, their providers would probably not take the time to explain the disease or answer questions. Those who felt that healthcare providers do have a role in identifying Alzheimer's symptoms stated that their own doctors are generally responsive to their needs and requests.

Most older Hispanics said that they had not spoken with their healthcare providers about Alzheimer's. Reasons cited included simply not having thought about it, not having been given sufficient time by their doctors to ask questions, and not feeling that they would ever develop the disease. Similarly, most caregivers had not discussed Alzheimer's with the patients' healthcare providers, because, they reported, the family members would not accept the doctors' diagnosis or tell their caregivers about their appointments, and the doctors seemed uninterested in discussing the disorder or the patient's symptoms.

Most older adults reported that their healthcare consultations were conducted in Spanish. Caregivers confirmed that conversations were usually in the patient's language of choice, and that Spanish interpreters were available when needed. As indicated above, however, they have not talked with their provider about Alzheimer's.

Caregivers reported that some of the older adults did have regular healthcare providers, while some visited doctors but did not have regular healthcare providers. Other older adults did not have regular healthcare providers because they were unable to afford healthcare.

Enabling Factors

Most Latino older adults reported that they do not have health resources available and accessible to them that can help them understand Alzheimer's. Moreover, they reported that there are no

Alzheimer's resources, such as screening tools, screening centers, or referral centers available to them. They indicated that, if there are, they do not have the information or access to them. Similarly, caregivers reported that there very few, if any, resources available to them for caregiving.

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Healthcare providers stated that there are generally no resources in Spanish that can help Latino older adults or their caregivers understand Alzheimer's. They were almost unanimous in declaring that there are no culturally- and linguistically-appropriate Alzheimer's resources for Latino older adults. One provider noted that some services are available to people who have health insurance, but many older Latinos do not. They offered a wide range of opinions as to whether there were a sufficient number of healthcare providers to serve the older adults in their areas.

The healthcare providers from Texas who participated in this study reported that Latino older adults in that region live in an environment that is not conducive to obtaining Alzheimer's screening. "Unless prompted by a nurse or a caretaker or a doctor, the elders are unlikely to seek screening," explained a provider. Another barrier providers cited was prevalent misinformation or unfounded assumptions about Alzheimer's disease, such as the belief that the disease's symptoms can be explained as being due simply to old age.

In contrast, healthcare providers in Washington, DC, stated that the healthcare environment there does promote Alzheimer's screening; however, older adults are not aware of the availability of the screening. Providers stated that older Latinos are encouraged to get checked for Alzheimer's when, for example, friends or family point out forgetful behavior.

When asked them if they thought they had the skills needed to manage the disease, some older adults described themselves as possessing the skills to manage self-care and follow recommended guidelines about such matters as exercise. Others felt that they lacked those skills. Interestingly, even among caregivers who were already caring for someone with Alzheimer's they cited a personal perceived lack of skills, acknowledging that they felt they needed to know more about how to care for patients, in addition to providing such necessities as patience and affection.

According to Latino older adults, the best channels of communication to reach them with Alzheimer's detection messages were TV and radio, followed by dissemination of information at doctor's offices and community centers.

All participating older adults felt that in-person meetings, such as classes or workshops at community centers, or special topical meetings, would be an effective means of education about

Alzheimer's. This approach was favored above all other channels of communication because it would enable the participants to ask questions and learn more by listening to the comments of others.

Reinforcing Factors

In reference to community based support, members of all three categories of respondents (older adults, caregivers and healthcare providers) indicated that they were unaware of any community-based support for getting screened for Alzheimer's.

When asked about the organizations or individuals they see for health advice, older adults responded that, aside from their doctors or clinics, they do not have persons or organizations to which to turn for advice.

In terms of receiving appropriate advice, recommendations, or feedback from healthcare providers, most of the participants from both groups -- older adults and caregivers -- expressed that they did not get Alzheimer's information or advice from their providers.

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Caregivers Challenges

Caregivers reported facing several challenges while taking care of a person with Alzheimer's. The most overwhelming was the time needed to care for the person, handling the physical and emotional stress, and coping with the financial stress, Caregivers also cited a lack of resources to support them as they support the patients, and expressed wishes for access to hotlines, blogs, seminars, conferences, and Alzheimer's specialists, and for help obtaining government assistance to help their relatives with Alzheimer's. They spoke of the difficulties of caring for someone with Alzheimer's disease, such as emotional and financial stress, the importance of maintaining patience, and the need to provide a good quality of life on a daily basis.

Respondents rated their stress level between eight and 10 on a 10-point scale, with 10 indicating the highest level of stress. They reported spending anywhere from one or two to 24 hours a day caring for the older adults.

Caregivers stated that they would strongly resist the idea of placing a loved one with Alzheimer's in a nursing home. They indicated that they would look for alternatives, such as home-health services, but avoid a nursery home. Only one person indicated that she would do so, but only if necessary to protect other family members.

Some caregivers described caring for a person with Alzheimer's as very expensive, involving costs for medication, therapy, and additional caregivers.

Conclusion

As a result of this study, NHCOA found that there is a lack of knowledge, resources, and information about Alzheimer's disease in the Hispanic community. Also, caregivers face significant challenges in their responsibilities of aiding Hispanic older adults suffering from Alzheimer's.

The study showed that there is a lack of factual knowledge about Alzheimer's, its causes, and treatment options in the Hispanic community. Many people incorrectly attributed early Alzheimer's symptoms to the aging process, mental illness, or other diseases, which ultimately delays the decision to seek medical help for their symptoms.

Healthcare providers identified the importance of encouraging screenings and offering free screenings, seminars, and educational materials as the greatest contributions that can be made by the healthcare profession in regards to Alzheimer's disease.

The study showed that even when Hispanic older adults and their caregivers seek help, there are few adequate options, however. In fact, healthcare providers almost unanimously concluded that there were no linguistically and culturally appropriate resources and information about Alzheimer's disease for Hispanic older adults and their caregivers. This lack of information and resources, combined with the lack of knowledge, leaves the Hispanic community at a severe disadvantage when dealing with this devastating disease.

Additionally, Hispanic caregivers reported feeling high levels of stress as a result of their caregiving responsibilities for Hispanic older adults with Alzheimer's disease. They felt they had little support and resources to aid them in these responsibilities.

After reviewing these results, NHCOA makes the following two recommendations:

1. NHCOA determined that there is a need to expand research on Alzheimer's among Hispanic older adults and caregivers. Accordingly, NHCOA urges more research be conducted on this topic and the Latino population, especially to explore understanding among different subgroups from different geographic regions and acculturation levels
2. NHCOA recommends the development of a campaign to increase knowledge and provide resources to caregivers. This campaign should target key stakeholders including patients, caregivers, providers, advocates, and policy makers. This campaign will aim to:
 - Increase knowledge about the disease and the importance of getting screened for Alzheimer's disease symptoms among older adults and caregivers;
 - Develop and disseminate information on Alzheimer's that is culturally- and linguistically-appropriate, age sensitive, and tailored to older adults and caregivers;
 - Improve communication between healthcare providers and patients;

- Increase resources and education for caregivers. Caregivers are key for the detection of Alzheimer's symptoms; however, they need to learn about these symptoms in order to recognize them.