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HISPANICS/LATINOS AND ALZHEIMER'S DISEASE



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Introduction

Dementia is a looming but unrecognized public health crisis in Hispanic/Latino communities in the United States. During the first half of the 21st century, the number of Hispanic elders suffering from Alzheimer's and related dementias could increase more than **six-fold**, from fewer than 200,000 today to as many as 1.3 million by 2050.¹

While research is only beginning to uncover the impact of Alzheimer's disease among Hispanics, what we have learned to date suggests that Hispanics may be at greater risk to develop dementia than other ethnic or racial groups. Moreover, the burden of disease is falling heavily on Hispanic/Latino families, particularly daughters and other female relatives, in part because of the strong sense of filial responsibility and the role of women in these communities but also because of the lack of culturally and linguistically appropriate and responsive health and community services.

Consideration of dementia is confounded by the heterogeneity of the Hispanic/Latino population in the United States. As defined by the U.S. Census, Hispanics may be of any race and from more than 25 subgroups by country of origin. A large proportion, particularly of the elderly, were born outside the United States and may not be comfortable in English or acculturated to U.S. systems. The diversity of this large ethnic group, with its tremendous variation in origins, generational experience, native vs. English language, and acculturation, must be taken into account in designing research, services, and policy to address the issue of dementia in Hispanics/Latinos and the needs of those individuals and families affected by it.

(Note: This paper uses the terms Hispanic and Latino interchangeably. Where findings from research are cited, we use the term as it appears in the particular study cited.)

The Alzheimer's Association is issuing this report to raise awareness of the increasingly alarming reality of dementia among Hispanics/Latinos in America that is beginning to emerge from research and practice, and to sound a call to action to prevent a public health disaster while there is still time to do so.

Hispanics/Latinos Face High Risk of Alzheimer's Disease and Other Dementias

Our projection of Alzheimer's disease in Hispanics is conservative. It assumes that prevalence of dementia in Hispanics/Latinos is the same as it is for the population as a whole. In fact, there is evidence that they are at greater risk, given the prevalence of known or suspected risk factors for Alzheimer's in these communities.

- **Age** is the single greatest risk factor for Alzheimer's – prevalence doubles every 5 years beyond the age of 65 and reaches 47% of persons 85 and older.² Hispanics are disproportionately represented in the older age groups most at risk of Alzheimer's disease. Their life expectancy will increase to age 87 by 2050, surpassing all other ethnic groups in the United States.³ By the middle of the century, Hispanics will increase as a proportion of the total elderly population from 5% today to 16%.⁴
- **Education** appears to have some protective effect against Alzheimer's. Hispanics have the lowest education levels of any group in the United States. One in 10 Hispanic elders have no formal education.⁵ Over half have 8 years of schooling or less.⁶
- A growing body of evidence indicates that **vascular disease risk factors -- including diabetes --** may also be risk factors for Alzheimer's disease and stroke-related dementia. Hispanics/Latinos have high rates of

each of these risk factors.⁷ The high incidence of diabetes – 64% higher than non-Hispanic white Americans⁸ -- is a matter of particular concern, in light of new findings that diabetes is the one vascular risk factor related to risk of Alzheimer's disease in the absence of stroke.⁹ A study of older Mexican Americans found that type 2 diabetes and hypertension contribute more to dementia in this ethnic group than in people of European ancestry. 43% of those with dementia had diabetes, stroke or both.¹⁰

Research Is Only Beginning to Sort Out the Complicated Picture of Dementia Among Hispanics/Latinos

Alzheimer's disease is a complex puzzle of genetic and environmental factors, further complicated by the racial and cultural diversity of Hispanics in the United States. The limited research that has been done to date suggests that within-group differences may affect incidence and presentation of the disease. But the picture is far from clear and much more work needs to be done to point the way to effective treatment, management, and prevention of dementia in this population.

For example, studies of Caribbean Hispanics in Manhattan have found significantly higher incidence rates of Alzheimer's, independent of comorbidities and education.¹¹ A study of Mexican and Central American Hispanics in California found a similar proportion with Alzheimer's and a higher proportion with vascular dementia than might have been expected based on data from the non-Hispanic white population.¹²

The picture is further complicated by examining genetic risk factors for Alzheimer's. The one known genetic risk factor for late onset Alzheimer's disease – the APOE-e4 allele – appears to have the same impact in Hispanics as in non-Hispanic whites. But the APOE-e4 allele is less present in at least some Hispanic subgroups.¹³ In the absence of APOE-e4, Caribbean Hispanics appear to have a cumulative risk for Alzheimer's that is twice that of non-Hispanic whites.¹⁴ Further research has found

evidence of other susceptibility genes in Hispanic subgroups, especially in APOE-e4 negative families.¹⁵ Some recent research has focused on genetic factors linked to insulin metabolism, supporting the notion that there are vascular and metabolic pathways by which Alzheimer's may develop.¹⁶

Hispanics/Latinos Are Not Receiving the Health Care They Need to Reduce Their Risk or Manage Their Dementia

There is a substantial body of evidence, reinforced by clinical experience, that Hispanics/Latinos with dementia are low users of formal services. They are less likely than non-Hispanics to see a physician and much less likely to use services provided by other health professionals. Among adults with diabetes, high blood pressure, or heart disease – all potential risk factors for dementia -- they are less likely to receive services to help monitor and control those conditions.¹⁷

This failure of the health care system may increase the risk of dementia for Hispanics/Latinos. It delays identification and diagnosis of dementia and leads to high levels of impairment and heavy and prolonged caregiver burden.¹⁸ Failure to recognize signs of cognitive impairment leaves persons with dementia at risk. Delay in diagnosing means they are not getting early treatment of their cognitive symptoms, when that treatment is most likely to be effective.¹⁹ One study found that 40% of foreign-born elderly Hispanics had undiagnosed cognitive symptoms for 3 years or more.²⁰

There are multiple factors contributing to the poor care that Hispanics/Latinos with dementia are receiving, but they are still not understood fully. Nor have we devoted sufficient resources to develop and implement effective approaches to overcome them. One study of older Hispanics, most of them Mexican-Americans, found personal beliefs, language proficiency and economic status to be the most frequently perceived barriers to health care and particularly to early diagnosis and

treatment.²¹ Among the well-documented barriers to care are the following:

- Large numbers of Hispanic elders – particularly the old-old who are most at risk of Alzheimer’s -- are first generation immigrants who are not necessarily comfortable in English or trusting of a health care system. 54% of Cubans, 46% of Puerto Ricans, 28% of Mexican Americans, and 25% of other Hispanics in the U.S. have limited English language skills.²² The lack of Spanish-language capability and the cultural insensitivity in many health and community care systems instills distrust in Hispanic/Latino elders, limits access to care, and adversely affects the quality of the care they do receive. In addition, it imposes further burdens on the extended family to serve as interpreters – linguistic and cultural - - between older Hispanics/Latinos and the health care system.
- Cultural biases in cognitive testing and inadequate translation of diagnostic tools may skew diagnosis of dementia in Hispanics. Coupled with the lack of bilingual professionals in this field nationwide, testing and diagnosis of monolingual Spanish-speaking elders is especially challenging. While significant progress has been made in developing culturally sensitive tools, they have not been standardized or normed across subgroups of Hispanics, nor are they being widely used outside of academic or specialized research settings.²³
- Older Hispanics have far less health insurance than their non-Hispanic contemporaries. More than one-fourth of Hispanics age 50 to 64 who have a chronic condition are uninsured; less than one-third are covered for the prescription drugs they need to manage those conditions. Hispanics age 65 and over rely solely on public insurance (Medicare and Medicaid) in higher proportions than non-Hispanic elders. It is not surprising therefore that median health care expenditures for non-Hispanics are 40% higher than expenditures for Hispanics.²⁴

These factors not only limit access to early diagnosis and appropriate treatment and services. They create barriers to participation by Hispanics/Latinos in the essential research, including collection of brain tissue through autopsy that is necessary to understand dementia and the interplay between genetics and environment in these communities.

Dementia Inflicts Especially High Burdens on Hispanic/Latino Families

The strong cultural value of family responsibility is a strength of Hispanic/Latino communities. Studies have demonstrated the high sense of filial responsibility for elders, particularly among Hispanic daughters. Others show a high acceptance of cognitive impairment and dementia as a normal part of aging to be managed within the family.²⁵ As a result, Hispanic/Latino families, particularly daughters and other female relatives, provide a disproportionate share of Alzheimer care. They do so for longer periods of time and at higher levels of impairment than is the case in non-Hispanic families.²⁶

This means that Hispanics/Latinos are less likely to be living in long term care facilities and more likely to be living with relatives than any group other than Asian-Americans.²⁷ Those who do live in nursing homes have more cognitive and functional impairments than non-Hispanic whites and are more likely to have been living with someone before admission.²⁸ Studies of use of community-based services report similar findings: for example, older Hispanic enrollees in formal service programs in the communities exhibited higher rates of functional impairment even though they were on average six years younger than their non-Hispanic white counterparts.²⁹

Research has documented a number of reasons why Hispanics/Latinos are reluctant to use formal services until they are completely overwhelmed. These include distrust of outsiders, acceptance of stress as a normal and expected part of the familial

role, and resistance to sharing familial problems with outsiders or admitting that care is too demanding.³⁰

This commitment to family caregiving is a strength of the Hispanic/Latino community. But families need information; help and support to sustain their role as carers and to assure that the person with dementia is getting treatments that may help lessen the burden of the disease. Those services must be provided in a way that reinforces family values and overcomes cultural barriers to service. Comparative studies of Anglo and Latina caregivers, conducted in multiple sites across the country, suggest that Latina caregivers participate and benefit most from services that are designed to meet their very specific needs.³¹

A Call to Action

The Alzheimer's Association is sounding the alarm about dementia in Hispanic/Latino communities, not to cause panic but to stimulate action to prevent disaster. Alzheimer's disease is no longer a hopeless cause. By mobilizing public and private resources in a campaign to fight Alzheimer's, and by enlisting Hispanic/Latino communities in that campaign, we can change the course of Alzheimer's for families who are now at risk. This campaign includes three interrelated strategies:

- Research
- Education and Outreach aimed at risk reduction, early diagnosis, and treatment
- Community health and social support services for patients and families.

The Alzheimer's Association Is Doing Its Part

The Alzheimer's Association recognizes its central role in this campaign as the single largest private funder of Alzheimer research and the only network of community-based agencies organized nationwide to support and assist people with dementia, their families, and their health and long term care providers.

- Research on Alzheimer's in ethnic and cultural minorities is a focus of the Association's scientific program. We convened the research community to examine global issues and barriers to research on ethnic and racial communities and have issued a publication on Cultural Diversity and Alzheimer's Disease for the research and practice communities. In collaboration with the National Institute on Aging, we are increasing the diversity of Alzheimer researchers and study participants. This year, we are funding specific research on Hispanic and other underserved communities, including studies on Literacy and Alzheimer's Disease, Hispanic Caregiver Training, and Neuropsychological Tests as Predictors of Functional Status.
- The Alzheimer's Association Contact Center is staffed 24 hours a day and 7 days a week with Spanish-speaking information specialists and professional care consultants to provide immediate assistance to individuals and families who need help, no matter where they live. Accessible through a single toll-free number and web site (1-800-272-3900; www.alz.org), the Center provides immediate information and advice and links callers directly to local offices of the Alzheimer's Association for ongoing help and support. Under a new collaboration with the Administration on Aging, the Contact Center is expanding its reach and engaging the aging network in this effort.
- Our nationwide network of Alzheimer's Association chapters, with more than 300 local points of service, provide information, family education, support groups for persons with dementia and their caregivers, and training for health and long term care providers working with people with dementia. Our chapters have been leaders in developing culturally and linguistically appropriate materials about dementia and creating community programs with Hispanic/Latino communities to meet their unique needs.

El Portal is a national model of culturally and linguistically sensitive dementia services developed by the Alzheimer's Association of Los Angeles to respond to specific identified needs of Hispanic/Latino families dealing with Alzheimer's disease in South Central and Eastern Los Angeles. With initial funding from the federal Alzheimer's Demonstration Program and staffing from the community, the chapter developed partnerships with over 100 community organizations and service providers to offer dementia-friendly services that include education, training and outreach to Alzheimer families, case management, adult day care, in-home respite, support groups, legal assistance, transportation, home safety intervention, and a Spanish-language helpline.

- Our on-line Diversity Toolbox provides information and resources in Spanish for families, volunteers, and health and long term care professionals working with Hispanic families dealing with Alzheimer's disease and other dementias.
- We are aggressively recruiting national and local Hispanic/Latino organizations to join us in a Coalition of Hope, to extend our outreach to Hispanic/Latino families, to raise awareness of Alzheimer's disease, to encourage prevention, and to mobilize advocacy for the public policy objectives outlined below.

Investing in a Future Without Alzheimer's Disease -- A Public Policy Agenda

Alzheimer's is too big a challenge for families and voluntary organizations to conquer without a concerted public commitment to research, education, and culturally competent health care and supportive services. The Alzheimer's Association and its Coalition of Hope call on Congress, the White House, and state governments to take immediate steps to change the course of Alzheimer's disease for Hispanic/Latino families and for all Americans:

- **Recommendation #1 – Research.** We call on Congress and the National Institutes of Health to make an annual investment of \$1 billion in Alzheimer research. That investment would be sufficient to maintain and accelerate the overall Alzheimer research agenda while providing sufficient resources for essential work that must be done now in Hispanic/Latino communities. That should include: an increased investment in epidemiological work in Hispanic subgroups; resources to Alzheimer's Disease Centers and other academic centers involved in Alzheimer research to increase participation of Hispanics/Latinos in research and clinical trials in sufficient numbers to draw valid conclusions; an intensive effort to elucidate the linkages between Alzheimer's and vascular disease including particularly in Hispanics/Latinos; and social, behavioral and health services research to understand more fully the underlying reasons that Hispanics/Latinos delay diagnosis and underutilize services and to identify culturally and linguistically appropriate approaches that will be successful in overcoming them.

It must all include full support for current initiatives at the National Institute on Aging and NIH in genetics, imaging, and clinical trials, with resources targeted to assure sufficient numbers of participants from culturally diverse communities. This will require resources for community outreach to educate these communities about the importance of research and to respond effectively to cultural concerns about participation, particularly on sensitive matters like the collection of brain tissue and genetic information.

- **Recommendation #2 – Community Services.** We call for an expansion of the proven successful Alzheimer Demonstration Grant Program at the Administration on Aging to at least \$25 million annually, to allow every state to participate with the Alzheimer's Association in developing and testing culturally and linguistically appropriate community programs that support Hispanic/Latino families and other

underserved communities dealing with Alzheimer's disease. Concerted efforts must be undertaken to integrate the learnings of successful demonstrations into state and local home and community based long term care and caregiver support programs.

- **Recommendation #3 – Outreach and Education.** We call on the Centers for Disease Control to embark on an aggressive evidence-based Alzheimer health promotion and risk reduction education and outreach effort, in collaboration with state health departments and the Alzheimer's Association and with particular emphasis on Hispanics/Latinos. The goals of such an initiative would be to reduce the risk of Alzheimer's through reduction of vascular risk factors, to encourage early recognition and diagnosis of dementia, and to train public health personnel to recognize, assess, diagnose and treat Alzheimer's disease in ways that are culturally appropriate and supportive of families.
- **Recommendation #4 – Medicare Payment for Chronic Care.** Medicare must provide sufficient payment to health care providers, particularly primary care providers, to provide culturally and linguistically competent management of patients with multiple and complex chronic conditions including especially Alzheimer's disease, diabetes, and vascular disease, to prevent acute care crises, excess disability and premature functional decline. The benefit should include adequate payment for the time it takes to assess, diagnose and treat a person with dementia, particularly patients with limited English, and to coordinate those services with family and others providing care to the person with the disease. A chronic care benefit should be available to any beneficiary who meets medical criteria, whether she or he is enrolled in a managed care organization or in traditional fee-for-service.

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The Alzheimer's Association is the world leader in Alzheimer research and support. Having awarded more than \$150 million to nearly 1,300 projects, the Alzheimer's Association is the largest private funder of Alzheimer research. The Association's vision is a world without Alzheimer's disease. For more information about Alzheimer's disease, visit www.alz.org or call 800-272-3900.

¹ These figures are derived by applying the estimate of prevalence of Alzheimer's disease over the age of 65 from D.A. Evans et al, "Estimated Prevalence of Alzheimer's Disease in the United States" *The Milbank Quarterly* 68:2 (1990) 267-289 to Census figures on total number of Hispanics in the United States age 65 and over in 2000 and projections for 2050. US Census 2000 PHC-T-8 Race and Hispanic or Latino Origin by Age and Sex for the United States 2000, Table 8. US Census Bureau. Projections of the Total Resident Population by 5 Year Age Groups, Race, Hispanic Origin with Special Age Categories Middle Series, 2050 to 2070 (NP-T-4-G), found at www.census.gov.

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