Latinos & Alzheimer's Disease:
New Numbers Behind the Crisis

Projection of the costs for U.S. Latinos living with
Alzheimer's Disease through 2060
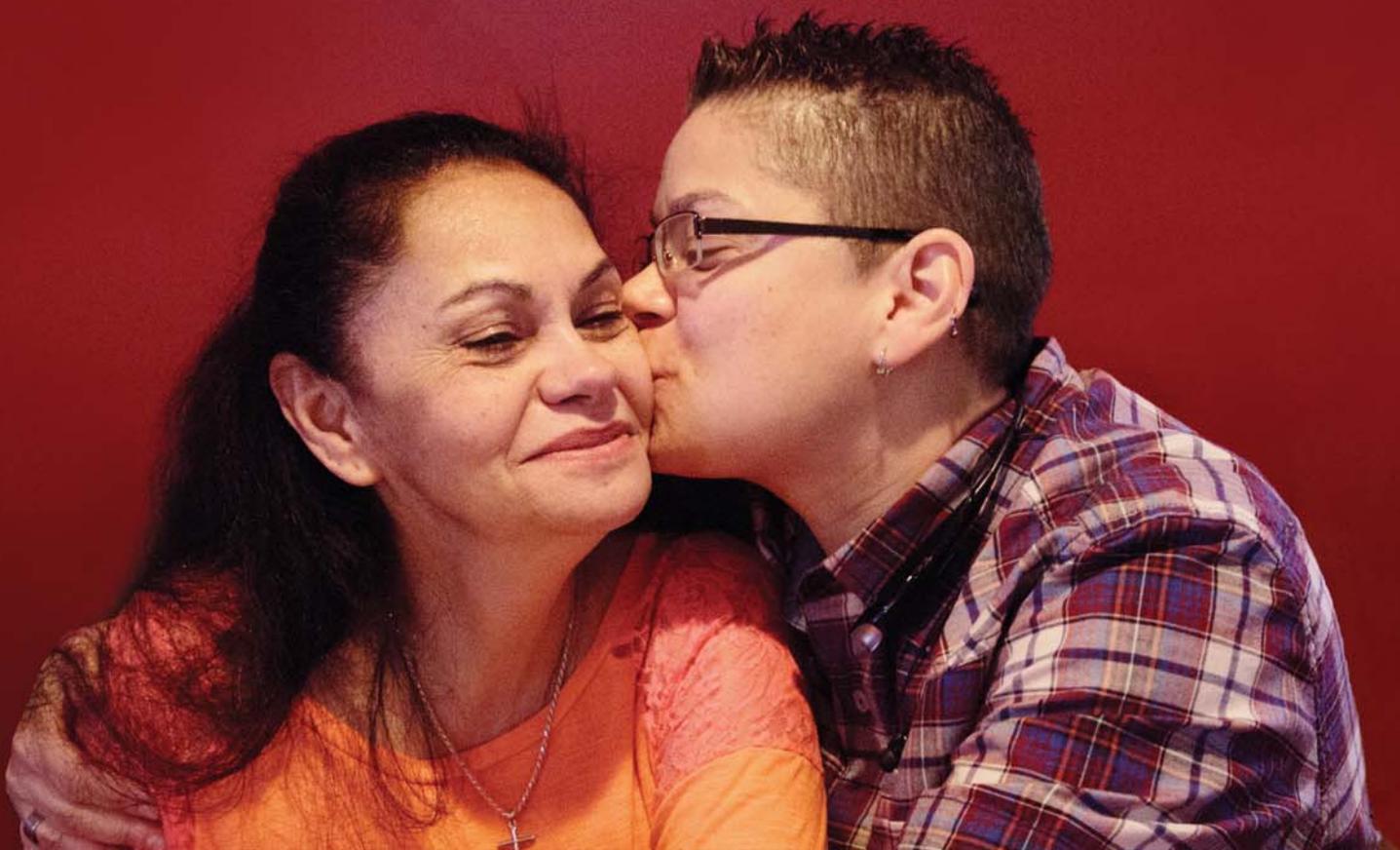
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Latinos4gainstAlzheimer's
A Network of *Us*AgainstAlzheimer's

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*Us*4gainstAlzheimer's
NETWORK

Acknowledgments

This project marks an important collaboration between the USC Edward R. Roybal Institute on Aging, the USC Suzanne Dworak-Peck School of Social Work, and UsAgainstAlzheimer's to increase the understanding of the growing impact of Alzheimer's disease on the Latino community and the nation.

The authors would like to thank Daisy Duarte, Carmen Pastor, Theresa Vasquez, Yvonne Latty, and Arturo Vargas for spending precious time away from their roles as caregivers to interview with the report authors and provide critical insights into their experiences caring for loved ones living with Alzheimer's. Their accounts were critical to grounding this work.

Additionally, we would like to thank George and Trish Vradenburg for their continued commitment to building an inclusive Alzheimer's disease movement through their investments in awareness, research, and advocacy focused on diverse communities.

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About the USC Edward R. Roybal Institute on Aging

The Edward R. Roybal Institute on Aging builds upon the USC Suzanne Dworak-Peck School of Social Work's longstanding tradition of conducting socially relevant research, innovating educational practices, influencing policy making, fostering community-university partnerships and sharing best practices with direct service providers.

The USC Roybal Institute maintains a strong interdisciplinary focus, with collaborations among faculty and professionals in such fields as social work, gerontology, psychology, preventive medicine, family medicine, psychiatry, oncology, American studies and ethnicity, and public policy.

The mission of the USC Roybal Institute is to advance research whose goal is to enhance optimal aging for persons in minority and low-income communities.

About LatinosAgainstAlzheimer's, a Network of UsAgainstAlzheimer's

The LatinosAgainstAlzheimer's Network and Coalition drives awareness and action to address the disproportionate impact of Alzheimer's and dementia on the Latino community through strategic convening, policy analysis, and advocacy—activating diverse health, community, and policy stakeholders in the race for an Alzheimer's disease cure by 2020. LatinosAgainstAlzheimer's is a network of UsAgainstAlzheimer's, a disruptive, entrepreneurial organization advancing solutions to the Alzheimer's challenge by 2020.

UsAgainstAlzheimer's (USA2) is an innovative non-profit organization demanding— and delivering—a solution to Alzheimer's. Driven by the suffering of millions of families, UsAgainstAlzheimer's presses for greater urgency from government, industry and the scientific community in the quest for an Alzheimer's cure—accomplishing this through effective leadership, collaborative advocacy, and strategic investments.

Congresswoman Lucille Roybal-Allard (D-CA-40th)

As the first Mexican-American woman elected to Congress, I have worked tirelessly to improve the health of Californians and all Americans. I have been inspired by the dedicated public service of my father, Congressman Edward R. Roybal. He was one of the first members of Congress to make health issues related to aging a priority. I share his commitment to these critical issues, particularly through my support of families impacted by Alzheimer's and dementia.

Over the course of three decades, my father Edward R. Roybal worked to improve the lives of underserved and vulnerable Americans. In fact, he championed the first federal funding for Alzheimer's Disease and was instrumental in renewing legislation to provide medical services to people living with the disease. Today his legacy lives on in the important work of the USC Edward R. Roybal Institute on Aging, a thought leader on Latino aging issues and policies, and the work that I do to support individuals and families impacted by Alzheimer's. I have called for increased funding of the National Institutes of Health for Alzheimer's research and have raised awareness of the challenges faced by my aging constituents through my role on The Bipartisan Congressional Task Force on Alzheimer's Disease.

Latinos & Alzheimer's: New Numbers Behind the Crisis provides critical information on the economic impact of Alzheimer's on Latinos. While the emotional toll Alzheimer's has on families is incalculable, the financial impact is staggering and now well documented through this first of its kind report. Research has demonstrated that Latinos are disproportionately impacted by Alzheimer's yet are less likely than non-Latino whites to take preventative health measures or regularly see a primary care physician. It is critical to address these disparities through increased research funding, culturally tailored awareness and educational efforts, and community engagement. This report is an important resource to help policymakers, public health officials, and community leaders better understand Alzheimer's impact on society and will be vital for developing policies to help ease the financial hardship of the disease on Latino families.

As our multicultural society grows and ages over the coming decades, we must make Alzheimer's a public health priority for Latinos and beyond. We cannot afford to ignore this emerging crisis.

Lucille Roybal-Allard

Congresswoman Lucille Roybal-Allard

Congresswoman Linda T. Sánchez
(D-CA-38th)

I want to thank the USC Edward R. Roybal Institute on Aging and UsAgainstAlzheimer's for their work on measuring the impact of Alzheimer's disease in the Latino community. Research has shown that Latinos are at greater risk of developing Alzheimer's than any other racial group. This debilitating disease is further exacerbated in our community where certain cultural stigmas erect barriers to care and health literacy. The release of *Latinos & Alzheimer's Disease: New Numbers Behind the Crisis* sheds new light on the unique challenges faced by Latinos including our community's underutilization of formal caregiving and underrepresentation in clinical research and trials.

Alzheimer's disease is an urgent health issue for our country, and the release of this report is timely for our community, but especially so for my family. As the daughter of a mother and a father living with Alzheimer's, I am acutely aware of the pain and hardship that Alzheimer's disease inflicts on families all across this country. This year, the costs of caring for those with Alzheimer's is projected to be $236 billion, including $160 billion in costs to Medicare and Medicaid. Unfortunately, this situation is only going to get worse. The number of Americans living with Alzheimer's is projected to grow to sixteen million and the costs of caring for these people will grow to over $1 trillion by 2050.

These numbers are daunting for all Americans but even more so for Latino families. That's why I have worked relentlessly in Congress to increase awareness of Alzheimer's and dementia's unique impact on Latino families by calling for culturally tailored awareness programming and health promotion efforts targeting Latinos. I have also urged the National Institute on Aging and others to increase the participation of minorities in Alzheimer's and dementia research and clinical trials.

Latinos & Alzheimer's: New Numbers Behind the Crisis brings a new sense of urgency to so many people's efforts and to our national commitment of preventing or effectively treating Alzheimer's disease by 2025, a goal set by the National Alzheimer's Project Act (NAPA). The report provides critical insights into this growing crisis and better equips policymakers to develop the solutions that millions of families are desperately waiting for.

I sincerely hope that the release of this report will mark the starting point at which the Latino community started to fight back against Alzheimer's Disease. Thank you for all of your hard work and I want you to know that I will continue to fight for Alzheimer's research in Washington.

Congresswoman Linda T. Sánchez

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Executive Summary

This report examines the far-reaching impact of Alzheimer's disease (AD) on Latinos in the United States (U.S.). Latinos today represent the youngest racial or ethnic group in the U.S., with an average age of 27.[1] While this Latino millennial community is thriving now, it is also paving the way for a Latino age wave that our country's healthcare system and economy are inadequately prepared for. In fact, the Administration on Aging projects that between 2008 and 2030 the Latino population aged 65 years and older will increase by 224% compared to a 65% increase for the non-Latino white population in the same age category. There are approximately four million Latinos over the age of 65 living in the U.S. today, twice as many as in 2000. Latino families are highly under-resourced in terms of income, retirement benefits, and pension benefits. As the Latino population ages, a growing number of Latino communities, families, and systems of care will be confronted by the growing crisis of AD with the fewest resources to manage it.[2]

We project the number of Latinos living with AD could increase from 379,000 in 2012 to 3.5 million by 2060—a growth of 832%—if a medical breakthrough is not discovered that cures or slows the progression of the disease. As the number of Latino families touched by AD increases over the coming decades—as individuals or as caregivers—the economic impact of AD on the Latino community will reach a cumulative $2.35 trillion (in 2012 dollars) by 2060 according to our projections. This perfect storm poses significant challenges that should be examined through a health equity and economic justice lens and be addressed with the utmost urgency by policymakers, healthcare systems, and industry and community leaders.

FIGURE 1. PROJECTION OF TOTAL DIRECT & INDIRECT COSTS OF AD ON LATINOS (IN $ BILLIONS)
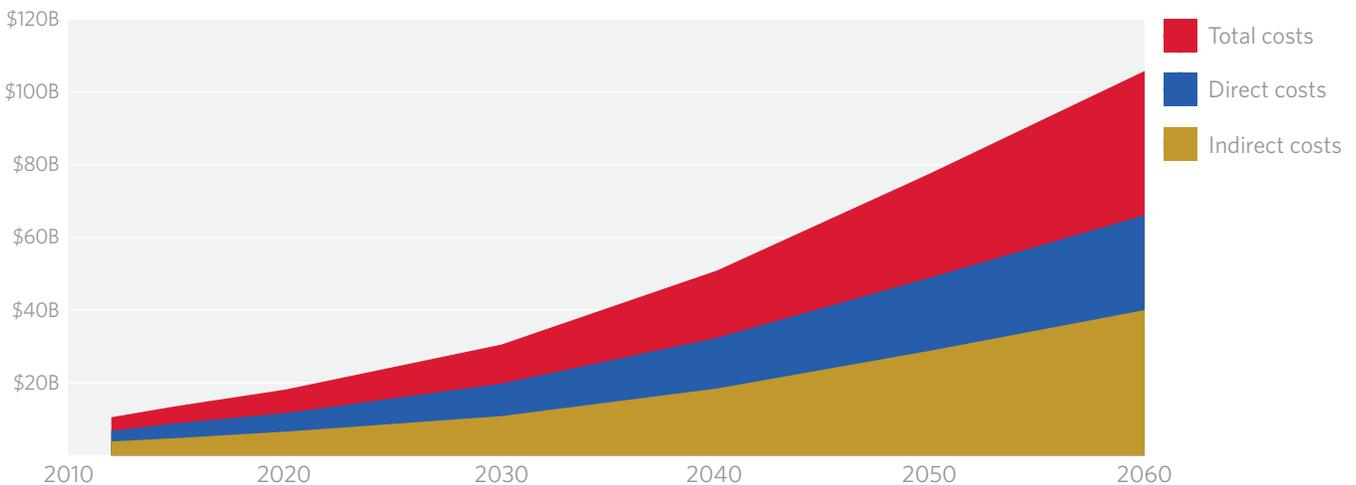
AD is an irreversible, progressive brain disease that slowly destroys memory and cognitive skills, and causes behavioral changes that eventually limit the ability for an individual to carry out even the simplest tasks. It is the most common cause of dementia in older people but is not a normal part of the aging process. Due to a range of socio-economic determinants, including advanced age, Latinos are at least 50% more likely than non-Latino whites to develop AD. Currently, AD is the eighth-leading cause of death among Latinos—a number likely underreported due to stigma, low levels of awareness, and misdiagnosis. Nationally, AD afflicts over five million American families, a number projected to grow to 15.8 million without a medical breakthrough to slow, prevent, or cure the disease.[3] This report uses data from

multiple sources, including the Medical Expenditure Panel Survey (MEPS) and the Centers for Disease Control and Prevention (CDC), to estimate the burden of AD for the Latino population through 2060.

FIGURE 2. PROJECTION OF LATINOS WITH AD THROUGH 2060, BY AGE (IN MILLIONS)
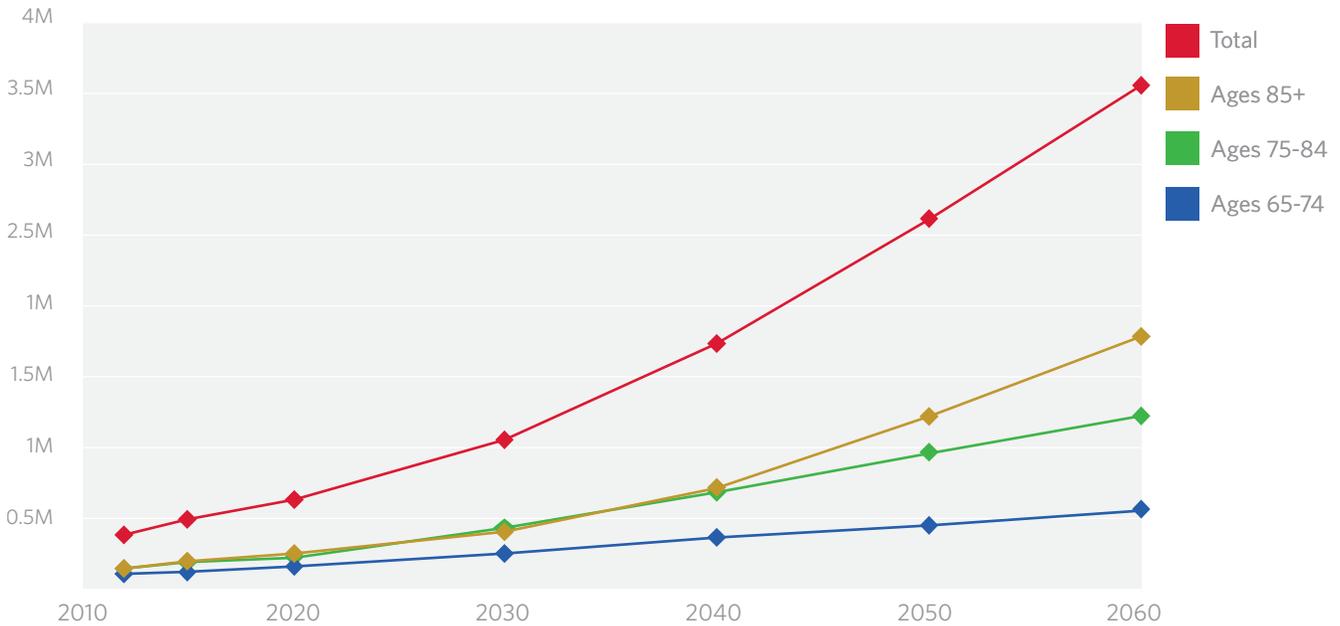
The primary objective of this report is to provide data on the increasing direct and indirect costs and prevalence of AD in the Latino community and to outline key public policy recommendations to address the challenges that AD poses to Latinos. As the U.S. grapples with the devastating growth of AD, we believe this information is critical to:

- Raising public awareness of AD as a health disparity with important ramifications for Latino population health. Quantifying—for the first time—the economic burden and hardship of AD on Latino families, caregivers, and communities.

- Better preparing policymakers, healthcare systems, and community leaders to adequately address this public health crisis.

- Encouraging culturally tailored solutions to the barriers and problems identified by the report by better understanding the scale of AD's impact on Latino communities.

Key Findings

- With the continuing growth and overall aging of the Latino population, this report projects a striking increase in the number of Latinos with AD through 2060. The number of Latinos with AD is expected to increase more than nine fold from 379,000 in 2012 to 1.1 million by 2030 and to 3.5 million by 2060—a growth of 832 percent.

- Total direct and indirect costs for Latinos with AD will reach approximately $105.5 billion by 2060 (in 2012 dollars)—costing the U.S. economy a total of $2.35 trillion (in 2012 dollars) through 2060.

- Direct costs for Latinos with AD, including expenditures for medical and long-term care, are estimated to be $7 billion in 2012 and projected to more than double in 2030 to $19.6 billion (in 2012 dollars). In 2060, these costs will increase more than nine times to $65.7 billion (in 2012 dollars).

- Indirect costs for Latinos with AD, including unpaid informal care and earnings lost by persons with AD, are projected to increase tenfold from $3.9 billion in 2012 to $39.8 billion (in 2012 dollars) in 2060.

- Latino families are less likely to use formal care services such as nursing home care and hospice care, and instead turn to more affordable long-term care services (such as adult day care) and unpaid informal care compared to non-Latino whites.

- Although Latinos with AD are more likely to choose the most affordable care alternatives and rely heavily on unpaid informal care, total costs for Latinos with AD will grow faster than non-Latino whites.

Based on these findings, this report proposes the following recommendations to ensure our nation adequately addresses disparities in AD.

- It is imperative to increase research funding for AD to the levels experts say is needed to develop an effective treatment ($2 billion annually). Further, we must invest in research that expands our understanding of the clinical and social determinants of AD in Latinos and other minority groups.

- Government, community, philanthropic, health, and industry partners should collaborate on the development and rollout of culturally tailored community engagement and education efforts to promote AD health literacy and early detection among individuals, families, and community stakeholders.

- With an estimated 1.8 million Latino family caregivers caring for someone with AD and other dementias, it is critical to improve access to AD caregiving resources and training for informal caregivers in multiple languages. These efforts should include national, regional, and state-based coordination.

- As the number of Latinos impacted by AD grows, it is critical improve the underrepresentation of Latinos in AD clinical research by increasing community awareness and collaboration among industry, academic research, and community based organizations and health institutions. Further, recruitment strategies and trial designs should better reflect the demographic heterogeneity, social needs and economic realities of Latino communities, from low levels of health literacy to issues around trust and transportation.

- Improve AD surveillance and monitoring with a focus on subgroup prevalence to adequately inform the development of scientific research, policy, and tailored health interventions.

- To address low diagnosis rates and improve treatment and care utilization of Latinos living with AD, we must improve the outreach, recruitment, and training of minority serving healthcare professionals, including primary care physicians, neurologists, nurses, and community based health navigators. At the same time, it is critical for Medicare to cover and pay for comprehensive AD diagnosis and care planning services for beneficiaries and their caregivers.

- To ensure continued collaboration and progress in addressing AD's impact on Latinos, stakeholders should establish goals and strategies for eliminating disparities in Alzheimer's diagnosis, care utilization, and research participation rates in federal and state based action plans that focus on AD, brain health, and health disparities.

Introduction

The U.S. Census Bureau projects that the Latino population will double from approximately 49 million in 2009 to 106 million people by the year 2050. In fact, by 2044, more than half of all Americans are projected to belong to a minority group.[4] The growth of the Latino community will have tremendous implications for our nation's health, education, and workforce sectors. It is essential that our nation's policymakers and community leaders better understand these consequences to adequately address the public health needs of an increasingly multicultural society.

The Nation's Growing AD Crisis

One trend that deserves immediate and sustained attention is the impact of a rapidly aging society on disparities in brain health, particularly among Latinos, the nation's largest minority group. According to the Administration on Aging, between 2008 and 2030 the Latino population aged 65 years and older will increase by 224% compared to a 65% increase for non-Latino whites.[5] This age shift will have serious consequences for the nation's healthcare system, including the impact of a significant rise in the number of Latino older adults living with AD and the number of Americans caring for them.

> **❝** *There had been situations when we walked into the house and the gas has been on for some time and her not realizing because, over time, she's also lost her sense of smell... It was points like that where we realized, okay, she needs 24/7 care.*
>
> Arturo Vargas, caregiver for his mother with dementia

AD is the most common form of dementia. Like other dementias, it is characterized by a profound deterioration in memory, language and communication abilities, problem-solving capabilities and other aspects of cognition that affect a person's ability to perform everyday activities. However, AD is a specific form of dementia with specific brain abnormalities and is incurable at this time, while some forms of dementia can be treated.[6] AD is the sixth-leading cause of death in the U.S. and the fifth-leading cause of death for those age 65 or older, however, new research suggests that Alzheimer's may be the third leading cause of death among older adults.[7] The leading risk factor of AD is advanced age; current estimates are that the likelihood of developing AD doubles about every five years after age 65; after age 85, the risk reaches nearly 50%.[8] Positive changes in public health trends and new therapeutics may eventually reduce AD incidence and progression. Such advances, if they occur, will only benefit Latinos if accompanied by adequate intervention responses of U.S. health care systems to Latino communities.

AD can place a tremendous financial and emotional burden on individuals living with the disease and their families and friends.[9] The economic burden of AD, including direct care costs and the costs of unpaid informal care, was estimated to be between $157 billion and $215 billion in 2010 by RAND Corporation.[10] With the rapid aging of the U.S. population, costs of AD are predicted to reach $1 trillion by 2050.[11]

From Diagnosis to Public Policy: Unaddressed Disparities in AD

Despite the growing impact of the disease on the Latino community, AD remains an unaddressed health disparity.[12] Growing evidence suggests that AD disproportionately impacts racial/ethnic minority groups such as Latinos, African-Americans, and Native Americans, in part due to higher rates of risk factors such as obesity, metabolic syndrome, diabetes, and cardiovascular risk.[13] In fact, the prevalence of AD in Latinos is at least 50% greater than among non-Latino whites. These health risks and limited access to prevention services and medical care are associated with lower levels of educational attainment among Latinos.[14, 15] As a result Latinos are more likely to delay treatment and receive inadequate health care treatment for AD, exacerbated by difficulty communicating with providers and lower rates of health insurance coverage.[16, 17]

The lack of knowledge of AD is particularly problematic for older Latino adults, given the disproportionate impact of dementia on this population.[18] A 2013 study conducted by the National Hispanic Council on Aging (NHCOA) found Latinos have several misconceptions when it comes to AD. Healthcare providers reported that Latino older adults knew little about AD. According to the study, "older adults stated that some people get Alzheimer's disease because they think too much, are stressed, or have personality issues."[19] Further, missed diagnoses of AD are more common among older Latinos than among older non-Latino whites, resulting in families struggling with symptoms of AD in the shadows without access to proper medical treatment.[20] Latinos with AD often experience a longer delay between recognizing signs and symptoms and receiving a diagnosis.[21] This a disturbing trend as research suggests that symptoms of AD appear almost seven years earlier in Latinos than in non-Latino whites.[22]

Although the U.S. has made a broader push towards prevention of chronic disease through the National Prevention Strategy and the Affordable Care Act, the National Hispanic Council on Aging has reported that Spanish-language materials have not reached older Latinos because they are largely internet-based and many individuals in this population cannot or do not know how to access the Internet.[23] Further, the National Prevention Strategy fails to mention AD, dementia, or brain health as part of its section on eliminating health disparities and omits mention of these growing health issues overall as part of the strategy.[24] The National Plan to Address Alzheimer's Disease—which sets a national goal of curing AD by 2025—highlights the need to address disparities in AD and dementia but offers no strategy or goal for addressing these disparities.[25] Finally, the U.S. Department of Health and Human Services' national plan to reduce racial and ethnic health disparities fails to include AD among the targeted diseases it aims to address.[26]

The Economic Outlook for Latino Older Adults

The economic challenges affecting many Latino older adults and their family members create a difficult environment for addressing health issues like AD. Latino older adults largely live month-to-month on low fixed incomes, which makes them particularly vulnerable to unexpected health incidents that could be economically destabilizing like AD.[27] They are also more likely to experience poverty compared to other U.S. older adult populations.[28] According to a study by the RAND Corporation, families can expect to spend between $41,000 and $56,000 annually in dementia-related costs.[29] This does not bode well for low-income Latino families on the brink of financial hardship. With the median household income totaling $38,000 for Mexican families and $36,000 for Puerto Rican families—the two largest Latino

subgroups—Latino communities are largely unprepared for the financial hardship of AD.[30] The Institute on Assets and Social Policy finds that, "95% of African-American and 87% of Latino middle-class families do not have enough net assets to meet three-quarters of their essential living expenses for even three months if their source of income were to disappear."[31]

> **"** *We all basically went broke! I asked each family member to contribute some money monthly. I even asked her grandchildren which some willingly donated even to the smallest amount of $10.00 per month. Those who could not donate money, they donated groceries, ran errands, provided respite care by mama-sitting.*
>
> Theresa Vasquez, RN, caregiver for her mother with Alzheimer's disease

Latinos are further challenged by a severe retirement insecurity, stemming from lack of retirement savings, lack of affordable housing in major cities in the U.S., and lack of access to support programs that alleviate economic instability, such as SNAP.[32] Without Social Security benefits, more than half of all Latino older adults would live below the poverty level.[33] According to a recent study of Latino older adults conducted by the National Hispanic Council on Aging, 88% of individuals surveyed relied on Medicare, Medicaid, or both as their sole health insurance if they had any at all. The report pointed out that registering for these and other social service programs is becoming increasingly challenging for Latino older adults as registration moves from a paper-based to a computer-based system.[34] Moreover, many Latino older adults struggle to meet their daily needs and approximately 30% experience food insecurity.[35] In fact, 23.7% of Latino households experienced food insecurity in 2013, almost double the national average.[36] AD represents the financial "perfect storm" for Latino families already facing financial uncertainty.

> **"** *I'm still driving a 1997 Ford Explorer, I wish I could buy a new car, but that's not going to happen. There's sacrifices but, first and foremost, it's making sure that my mother has care… One of the things that I just did is I re-financed my house.*
>
> Arturo Vargas, caregiver for his mother with dementia

A Family Affair: The Caregiving Hardship

The many challenges of caring for someone with AD are well known, including high levels of caregiver emotional distress, bouts of serious depression, and a decline in physical health and financial impairment driven by the costs of care and lost wages.[37]

> 66 *My sister had my mom for a week and she couldn't handle it. She left her at my house and she's been with me ever since. My mom is always with me. It's basically like having a child.*
>
> Daisy Duarte, caregiver for her mother with Alzheimer's disease

According to the National Alliance for Caregiving, there are at least 8 million Latino family caregivers across the country and approximately 1.8 million are providing care for a loved one—oftentimes a parent—with AD. Further, Latino family caregivers tend to be in more intensive caregiving situations with 63% in high burden situations compared to 51% of non-Latino caregivers.[38] The typical Latino family caregiver is a 43 year-old female caring for an adult aged 62 or older, often a female.[39] Women are at the forefront of the AD crisis in the Latino community with a growing number of men in the caregiver role.

These informal caregivers provide the majority of care for individuals with AD; many studies have found these individuals to be burdened, anxious, and in need of social support.[40] Latino caregivers are often faced with multi-generation caregiving situations; more than half of Latino caregivers have a child under 18 living at home, juggling approximately 30 hours a week of caring for the individual with AD while having work and other family obligations.[41]

> 66 *Caring for a loved one with dementia or Alzheimer's disease changes your life forever… your priorities are now determined by what is needed by your loved one; your needs and wants are now secondary.*
>
> Carmen Pastor, caregiver for her mother with Alzheimer's disease

Compared with other groups, Latinos have been found to underutilize formal AD caregiving options, which can be financially prohibitive and inaccessible, relying instead on family support.[42] As the Latino older adult population skyrockets, it is essential that policymakers and health systems collaborate to improve the development and deployment of culturally tailored caregiving training, resources, and programming for Latino families living with AD.

The Urgent Need for Diverse Medical, Research, and Care Professionals to Address AD

A shortage of Latino and minority medical professionals in the U.S. represents another barrier to meeting the needs of the nation's growing Latino older adult population. In 2013, approximately 4.5% of all practicing physicians were Latinos yet Latinos represent 17% of the U.S. population.[i] According to the Association of American Medical Colleges, non-white physicians are more likely to provide primary care than specialization, which proves challenging when managing patients with complicated chronic illnesses such as AD.[43] In addition, Latinos account for only 3.5% of principal investigators supported by National Institutes of Health funding, limiting this critical perspective in health research.[44] Although approximately 20,000 geriatricians are needed to meet the needs of 14 million older Americans, as of 2014, only 7,423 certified geriatricians practiced nationwide, representing a significant shortfall of clinicians.[45] The lack of diverse clinicians and specialists focused on the care for older adults and minority communities represents a barrier to accessing an accurate and timely AD diagnosis.

> ❝ *We'd been sitting in a waiting room in the Bronx for an hour, in a room filled with people who were struggling, who barely spoke English, who needed help, only to have a smug doctor tell me to Google my mother's serious condition and devise a plan for her. He even wrote out a few URLs to get me started.*
>
> Yvonne Latty, caregiver for her mother with Alzheimer's

Further, bilingual and culturally diverse healthcare professionals and researchers are critical to addressing the severe underrepresentation of Latinos enrolled in clinical research for diseases like AD. In fact, Latinos make up approximately 1% of clinical research participants despite making up 17% of the general population.[46] Research has demonstrated that minority participants are more likely to participate in clinical research if they are recruited by research staff they can identify with.[47] Additionally, minority researchers and physicians are more likely to focus their research in minority populations and are "often best suited to gain trust of minority communities."[48]

New Numbers Behind the Crisis

This report projects a tremendous growth in the prevalence and costs for Latinos in the U.S. with AD through 2060. With the Latino older adult population continuing to rise at a rapid pace, the economic impact of AD will be an increasing concern for families and society. Policymakers, health professionals, community leaders and researchers must collaborate to address this major health disparity issue before it destabilizes a community critical to the future health and wellbeing of the nation.

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[i] This statistic reflects all practicing MDs in the U.S., DO figures were not included.

Methods

We estimated the prevalence of AD in age-specific subgroups of older Latinos based on results from studies that used a standardized method of evaluation to identify AD cases. We focused on the AD prevalence among people 65 years or older because age is the greatest risk factor for AD.[ii, 49] Diabetes is another major risk factor for AD.[50] From 1997 to 2010, the incidence of diabetes in the Latino community in the U.S. rose 60%.[51] This trend is projected to continue in the future.[52, 53] We expect that the diabetes crisis among Latinos in the U.S., as described by the Institute for Alternative Futures, to contribute to the rise of AD among Latinos.[iii, 54]

We used the cost of illness (COI) approach to estimate the costs for Latinos with AD.[55] The COI includes direct and indirect costs. We estimated the direct costs as the sum of medical care costs and long-term care costs. Patients may live with AD for many years, and routine medical care visits and long-term care services are often required. Indirect costs include unpaid informal care and patient's earnings lost due to AD. People with AD have difficulty performing everyday activities (e.g. dressing, bathing, eating, managing memory, communicating) and require increasing levels of care over time. Earnings lost due to AD are predicted to be a minor proportion of the total costs because most people with AD are older adults that are out of the labor market.

Published studies and data from the Medical Expenditure Panel Survey (MEPS), the Centers for Disease Control and Prevention (CDC) report on *Long-Term Care Services in the United States: 2013 Overview* (18), and the CDC's National Vital Statistics were used to estimate the prevalence of AD and costs.[56] We used the U.S. Census Bureau's population projection in combination with the estimated prevalence and costs to project the economic impact of AD for Latinos. We also used a similar method to project costs for non-Latino whites and African-Americans with AD and provide a comparison to Latinos. A more detailed description of the methods is provided in the appendix.

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ii We recognize that early onset of AD is an important subtype. Unfortunately, there are few studies that offer reliable data on early onset AD for Latinos, which could be an area for future research. This subtype was not included in our model.

iii The growth trend of Latinos with diabetes is projected to continue through 2050. We assumed the prevalence of AD for Latinos with or without diabetes would not change over time. We projected the prevalence of AD in Latinos through 2060 based on the forecast for diabetes in Latinos and our estimate of the prevalence of AD in Latinos with or without diabetes.

Findings

Prevalence of AD in Latinos

The Latino population in the U.S. is projected to increase to over 106 million by 2050, a trend that will precipitate a significant increase in the number of Latinos older adults living in the United States. In 2012, Latinos age 65 or older constituted 5.6% of all Latinos; this percentage will rise to 18.1% in 2060 (See Table 1).[57] The number of Latinos age 65 or older will increase more than sevenfold from 3 million in 2012 to 21.5 million in 2060.

TABLE 1. PROJECTION OF LATINO POPULATION THROUGH 2060 (IN MILLIONS, ESTIMATED BY THE U.S. CENSUS BUREAU)

Year	Ages 65-74	Ages 75-84	Ages 85+	Total: Ages 65+	Total: All Latinos	Percentage Ages 65+
2012	1.8	0.9	0.3	3.0	53.1	5.6%
2015	2.3	1.1	0.4	3.8	56.8	6.7
2020	3.1	1.4	0.5	5.0	63.6	7.9
2030	5.1	2.5	0.8	8.4	77.5	10.8
2040	6.9	4.1	1.5	12.5	91.6	13.6
2050	8.7	5.6	2.5	16.8	105.6	15.9
2060	10.7	7.2	3.6	21.5	119.0	18.1

There are currently no existing studies that use a nationally representative sample and a standardized method of evaluation to identify people with AD, which makes it difficult to estimate the prevalence of AD among Latinos. However, we identified two regional studies conducted in California and New York. Both of the studies were conducted prior to 2000. Results from the two studies were pooled and adjusted to obtain an estimate of the prevalence of AD among Latinos in 2000:

| Age 65-74	Age 75-84	Age 85 or older
4.7%	15.2%	44.4%
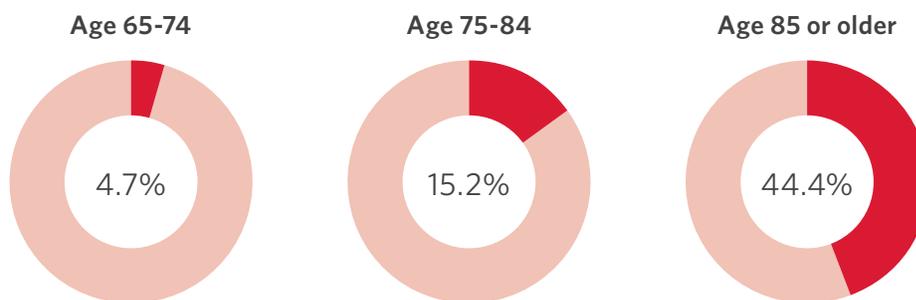
The prevalence of diabetes in Latinos has increased since 2000 and is projected to keep increasing in the coming decades.[58, 59] The presence of diabetes increases the risk of AD by 54%.[60] Given the growing number of Latinos with diabetes and the overall aging of the Latino population, we project the prevalence of AD will rise among Latinos (See Table 2).

TABLE 2. PROJECTION OF NUMBER OF LATINOS WITH AD THROUGH 2060

Year	Ages 65-74		Ages 75-84		Ages 85+		Subtotal (Thousands)
	Subtotal (Thousands)	Prevalence	Subtotal (Thousands)	Prevalence	Subtotal (Thousands)	Prevalence	
2012	91	4.9%	143	16.2%	145	46.8%	379
2015	112	5.0	175	16.3	193	46.8	481
2020	154	5.0	226	16.3	249	47.0	628
2030	257	5.1	416	16.5	393	47.5	1,066
2040	352	5.1	688	16.8	706	48.2	1,745
2050	447	5.2	957	17.0	1,220	49.0	2,624
2060	553	5.2	1223	17.0	1,777	49.0	3,553

The number of Latinos with AD is projected to more than double by 2030 (Table 2 and Figure 1)—increasing more than nine fold from 379,000 in 2012 to more than 3.5 million in 2060. The most dramatic growth will be among Latinos age 85 or older, which will increase by more than 12 times from 145,000 in 2012 to more than 1.7 million in 2060.

FIGURE 2. PROJECTION OF LATINOS WITH AD THROUGH 2060, BY AGE (IN MILLIONS)
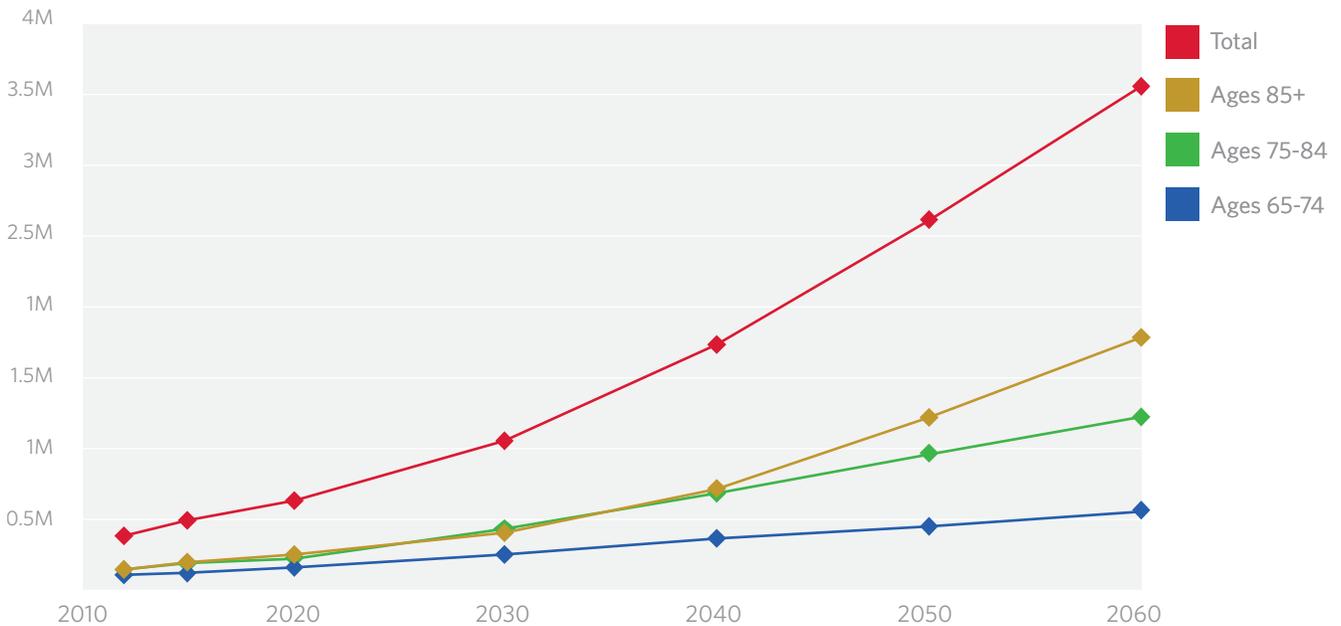
Direct Costs

Direct costs are estimated as the sum of medical care costs and long-term costs. Medical care costs include expenditures for office- and hospital-based care, home health care, dental care services, vision aids, and prescription medications. After adjusting for demographics, socioeconomic status, location, and comorbid conditions of AD, the medical care costs (in 2012 dollars) for Latinos with AD are estimated on average to be $7,496 per year for Latinos age 65 or older, specifically:

	Age 65-74	**Age 75-84**	**Age 85 or older**
	$7,046 PER YEAR	**$8,133** PER YEAR	**$7,813** PER YEAR

We also estimated the medical care costs (in 2012 dollars) for Latinos age 65 or over with AD by gender:

|	**Female**	**Male**
	$7,943 PER YEAR	**$6,978** PER YEAR

Long-term care costs include expenditures for nursing home care, adult day care, residential care facility, and hospice care. Table 3 shows the estimated percentage of Latinos with AD using various types of long-term care and the respective daily costs.

TABLE 3. LONG-TERM CARE COSTS FOR LATINOS WITH AD

Long-term Care Type	Usage		Average Daily Cost
	Percentage	Average Total Days Spent in Care per Year	
Nursing home care	13.5%	264 days	$220
Adult day care	4.6	143	65
Residential care facility	2.7	250	120
Hospice care	10.0	72	200

We projected the direct costs for all Latinos with AD through 2060 (Figure 2 and Table 4) with the assumption that these annual costs per person do not change over time for the stability of the estimate, and these costs are presented in 2012 dollars. The largest expenditures are medical and nursing home care costs. The total direct costs are estimated to be $7.0 billion in 2012, and projected to more than double in 2030 ($19.6 billion, in 2012 dollars). In 2060, the costs will increase more than nine fold to $65.7 billion (in 2012 dollars).

FIGURE 3. PROJECTION OF THE DIRECT COSTS FOR LATINOS WITH AD THROUGH 2060 (IN $ BILLIONS, IN 2012 DOLLARS)
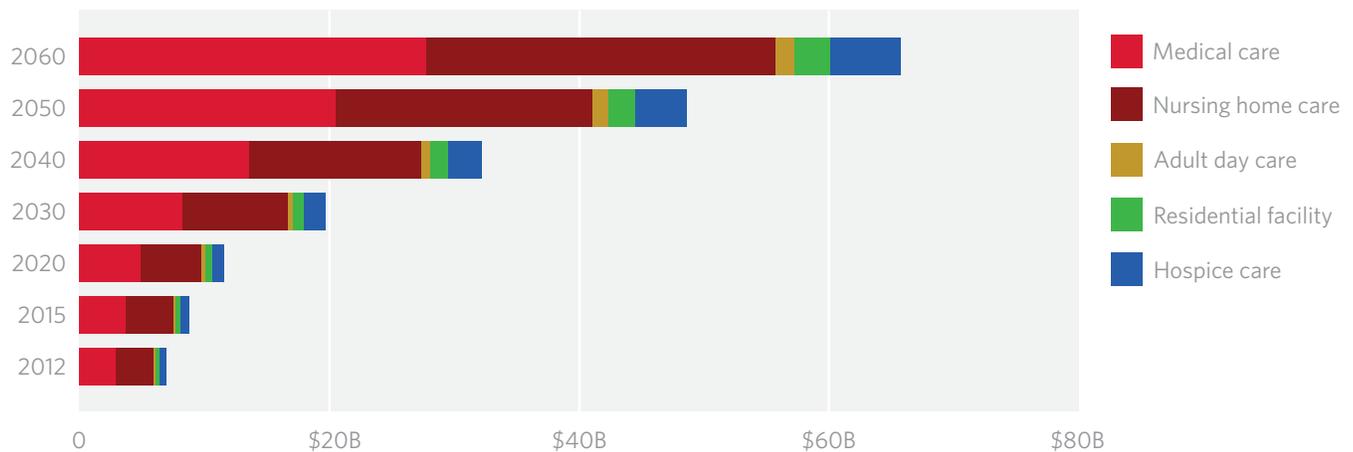
TABLE 4. PROJECTION OF THE DIRECT COSTS FOR LATINOS WITH AD (IN $ MILLIONS, IN 2012 DOLLARS)

Year	Medical Care	Nursing Home	Adult Day Care	Residential Care Facility	Hospice Care	Total Direct Costs
2012	$2,938	2,978	162	307	604	6,989
2015	3,725	3,744	206	389	765	8,859
2020	4,864	4,935	269	509	1,000	11,578
2030	8,261	8,367	456	863	1,696	19,643
2040	13,586	13,706	746	1,414	2,778	32,230
2050	20,466	20,608	1,222	2,126	4,178	48,499
2060	27,727	27,903	1,519	2,878	5,656	65,684

We used the projections of inflation rate in the U.S. through 2060 from the Organization for Economic Co-operation and Development (OECD) to project the costs adjusted for inflation (Table 5) (20). In 2060, the total direct costs will be $169.1 billion after adjusting for inflation, which is twenty-four times greater than the costs in 2012.

TABLES 5. PROJECTION OF THE DIRECT COSTS FOR LATINOS WITH AD (IN $ MILLIONS, ADJUSTED FOR INFLATION)

Year	Medical Care	Nursing Home	Adult Day Care	Residential Care Facility	Hospice Care	Total Direct Costs
2012	$2,938	2,978	162	307	604	6,989
2015	3,900	3,951	215	408	801	9,274
2020	5,600	5,682	309	586	1,152	13,328
2030	11,632	11,782	642	1,215	2,389	27,660
2040	23,401	23,607	1,285	2,435	4,786	55,515
2050	43,097	43,397	2,363	4,476	8,798	102,131
2060	71,386	71,837	3,911	7,410	14,563	169,107

Indirect Costs

The indirect costs include unpaid informal care and patient's earnings lost due to AD. Based on the MEPS we estimated the unpaid informal care days provided by people (typically family members or friends) not living with an AD patient to be 8.5 days per year for Latinos age 65 or older, specifically:

Age 65-74	**Age 75-84**	**Age 85 or older**
4.5	11.6	18.2
DAYS PER YEAR	DAYS PER YEAR	DAYS PER YEAR

We assumed that the unpaid informal care days provided by people not living with an AD patient constitute 15% of total informal care received by Latinos with AD. The assumed value of the care is $114 per day (i.e., average costs for a six-hour visit by a home health aide). The total costs of unpaid informal care are estimated to be $3.6 billion in 2012 and will increase more than tenfold to $37.3 billion in 2060 (in 2012 dollars) as shown in Figure 3 and Table 6.

We estimated the patient's earnings lost due to AD in Latinos to be $624 per year for Latinos age 65 or older, specifically:

Age 65-74	**Age 75-84**	**Age 85 or older**
$715	$604	$534
PER YEAR	PER YEAR	PER YEAR

Latino patients' earnings lost due to AD are projected to increase over 10 times from $272 million in 2012 to $2.7 billion in 2060 (in 2012 dollars, Figure 3 and Table 6).

We also projected the indirect costs adjusted for inflation as shown in Table 6. In 2060 the inflation adjusted costs of unpaid informal care are estimated to be $95.9 billion, and the patient's earnings lost due to AD are projected to be $6.5 billion.

## FIGURE 4. PROJECTION OF THE INDIRECT COSTS FOR LATINOS WITH AD (IN $ BILLIONS, IN 2012 DOLLARS)

Legend: Unpaid informal care, Earnings lost
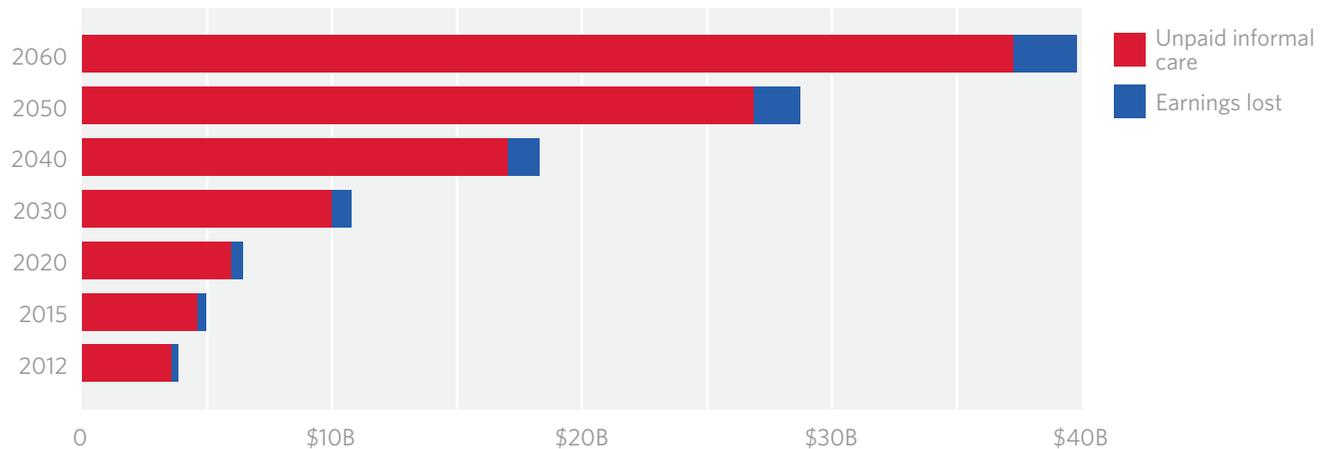
TABLE 6. PROJECTION OF THE INDIRECT COSTS FOR LATINOS WITH AD (IN $ MILLIONS, IN 2012 DOLLARS AND ADJUSTED FOR INFLATION)

Year	Unpaid Informal Care		Patient's Earnings Lost due to AD		Total Indirect Costs	
	2012 Dollars	Adjusted for Inflation	2012 Dollars	Adjusted for Inflation	2012 Dollars	Adjusted for Inflation
2012	$3,580	3,580	271	271	3,851	3,851
2015	4,601	4,817	344	360	4,945	5,177
2020	5,960	6,862	449	517	6,410	7,379
2030	9,981	14,055	762	1,073	10,743	15,128
2040	17,029	29,332	1,248	2,149	18,277	31,481
2050	26,839	56,519	1,876	3,951	28,715	60,470
2060	37,257	95,922	2,541	6,541	39,798	102,463

Comparison with Other Racial/Ethnic Groups

We compared our projections for the growth of Latinos with AD to non-Latino whites and African-Americans. The U.S. Census Bureau projects that the number of older adults who are Latino, African-American, and non-Latino white will grow dramatically in the future (Figure 4). In 2012, the population of non-Latino whites age 65 or older was estimated to be 34.2 million and projected to grow to peak levels in 2036 (54.8 million), reflecting the aging of the baby boomer population. The Latino and African-American age 65 or older populations will grow rapidly through 2060, with Latinos outpacing African-Americans and non-Latino whites. Although the Latino age 65 or older population was smaller than the African-American population in 2012 (3 million Latinos; 3.7 million African-Americans), it is projected that by 2015 Latino older adults will exceed African-American older adults (6.6 million Latinos 6.5 million African-Americans). Data indicates that by 2060, there will be 21.5 million Latinos, 53.6 million non-Latino whites, and 12 million African-Americans who are age 65 or older.

FIGURE 5. PROJECTION OF THE PEOPLE AGE 65 OR OLDER IN THE UNITED STATES THROUGH 2060, BY RACE/ETHNICITY (IN MILLIONS)

We compared our projections for the growth of Latinos with AD to non-Latino whites and African-Americans. The U.S. Census Bureau projects that the number of older adults who are Latino, African-American, and non-Latino white will grow dramatically in the future (Figure 4). In 2012, the population of non-Latino whites age 65 or older was estimated to be 34.2 million and projected to grow to peak levels in 2036 (54.8 million), reflecting the aging of the baby boomer population. The Latino and African-American age 65 or older populations will grow rapidly through 2060, with Latinos outpacing African-Americans and non-Latino whites. Although the Latino age 65 or older population was smaller than the African-American population in 2012 (3 million Latinos; 3.7 million African-Americans), it is projected that by 2015 Latino older adults will exceed African-American older adults (6.6 million Latinos 6.5 million African-Americans). Data indicates that by 2060, there will be 21.5 million Latinos, 53.6 million non-Latino whites, and 12 million African-Americans who are age 65 or older.

Findings from the Aging, Demographics, and Memory Study (ADAMS) show that the prevalence of AD is 21.3% in African-Americans age 71 or older and 11.2% in non-Latino whites age 71 or older.[61] As the risk of AD rises with age, we assume the prevalence for people age 65 or older is slightly lower than that for people age 71 or older: 21% in African-Americans age 65 or older and 11% in non-Latino whites age 65 or older.[62] An important caveat is recent reports that White non-Latino prevalence rates in older population segments are declining, but no similar decreases are reported for African-Americans or Latinos, a difference likely based in different patterns of chronic disease and education.[63] If this trend persists it would result in an even greater divergence in AD rates over time.

We increased the estimate of the prevalence of AD to adjust for the increasing prevalence of diabetes in the U.S. The growth rate of diabetes in Latinos and African-American older adults is projected to be higher than non-Latino white older adults through 2050. [64, 65] We assumed the prevalence of AD will increase 0.2% every five years for African-Americans and 0.1% every five years for non-Latino whites through 2050. We also assumed the prevalence will not change from 2050 to 2060. With the aging of baby boomers, the number of non-Latino whites with AD is projected to increase 1.7 times from 3.8 million in 2012 to a peak of 6.3 million in 2036. The number of Latinos with AD is estimated to be 380,000 in 2012, which is about half the total of African-Americans (770,000). However, the number of Latinos with AD will grow faster than the number of African-Americans with AD, primarily due to the dramatic growth of Latino older adults. In 2060, there will be 3.6 million Latinos with AD, 6.3 million non-Latino whites with AD, and 2.7 million African-Americans with AD.

FIGURE 6. PROJECTION OF AD CASES IN THE UNITED STATES THROUGH 2060, BY RACE/ETHNICITY (IN MILLIONS)

Legend:
- Latinos
- Non-Latino Whites
- African-Americans

X-axis: 2012, 2016, 2020, 2024, 2028, 2032, 2036, 2040, 2044, 2048, 2052, 2056, 2060

Y-axis: 1M, 2M, 3M, 4M, 5M, 6M, 7M
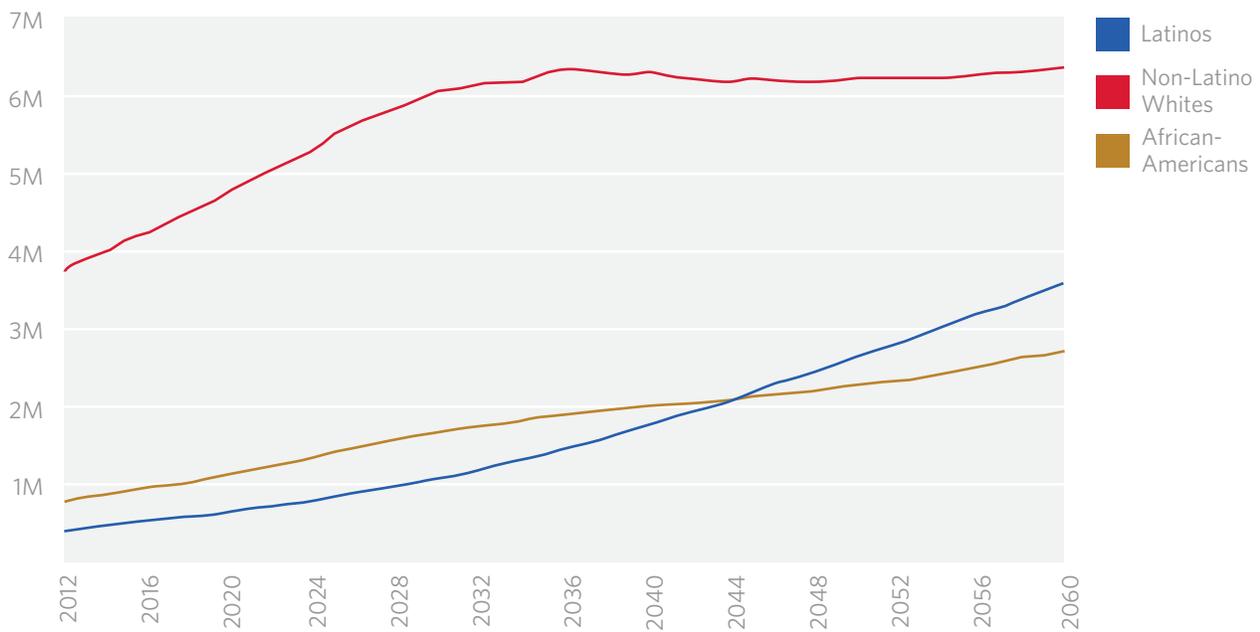
Conclusion and Recommendations

Adequately Addressing the Dramatic Increase of AD in the Latino Community

For the first time, this report quantifies the economic hardship underpinning the AD crisis brewing in the Latino community. The growth of chronic diseases like diabetes among Latinos combined with the rapid growth of the Latino older adult population could lead to a dramatic growth of Latinos living with AD. This trend will increase the enlisted ranks of informal caregivers, adding tremendous cost—$2.35 trillion by 2060—and stress to the Latino community. The growing burden of AD costs and care risks further destabilizing Latino older adults who disproportionately live near poverty, depend almost entirely on social security benefits, and possess few assets. Immediate attention and action from policymakers, healthcare providers, community and philanthropic leaders, and researchers is necessary to equitably address AD's far-reaching impact on Latino public health.

Public Policy Recommendations

Develop Goals and Strategies for Eliminating AD Disparities in Federal and State-Based Action Plans

Policymakers, health care providers, and researchers should become more informed about the dramatic growth of Latinos with AD, and the burden of care falling on a population with disproportionately low median household income and longstanding health disparities. Population health approaches should address the multiple "upstream" determinants of AD, such as strongly promoting early life cognitive development and reducing trauma exposure, and addressing basic population gains in education, income, food access and diet, and exercise. Further, these realities should be reflected in federal and state based action plans that aim to address brain health and the elimination of health disparities. For example, the National Prevention Strategy, the HHS Action Plan to Reduce Racial and Ethnic Health Disparities, the CDC's Healthy Brain Initiative, and the National Plan to Address Alzheimer's Disease should all emphasize the unique challenges that AD poses to vulnerable Latino communities, and offer strategies and goals for overcoming these challenges.

Improve AD Surveillance and Monitoring with a Focus on Subgroup Prevalence

New research using a standardized evaluation protocol to identify the prevalence of AD cases based on a nationally representative sample is needed to obtain an accurate and valid measure of the prevalence of AD among U.S. Latinos. Only two such studies from regional samples were conducted more than 15 years ago. Model assumptions made in this report are based on extrapolations from smaller studies and should be considered provisional until reliable population prevalence estimates are available. A recent longitudinal medical record study of northern California members of Kaiser Permanente found disparities in risks of AD between different racial and ethnic groups.[66] Studies like this provide useful reference for incidence of AD with a selected clinical population. However, given the underutilization of healthcare and underdiagnoses of AD in Latino population, a representative, updated prevalence study of AD in community-dwelling populations that compares different racial ethnic populations is needed.

Costs in this report are likely being underestimated because our models do not account for changes in the demographic structure of U.S. population in terms of income and education over the next four decades, which could impact both formal and informal cost projections.

Large scale studies are needed internationally, nationally, and locally using consistent and comparable methods to fill the gap. Additionally, efforts are needed to address Latino population heterogeneity in establishing firm AD rate estimates due to the likelihood of variations in subgroup rates by ethnicity, nativity, socioeconomic status, or region, including differential exposure to risk factors such as metabolic syndrome and diabetes. These factors are critical to designing targeted interventions such as health literacy campaigns to increase public awareness.

Increase the Capacity and Pipeline of Diverse Healthcare Professionals Able to Detect, Treat, and Assist Latinos Living with AD

It is vital to develop strategies for improving the detection and diagnosis of AD among Latinos for health care professionals and providers, with a particular emphasis on engaging diverse primary care physicians serving minority populations. According to research, the physician-primary care setting is an important point of intervention for information and education regarding AD in the Latino community.[67] It is critical that we provide enhanced training and capacity to Latino serving physicians and health professionals to improve detection, diagnosis, and coordinated care planning and resources for Latinos with AD. Further, given the shortage of diverse specialists in geriatrics, neurology, and nursing, it is critical that we invest in improving the pipeline of diverse health professionals serving the nation's growing multicultural society. Additionally, the use of health promoters, or lay community health workers, should be expanded to raise awareness of AD in underserved populations and to bridge the gap between health institutions, available resources, and communities.

Increase Research Funding for AD to the Levels Experts Say is Needed to Develop Effective Treatments and Fund Research that Explores the Determinants of AD in Latinos and Other Minority Groups

AD disease alone is estimated to cost our nation collectively more than $225 billion annually, about 70% of which is borne by Medicare and Medicaid. If the current trajectory remains unchanged, the total cost of this disease likely will exceed $1 trillion annually by 2050. A study released in 2014 indicates that each year more than 500,000 deaths of persons over the age of 75 in the U.S. are attributable to AD, which would make it the nation's third leading cause of death.[68] Despite this, AD is the only leading cause of death that lacks any disease-modifying treatment or means of prevention. However, it is clear that significant federal research investments in HIV, stroke and heart disease has saved lives and reduced overall health care costs. It is imperative to increase public research funding for AD research to at least $2 billion annually, the amount leading dementia researchers have recommended be committed to maximize our chances of meeting the nation's goal of preventing and effectively treating dementia by 2025. Additionally, it is critical to invest in research that explores the determinants of AD in Latinos and other minority groups, including differences in subgroup prevalence and genetic risk factors, as well as strategies for large scale prevention-through-wellness and early AD detection programs.

Improve the Recruitment and Retention of Latinos in AD Clinical Research

While Latinos make up 17% of the U.S. population, they make up less than 1% of participants in all National Institutes of Health clinical trials.[69] Further, Latinos make up just 7.5% of research participants across the approximately 32 Alzheimer's Disease Research Centers (ADRCs) funded by NIH.[70] Latino volunteers are needed to help researchers understand and develop treatments and health interventions for AD that work for all ethnic groups. As the number of Latinos impacted by AD grows, it is critical to improve the severe underrepresentation of Latinos in AD clinical research by increasing community awareness and direct engagement among industry, academic research, and community based organizations and health institutions. Further, recruitment strategies and trial designs should better reflect the needs and realities of Latino communities, from low levels of health literacy to issues around trust and transportation.

Develop Culturally Tailored Engagement Efforts and Educational Resources to Promote AD Health Literacy, Early Detection, and Caregiver Training Among Individuals, Families, and Community Stakeholders

It is critical that government, community, advocacy, and philanthropic partners collaborate to launch culturally tailored AD disease and dementia awareness campaigns at the national and state levels to increase public understanding of AD among Latinos, promoting early detection, diagnosis, and available bilingual resources. Studies have shown that culturally tailored outreach strategies, including Spanish and English helplines, bilingual print and online advertising, diverse community presentations, and consumer-to-consumer referrals have been effective in increasing knowledge of AD and in facilitating linkages to available services among Latinos.[71]

The Center for Disease Control and Prevention's (CDC) Partnering and Communicating Together to Act Against AIDS (PACT) initiative is a model that could be adapted for AD public education. PACT members include leading Latino and African-American organizations that work with the CDC to achieve the goals outlined in the National HIV/AIDS Strategy (NHAS). According to the CDC, "PACT members leverage existing organizational structures, networks, and communication platforms to disseminate campaign materials using a variety of channels including publications, meetings, conferences, media and other mechanisms."[72]

It is also important to improve access to culturally tailored AD caregiving resources and training for informal caregivers. Our report shows that Latinos with AD today use fewer medical care services ($7,496 per person per year compared to non-Latino whites at $14,821 and African-American at $10,559). They are also less likely to use more expensive services such as nursing home care and hospice care, and are more likely to use more affordable long-term care services (such as adult day care) compared to non-Latino whites and African-Americans. In addition, Latinos with AD rely more on unpaid informal care than non-Latino whites. These findings suggest that significant barriers may exist for Latinos in accessing timely, quality care for their disease. A study released by the National Council of La Raza (NCLR) in 2014 found that Latinos reported poor chronic disease management and face many barriers to receiving adequate care, including affordability, immigration status, and language.[73] Policymakers and health systems should address these barriers to improve the delivery of timely, quality care and increase access to culturally tailored training for caregivers of individuals living with AD.

Appendix

Estimating the Prevalence of AD among Latinos

We searched through the annual Alzheimer's Disease Facts and Figures reports from 2010-2015 (1, 12, 26-29) and the literature referred to in the reports to identify studies that used a standardized type evaluation to identify people with AD and determine the prevalence of AD in age-specific subgroups of older Latinos.[74, 75, 76, 77, 78, 79] The only study that used a standardized form of evaluation to identify people with AD that was based on a nationally representative sample is the Aging, Demographics, and Memory Study (ADAMS) (22, 30). However, the number of Latinos in ADAMS was too small to get valid estimates of the prevalence of AD for that group (12). Two studies with a larger community sample were identified: the Washington Heights-Inwood Columbia Aging Project (WHICAP) and the Sacramento Area Latino Study on Aging (SALSA).[80, 81] WHICAP identified AD cases from nursing home residents and through a house-to-house survey of 13 adjacent census tracts in the north Manhattan area. The WHICAP sample consisted of mostly Caribbean Latinos. SALSA used door-to-door neighborhood enumeration to identify dementia cases from 5 contiguous counties in the Sacramento area. In contrast to WHICAP, Mexican-origin Latino constitute a major proportion of the SALSA sample.

We adjusted and pooled the results of WHICAP and SALSA to estimate the prevalence of AD for Latinos in three age-specific subgroups: 65-74, 75-84, and 85 or older. SALSA reported dementia prevalence in four age-specific subgroups (i.e. 60-69, 70-79, 80-84, and 85 or older).[82] We assumed the age of AD cases were distributed uniformly in the four reported age groups and calculated the prevalence of AD in the three age-specific subgroups desired. We pooled results from the two studies by calculating the weighted mean of AD prevalence in each age-specific subgroup. We used weights 6 and 4 for the SALSA and the WHICAP respectively. We put a higher weight on SALSA because Mexican-origin Latinos constitute about 60% of all U.S. Latinos.[83]

Both the SALSA and the WHICAP were carried out before 2000. We used the weighted mean calculated above as an estimate of the prevalence of AD for Latinos in 2000. There has been a significant growth in the prevalence of diabetes in Latinos since 2000.[84] This growth trend is projected to continue through 2050.[85] Diabetes is a major risk factor for AD.[86] Based on the prevalence of diabetes for older Latinos adults in 2000 that was obtained from the CDC (34), our estimated prevalence of AD for Latinos in 2000, and findings from a meta-analysis that showed that having diabetes increased the risk of AD by 54%, we calculated the prevalence of AD for Latinos with or without diabetes according to age group: 65-74, 75-84, and 85 or older.[87, 88] We assumed the prevalence of AD for Latinos with or without diabetes would not change over time. Information about the historical prevalence of diabetes for Latinos was taken from the CDC.[89] In combination with the projections from Wild et al., we estimated the prevalence of diabetes for Latinos through 2050.[90] We assumed the prevalence of diabetes in Latinos would not change from 2050 to 2060. Finally, we projected the prevalence of AD in Latinos through 2060 based on the forecast for diabetes in Latinos and our estimate of the prevalence of AD in Latinos with or without diabetes.

Estimating the Direct Costs for Latinos with AD

We used the 2012 MEPS to estimate medical care costs, including expenditures for office- and hospital-based care, home health care, dental care services, vision aid equipment, and prescription medications. Adults age 65 or older with cognitive disorders including dementia, delirium, and amnesia and other cognitive disorders in the MEPS were identified using the clinical classification system code 653. Because most adults age 65 or older in the MEPS have medical costs larger than 0, we used generalized linear regression instead of the zero-inflated model for estimation. Specifically, we used a negative binomial regression model to account for the wide dispersion of the costs and adjusted for demographics, socioeconomic status, health status and the presence of common comorbidities of AD, and location to estimate the medical costs for Latinos with AD. The demographic measures included age, race/ethnicity, gender, and marital status. The socioeconomic status measures were education, family income, and health insurance status. The common comorbidities of AD include stroke, chronic heart disease, and diabetes. The location measures were census region and urban-rural residence. All statistical analyses in the report were carried out by STATA 14, which can appropriately incorporate design factors and sample weights in the data.

Long-term care costs include expenditures for nursing home care, adult day care, residential care facility, and hospice care. We obtained the number of Latinos who used each type of long-term care services in 2012 from the CDC report, *Long-Term Care Services in the United States: 2013 Overview.*[91] The CDC's report provided the proportions of users with AD for each type of long-term care service. Because all types of long-term care service except adult day care were found to be predominantly used by non-Latino whites and an expert panel had estimated that the prevalence of AD in Latinos is about 50% higher than it is of non-Latino whites—a conservative estimate given the recent lower rates reported for non-Latino whites, and we multiplied the proportions of users with AD provided by the CDC's report by 1.5 to get the proportions of Latinos users with AD for each type of long-term care service except for adult day care.[92] For adult day care, we assumed that the proportion of Latinos users with AD was the same as the overall proportion of users diagnosed with AD. For each type of long-term care service, we multiplied the number of Latinos users by the proportion of Latinos users with AD to obtain the number of Latinos users with AD in 2012. We used data provided by other publications (35-37) to estimate the average daily cost and average length of stay per year for each type of long-term care service and multiplied them to obtain the average cost per user per year for each type of long-term care service. Finally, we multiplied the average cost per user per year by the number of Latinos users who had AD in 2012 to obtain the costs of Latinos users with AD for each type of long-term care service.

Estimating the Indirect Costs for Latinos with AD

Eighty-five percent of unpaid informal care to older adults in the U.S. is provided by family members.[93] We used a two-part model to estimate the number of days of unpaid informal care provided by people not living with the same person. We assume this constitutes 15% of total unpaid informal care received by Latinos with AD. We assume the value of the care is $114 per day (i.e., the average cost for a six-hour visit by a home health aide) to estimate the total costs of informal care for Latinos with AD.[94] We used a generalized linear model to estimate the earnings lost due to AD based on the MEPS. We adjusted for the same factors as in the estimate of direct medical costs.

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