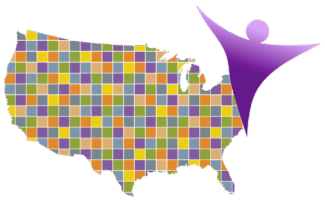
Calling All Voices

Stories from Latino Community Members on Learning to Live Well with Dementia

If we don't raise our voices, nobody will listen to us."

Heriberto Magana, care partner



Dementia Action Alliance

Global Council on Alzheimer's Disease

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Introduction

In 2021, the Global Council on Alzheimer's Disease (GCAD) and Dementia Action Alliance (DAA) co-authored a first-of-its-kind paper, *Hear Our Voices*. This paper shared insights from a series of interviews of people living with dementia and their care partners and sought to fill a gap in the literature by placing front and center their first-hand, authentic testimony.

As *Hear Our Voices* attempted to address one gap in the literature, it revealed another: the urgent need to hear from more diverse voices – voices that are too often marginalized, underserved, and unheard in dementia.

To address this gap, we launched Calling All Voices, a series of papers and podcasts dedicated to hearing and amplifying the distinct experiences of people living with dementia and care partners across diverse communities. In 2022 we were proud to launch *Calling All Voices: Stories from Black Community Members on Learning to Live Well with Dementia* and *Calling All Voices: Stories from LGBTQ+ Community Members on Learning to Live Well with Dementia*.

We are now delighted to share the latest installment in the series: *Calling All Voices: Stories from Latino Community Members on Learning to Live Well with Dementia*. In this paper, we provide a platform for the Latino community to share, in their own voices, their experiences living with dementia.

In the pages that follow, we share a set of "lived experiences" that we heard as we had conversations with thirteen members of the Latino community, four of whom are living with dementia and nine of whom are care partners. These individuals have different types of dementia, and varying levels of Spanish and English fluency. They come from diverse backgrounds and geographical regions – including six states within the U.S. of current residency and four countries/territories outside it of family origin. Although limited in number, we believe these conversations are largely representative of the Latino community in the U.S. and have relevant application beyond.

In our conversations, we heard about challenges that people in the Latino community have encountered in their dementia journey. Some of these challenges are very familiar to the broader dementia community, such as the lack of support from health care providers and difficulties managing behavioral symptoms associated with dementia. Other challenges are more specific, such as a lack of culturally appropriate support and resources, barriers related to language, and trauma resurfacing with dementia.

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We would, however, fail in our goal to hear and amplify these stories if we only shared challenges and difficulties. Throughout our interviews, we heard stories of hope, creativity, love, and tenacity. And we heard invitations to join the advocacy efforts to support the Latino community affected by dementia.

We would like to thank the generous people who shared their experiences with us. The insights and stories they shared are the only reason this paper came to be. Together, they advance us toward a better, more equitable future for Latino individuals and families impacted by dementia.

But the work cannot stop with them. We would therefore like to use this paper to call all voices of the Latino community to share their stories. Whether it's with GCAD, DAA, a support group, another person living with dementia, or anyone else, each voice propels us further along our collective journey of activism, compassion, and understanding.

Mary Michael
VP Patient Advocacy and Stakeholder Engagement,
Otsuka Pharmaceutical Development & Commercialization, Inc.
Chair, Global Council on Alzheimer's Disease

Janice Bays
Board Chair Emeritus, Dementia Action Alliance

*In this paper, we use the term "Latino". We do so at the direction of individuals we spoke with in the creation of this paper and for the purpose of consistency within it. This decision is also aligned with research suggesting that older adults continue to use Latino and Latina[1]. We would like to recognize however, that there is a plethora of alterative, equally valid terms: some of our source material used nomenclatures like "Hispanic" or "Latinx", and many of the individuals we interviewed refer to themselves in relation to their specific and diverse family heritage, e.g., "Cuban American" or "Puerto Rican". The conversation around terminology will always be ongoing. We welcome input and feedback as our intention is always to use the term preferred by the community.

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Acknowledgments

This project is in collaboration between the Dementia Action Alliance (DAA) and the Global Council on Alzheimer's Disease (GCAD). We would like to thank everyone who graciously shared a story with us and allowed us to share it with you. This project would not have been possible without their courageous voices.

We would also like to extend our deep gratitude to Paula Muller for her expert voice and the skill and compassion with which she led the conversations that became this paper.

Yoli Alvarez-Bell
Living with dementia in Texas
Family heritage: Mexico

Heriberto Magana
Care partner in Texas
Family heritage: Mexico

Lupita Casas
Care partner in Texas
Family heritage: Mexico

Carlos Olivas II
Living with dementia in California
Family heritage: Mexico

Ana Castaneda
Elderly Programs Manager in Wisconsin
Family heritage: El Salvador

Carlos Olivas III
Care partner in California
Family heritage: Mexico

Norma Delgado
Living with dementia in New York
Family heritage: Puerto Rico

Kimberly Scott
Care partner in Texas
Family heritage: Mexico

Susan Delgado
Care partner in New Jersey
Family heritage: Puerto Rico

Myra Garcia Solano
Living with dementia in California
Family heritage: Cuba

Mayra Gonzales
Care partner in Texas
Family heritage: Mexico

Alma Valencia
Care partner in California
Family heritage: Mexico

Juan Carlos Zaldivar
Care partner in Florida
Family heritage: Cuba

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Dementia in the Latino Community

In the U.S., the Latino community bears disproportionate health, economic, and care burdens of dementia. Currently, Latinos are 1.5 times more likely to develop dementia than non-Latino whites and over one in eight Latinos aged 65 or older has dementia[2]. These numbers are only expected to increase. By 2060, the Centers for Disease Control and Prevention predicts Latinos will have the highest prevalence of dementia among all racial and ethnic groups and the U.S. Census Bureau estimates that the number of Latinos with dementia will quadruple to nearly 20 million[3].

Latinos also face significant challenges in accessing and participating in dementia health care. One-third of Latino Americans report experiencing discrimination when seeking health care, and dementia clinical trials disproportionately exclude minority groups, including Latinos[2].

Adding to the challenge, Latino families are significantly under-resourced in income, retirement benefits, and pension benefits. Moreover, it is estimated that by 2060, dementia will cost Latino families a staggering $2.3 trillion[4]. This paints a bleak picture: as the number of Latinos with dementia increases, families, communities and systems of support will have insufficient resources to respond.

Geographic Inequity

Dementia is not experienced equally across the United States. A recent study revealing the U.S. counties with the highest rates of dementia, finds that these localities have higher percentages of older Latino and Black residents. Some of the individuals interviewed for this paper are among their inhabitants[8].

Despite these challenges, Latino community members have made progress living well with dementia. New clinical trials[5], care and caregiver programs[6], and efforts to raise awareness[7] are creating more resources for Latino individuals and families affected by dementia. Community members are further demonstrating creativity, perseverance, and the readiness to respond to systemic barriers.

This paper highlights the nuances of these challenges and responses through firsthand testimony from individuals living with dementia and care partners in the Latino community. It discusses stigma and lack of awareness, challenges navigating care systems, and barriers to living well with dementia. But in equal measure, the paper showcases how Latino community members are responding to these challenges by advocating for culturally specific resources and care and mobilizing familial support to develop pathways to living well with dementia.

Addressing Stigma and Lack of Dementia Awareness

> **In the Latino community we don't talk about mental health. It's very personal.**
>
> **Alma Valencia,** care partner

Stigma and limited awareness of dementia is common across the Latino community. According to a recent study, Latino community members tend to avoid discussions of dementia or treat it as a joke[9] and another found that Latinos with dementia are less likely to be aware of their condition than their white peers[10]. Together, stigma and lack of awareness can exacerbate the already vast health and care inequities facing the Latino community as families may delay seeking help due to denial or lack of acceptance of their loved one's condition[11].

In response, some of the individuals we interviewed are choosing to share their dementia journeys on public platforms, and with friends and family. They are responding to dementia bias in others and reflecting on their own. Together, they begin to unravel the mutually perpetuating cycle of stigma and lack of awareness.

Challenges: Stigma, Silence, and Lack of Awareness Pervade the Latino Community

Stigma and Silence

For many Latino community members, dementia, and mental health more broadly, is ensnared in deep, pervasive cultural stigma. Studies show dementia holds associations with the idea of individuals "losing their mind"[12] or "being demented."[1] As a result, community members can be reluctant to share their diagnosis, journey, or even to say the word "dementia."

> ***I did not want to tell anybody about my diagnosis. I felt I would be looked upon in a negative way. I felt people would think 'I'm not going to talk to her, she can't remember anything.'"***
>
> - Myra Garcia Solano, living with dementia

> ***My mom will ask me 'what doctor are we going to?' and I'll say, 'we're going to the neurologist, they have to explain an analysis.' But the idea of saying 'because you have dementia'… there's just so much trauma and cultural stigma linked to it. It's a word you don't mention – we're dealing with it and communicating about it, but we don't name it. It really bothers me."***
>
> - Juan Carlos Zaldivar, care partner

> ***In the Latino community we don't really talk much about dementia, it's not a part of our culture. We're barely getting comfortable with talking about cancer."***
>
> - Kimberly Scott, care partner

Spotlight: Embedded Stigma in Language

From our interviews we heard that cultural stigma around dementia can be entrenched in the very language used to discuss it.

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Each country has different words or ways to say things. If people are uneducated, maybe they live in remote, rural areas and then come to the US, they don't know what dementia is. They don't know what Alzheimer's is. They'll just use a term like 'loco' - 'my grandpa is crazy.'

Ana Castanda,
Elderly Programs Manager,
United Community Centercare partner

Lack of Dementia Awareness

Stigma, silence, and a systemic lack of resources and education all drive a persistent lack of dementia awareness in the Latino community. According to one study, nearly six in ten Latinos believe a significant loss of memory or cognitive abilities is a normal part of aging[13]. Community members discuss mistaking dementia symptoms for personality changes or natural aging, not understanding the implications of a dementia diagnosis, and in some cases, not believing dementia exists.

When we got the diagnosis, none of us thought much of it, no one ever thought about it being a big change because we had no idea what Alzheimer's was. The only thing I knew is that people forget things."

- Lupita Casas, care partner

I don't think people really understand what Alzheimer's is. Many in the Latino community don't have access to dementia information or are even aware of this disease. They might just think 'Auntie is not making any sense' or 'she's become mean and angry.' When I first heard about Alzheimer's I certainly didn't think it would be affecting me."

- Myra Garcia Solano, living with dementia

I didn't know anything about Alzheimer's. My uncles and aunts from the ranch said 'no, no, it doesn't exist, it's all in the mind or something like that.'"

- Mayra Gonzales, care partner

Everyone says 'oh, it's normal, it's just part of aging.'"

- Yoli Alvarez-Bell, living with dementia

Overcoming the Barriers: Tackling Stigma and Lack of Awareness Through Large- and Small-Scale Interventions

Addressing the Broader Community

In response to the stigma and lack of awareness that often surrounds dementia, people in the Latino community are working to raise awareness in the broader community. They are creating movies, pages, and educational programs that bolster awareness, shed light on the dementia journey, and point others to resources.

> ***I need to share so people are aware."***
>
> - Myra Garcia Solano, living with dementia

> ***I'm making a movie about my experiences with dementia, and I want to shift how we look at the disease. Ultimately, I want the movie to be a jumping off point for people to access dementia tools and education - information I wish I had before dementia came into my life."***
>
> - Juan Carlos Zaldivar, care partner

> ***I created my mom's page called Caregiver Comadre showing us and our journey. I use the page to talk about mental health and I show my mom when she's acting out or when she's having a moment. Some family members don't appreciate that I do that, but if we don't speak about this, how will we know how to help one another? If everything is kept private, there will be no progress, and there will be no healing."***
>
> - Alma Valencia, care partner

> ***In the Latino community, households are often multigenerational, so it's important to educate kids on what's happening to grandma or grandpa, or even mom or dad. We start with a nurse and social worker explaining what Alzheimer disease is. Then a neurologist shows brain samples. At the end, we take them through the Virtual Dementia Tour - an immersive experience of what it's like to have dementia. At first, the kids are really excited, but when they put on the goggles and gloves, and they're not able to do simple tasks, you can see the shock on their faces. We explain, this is what's happening to your loved one - that blurry vision and not being able to do something simple with their hands. It puts a lot of things in perspective, even for younger kids.***
>
> - Ana Castanda, Elderly Programs Manager, United Community Center

*Alma Valencia gained her mother's consent before posting about their experience on Instagram. Her mother agreed, expressing her desire to help others. The Global Council on Alzheimer's Disease and Dementia Action Alliance commend Alma for gaining her mother's direct consent, as it is important to always protect the privacy and dignity of people living with dementia.

Addressing Friends, Family, and Oneself

Addressing dementia stigma and lack of awareness requires a multi-level approach that spans large scale, public initiatives, and day-to-day, personal conversations and introspection. Every day, community members champion the latter by sharing their diagnosis with friends and family, reflecting on their own bias, and addressing it in others.

> ***Once I had the proper diagnosis, I created a whole list for myself of people to tell. My husband said, 'why do you have to do that? Why don't you just take it easy?' But I said 'no, no, I need to share so people are aware.' I felt that I had this important piece of information of who I am and why I do things a certain way. So, I started with my close family and then, little by little, I started telling all my friends across the country. It was very healing."***
>
> - Myra Garcia Solano, living with dementia

> ***Now I'm comfortable with this journey. I'm slowly but surely embracing it. It's taken a lot of effort to get here, but once you do, you understand there's resources that can help."***
>
> - Carols Olivas III, care partner

> ***I was having a conversation with someone who said, 'People with dementia stop being who they are, my grandfather is a different person now.' I respond, 'But I'm also a different person than I was seven years ago - I don't speak the way I used to, I don't believe certain things that I used to. Every cell in our body changes.' The idea that we define ourselves by our memories is problematic, and the idea that we define personality as something that's fixed is incorrect."***
>
> - Juan Carlos Zaldivar, care partner

Navigating Challenges in Care Systems

> **I'm not just another number. I'm not just another patient."**
>
> **Yoli Alvarez-Bell,**
> Living with dementia

Across U.S. health and care systems, Latinos navigate challenges to receiving quality, culturally appropriate support. Many individuals encounter problems finding resources in their preferred language and struggle to understand what services are available to them[14]. When seeking care, Latinos have fewer health screenings and follow-up care[15] and higher rate of delayed or missed diagnosis[16]. Community members further share that health care providers rarely provide appropriate support, information, and guidance to those seeking a diagnosis or ongoing care for dementia.

In response, individuals we interviewed share that they are advocating for themselves and their family members and furthering their own dementia education. They lean on support from their own strong family structures and are finding ways to assist others along the journey. They also offer a set of recommendations for how health care providers can better serve their patients.

Challenges: Health and Care Systems Underserve the Latino Community

Lack of Cultural Humility

Many members of the Latino community, particularly older adults, have varying degrees of fluency in English. Despite this, too few resources and care settings are equipped to deliver language appropriate, culturally humble care. This deficit has sweeping implications for health outcomes. Research shows that patients are evaluated differently when examined in Spanish versus English[18] and that language barriers increase the likelihood of miscommunication, adverse events, and inadequate follow up care[17].

According to a recent analysis,

6/100 physicians are Latino

2/100 non-Latino physicians are Spanish-speaking[17].

These challenges also pervade long term care settings. Less than half of Latinos believe it would be easy to find long-term care services or home aides who speak their language and even fewer believe care homes will provide the food they are used to or accommodate their religious or spiritual beliefs[19]. Community members affirm these issues and express a desire for more culturally humble care and resources.

> ***"There's no memory care unit for Latinos, no senior living community with just Spanish caregivers. When you progress further into dementia, you go back to your first language, which in this case is Spanish. Imagine not knowing where you are, not knowing who is who, and then not even being able to communicate your needs."***
>
> - Ana Castanda, Elderly Programs Manager, United Community Center

> ***"A lot of the resources out there, unfortunately, are not in Spanish. I wish there was more for our community, and I wish our community was better represented."***
>
> - Alma Valencia, care partner

> ***"My mom doesn't speak English and sometimes the healthcare provider doesn't speak Spanish, so I'll have to step in as her translator."***
>
> - Juan Carlos Zaldivar, care partner

Common Missed or Delayed Diagnoses

The diagnostic process for dementia is long and arduous and, too often, complicated by missed diagnosis. Latinos disproportionately experience this challenge. Research shows they are more likely to have a missed dementia diagnoses and have an average diagnostic delay of over 3.5 years compared to around 2.5 years for whites[16]. This is driven by a number of factors which include misdiagnosis with another, often comorbid, condition[1] , limited time during appointments, and insufficient knowledge on the part of the provider[1].

2.5 Years
Whites

3.5 Years
Latinos

Average diagnostic delay by race

> ***I had to really fight to get my proper diagnosis. It took at least 5 years. My physicians would do a simple test and they would say 'you're fine, I'll see you next year', and the same thing the next year, and the next. At one point my general practitioner actually told me that I had mild cognitive impairment, but he didn't tell me what that meant, and then he said 'you're doing fine. Don't worry about it.' The first neurologist I saw did a lot of testing, but at the end of the day, she decided it was Attention Deficit Disorder (ADD). But I continued having troubles. Finally, I saw a neuropsychiatrist, who after eight hours of testing diagnosed me with Alzheimer's."***
>
> - Myra Garcia Solano, living with dementia

> ***Latinos will often be more advanced that they should, by the time they get to see a health care provider."***
>
> - Ana Castanda, Elderly Programs Manager, United Community Center

> ***For the longest time, the doctors said it was depression. But we knew there had to be more to the diagnosis because we were seeing so many behavioral issues and so much we couldn't explain. It was only when we started noticing the memory, that doctors were like, 'okay, now it's dementia.'"***
>
> - Alma Valencia, care partner

Insufficient Guidance from Providers

According to a recent study, a staggering 85% of individuals living with dementia may not receive post diagnosis care[20]. As a result, individuals with dementia may not be offered treatment options or made aware of interventions to improve their quality of life. This study offers empirical evidence to an issue raised by every individual interviewed for this paper: too often health care providers fail to provide the guidance and support their patients need - both during a diagnosis and in the ongoing care and management of dementia that follows.

85% of individuals living with dementia may not receive post diagnosis care.

> ***There was no information given when my mom was diagnosed. They basically said, 'your mom has dementia, and good luck.' I would go back to them and say, 'her behavior is so challenging, how can I help her?' and they'd respond, 'that's part of the dementia.' There was no support, no explanation, no guidance, no direction to support groups, nothing."***
>
> - Alma Valencia, care partner

> ***My neurologist handed me a sheet with little check boxes of all these vitamins that I should be taking. Then said 'go on your way, see you in six months. That was nothing about diet or exercise. When I try to get more information or ask a question, I'm usually met with 'don't bother me, I'm busy.'"***
>
> - Yoli Alvarez-Bell, living with dementia

> ***Sometimes, in the Latino community, if your doctor tells you something, you just accept it. And you don't necessarily say 'but what about this, what about that?' Who am I to tell my doctor what's right? So, you might miss the opportunity to have a conversation."***
>
> - Myra Garcia Solano, living with dementia

Spotlight: Lack of Access for Undocumented Individuals

Accessing and navigating health care is challenging for most in the Latino community. For the roughly 13% of Latinos who are undocumented[21], it is even harder. Undocumented individuals are ineligible for Medicaid, which provides coverage for low-income individuals, and are four to six times more likely to be uninsured than U.S. citizens[22]. These barriers to health care contribute to the higher rates of morbidity and mortality among older undocumented adults[22].

> **When I asked for help for my wife, I was always told that because she was not an American citizen, she couldn't access anything. We were left alone."**

Heriberto Magana,
care partner

> **There are so many Latinos in this country that don't get any benefits because they are undocumented. They don't qualify for long term care or healthcare services. Even if they have lived here in the US for a long time, have paid Social Security, and have contributed to the US economy, they are not of legal status, so they don't qualify."**

Ana Castanda,
Elderly Programs Manager,
United Community Center

Overcoming the Barriers: Filling the Resource Gap Through Advocacy and Familial Support

Personal Education and Advocacy

In response to the substantial barriers to quality care, Latino community members are finding creative and tenacious methods for improving their, and others', dementia care experiences. Community members share that they are furthering their dementia education to better care for loved ones, launching initiatives to serve other care partners in urgent need of respite, and standing up to care providers who are not meeting their needs.

> ***We've started going to this support group and it has opened our minds. They've educated us and explained how to deal with the behavioral symptoms we've been seeing."***
>
> - Mayra Gonzales, care partner

> ***I started a nonprofit called Do as we Do. Each year we give money to care partners so they can take a day off. We're also working on having a therapy advocacy center where people can get free therapy and resources. We're trying to help people in that middle gap - where they don't qualify for aid but still need support."***
>
> - Kimberly Scott, care partner

> ***With the doctors, I've had to really put my foot down and say 'no, my mom is always going to see the same person, she's not going to see a different person every time.' Contact with one provider over a period of time is really important, and it's not prioritized in our healthcare system. So, I've advocated for her."***
>
> - Juan Carlos Zaldivar, care partner

Support Through Strong Familial Bonds

The dedication and unconditional support of families was one of the strongest throughlines of these interviews. Care partners shared how they have, without hesitation, dedicated time and resources to caring for their loved one – in many cases leaving jobs and reorienting their lives. Through this unwavering support, families help fill the gaps left by insufficient health and long-term care systems.

> ***I take care of my parents with all my heart, and I wouldn't want it any other way. I wouldn't want them to go to a nursing home."***
>
> - Lupita Casas, care partner

> ***I've made great strides and I've gone to great efforts to try to bring my mom to the best care providers as possible."***
>
> - Juan Carlos Zaldivar, care partner

> ***I can reach out to my daughters if I need anything."***
>
> - Norma Delgado, living with dementia

> ***When my dad was diagnosed, I was at a point where I was able to pivot my career. So, I just made a leap of faith to quit. I had a conversation with my daughter on how we were going to make it work and how we were going to support."***
>
> - Carols Olivas III, care partner

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Advice for Health Care Providers

Community members are making great strides to address gaps in care, and they call upon providers to do the same. Individuals share that they would like providers to spend more time with them, to listen, explain, share resources, and treat them as equal, respected partners in the care journey.

> ***Take the time to listen to your patients. Don't rush them out of your office, listen to what they have to say, and listen to their concerns, because they're scared. They need to know that you're there to help and you're fighting with them."***
>
> - Yoli Alvarez-Bell, living with dementia

> ***Know that your patients don't necessarily understand what you mean. Ask them questions and be attuned to their needs and backgrounds. Be advocates for us."***
>
> - Myra Garcia Solano, living with dementia

> ***There should be a mutual respect for everybody in the room, it's a partnership and we're all part of the same team."***
>
> - Alma Valencia, care partner

> ***When someone is diagnosed, direct them to resources or a support center so they and their family can better understand the disease and what the symptoms are."***
>
> - Lupita Casas, care partner

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Learning to Live Well with Dementia

> **It's so important to know that you are loved and that you have purpose."**
>
> **Myra Garcia Solano,** living with dementia

There are sadly many barriers to living well with dementia - many of which are common across the dementia community – but Latino's often bear these challenges disproportionately. In our interviews we heard about high financial burdens, experiences of trauma resurfacing with dementia, and the challenges of responding to behavioral symptoms – which Latino families contend with disproportionately[23]. While this list is by no means exhaustive, it covers some of the most frequently shared challenges.

In response, many of the individuals we interviewed share that they are engaging in financial planning, finding support through community, creating strategies for managing behavioral symptoms, and cultivating joy and meaning in their journeys.

Challenges: Finances, Trauma, and Behavioral Symptoms Create Challenges to Living Well with Dementia

Financial Challenges

It is estimated that the total lifetime cost of caring for an individual with dementia is a staggering $413,000, with much of that cost borne by care partners in the form of unpaid support and out of pocket expenses[24]. The challenge can be particularly acute for the Latino community due to higher rates of poverty[25] and lower rates of health insurance[26].

The financial burden is only expected to increase. By 2060, lost earnings for Latinos due to dementia are projected to reach $2.7 billion[23] and the total cost for families $2.3 trillion[4]. Community members give color to these colossal numbers through personal stories of lost income and financial strain.

By 2060, lost earnings for Latinos due to dementia are projected to reach $2.7 billion

> ***Nobody helped us. I had no money. I finally stopped working because my wife needed me all the time. Without working, it is difficult to survive here."***
>
> - Heriberto Magana, care partner

> ***I quit my job and my husband also had to leave his to help make sure I was safe. So that's changed our income level drastically. It's a risk we had to take while we waited for disability."***
>
> - Yoli Alvarez-Bell, living with dementia

> ***When I became my mom's full-time caregiver my income was literally cut in half, if not more. So, I've been trying to get as creative as possible with funds. We have a teen daughter that we have to consider, so we try to move money around so that she can have a normal life and that we don't limit her."***
>
> - Alma Valencia, care partner

Trauma Resurfacing with Dementia

The link between trauma and dementia is an emerging and pressing field of research. Early studies suggest a two-way link whereby PTSD can increase an individual's risk of developing dementia, and dementia can trigger the onset of PTSD[27]. This link is particularity important to consider as Latinos are disproportionately affected by trauma and have higher rates of PTSD than non-Latino whites in the Unites States[28]. Community members share their experiences of trauma resurfacing with dementia - both for the individual with dementia and for the care partner.

> ***My mom has a lot of traumas. She was very young when her father was killed and around 17 or 18 when her family immigrated to the States. So she went through a lot, moving from place to place, trying to restore her life and trying to forget the past. At this point in her dementia, the death of my grandfather is still very present. She mentions grandfather frequently, it's like she's reliving his death all the time."***
>
> - Alma Valencia, care partner

> ***When my mom was diagnosed, I began to see the post-traumatic stress in myself was coming back from our immigration from Cuba. And then I began to see it coming back in her as well. The post-traumatic stress that we all thought we had surpassed was being triggered all over again."***
>
> - Juan Carlos Zaldivar, care partner

> ***The short-term memories are the usually first ones to go, and then individuals with dementia go back to their past when they're in different places."***
>
> - Ana Castanda, Elderly Programs Manager, United Community Center

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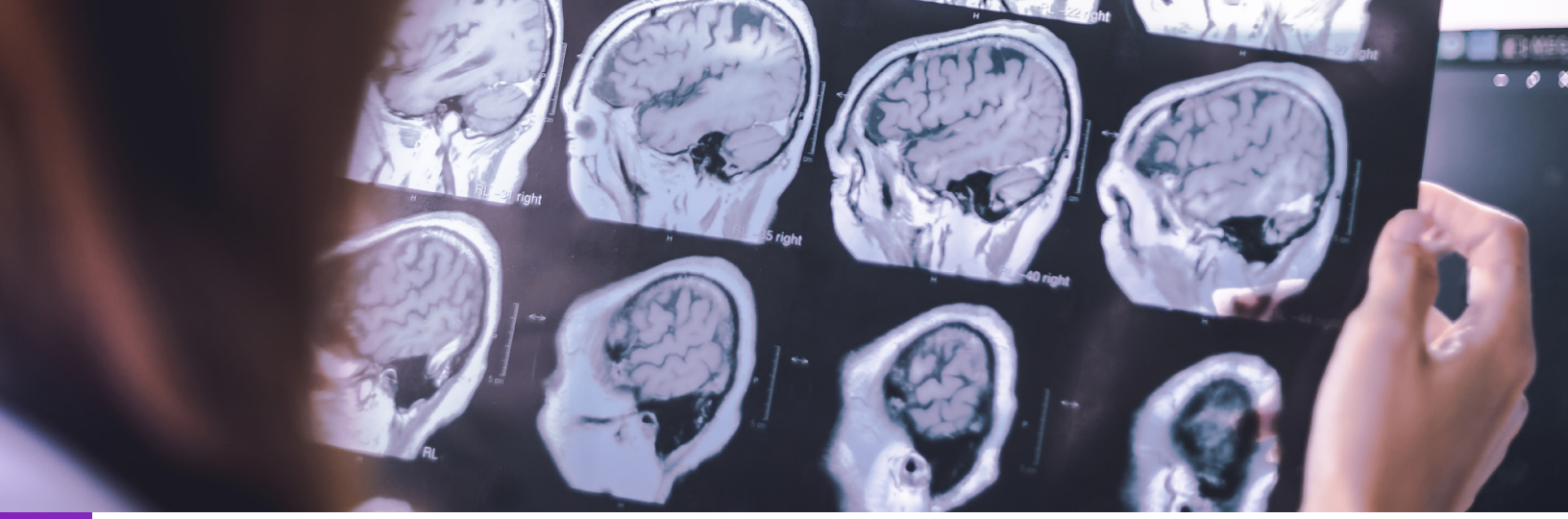


Difficult Experiences Associated with Dementia

Difficult experiences may manifest from behavior which can accompany the more recognized symptoms of dementia such as memory loss and cognitive decline. At times, people living with dementia may act and respond in ways that people, especially care partners, may not understand, find concerning or challenging, or perceive as "out of character" for the person. Checking in with the person living with dementia can help identify any stressors or points of discomfort that might be causing or aggravating these experiences. For any family, the care and response to difficult experiences can take tremendous emotional, physical, and financial effort. For Latino families, the responsibility is even greater. Studies show that Latino families deal with higher levels of difficult experiences, or "behavioral symptoms", related to dementia and provide higher intensity care[23].

Behavior Associated with Dementia

Associated with Dementia
People's behavior - actions, reactions, words, and gestures - may represent a variety of things. For a person living with dementia, their behavior could be an attempt to communicate an unmet need,[32] a response to their physical environment, or a reaction to the way others are engaging with them.[33] As we heard in our interviews, behavior can also be a reflection of an individual's past life, patterns, and preferences[34].

Resources

There are a number of resources available that can help families understand and respond to behavior as it arises. The Dementia Action Alliance "Pathways to Well-being with Dementia" manual provides useful sections both on "Coping with Expressions of Distress" (page 363) and "Changes in Personality and Behavior" that might occur in each of the types of dementia (starting page 398).

Sometimes my dad could be violent. He got angrier. He got hallucinations and imagined things that were not there, and that caused a lot of problems. He would get mad at mommy because he thought someone was coming to see her or that someone was talking to her outside. He got in the car twice and left and we couldn't find him. He is very afraid that someone is looking for him and he will want to hide in the closet. If we are talking, he'll say 'shut up, don't talk, they are looking for me, they will hear us.'"

- Lupita Casas, care partner

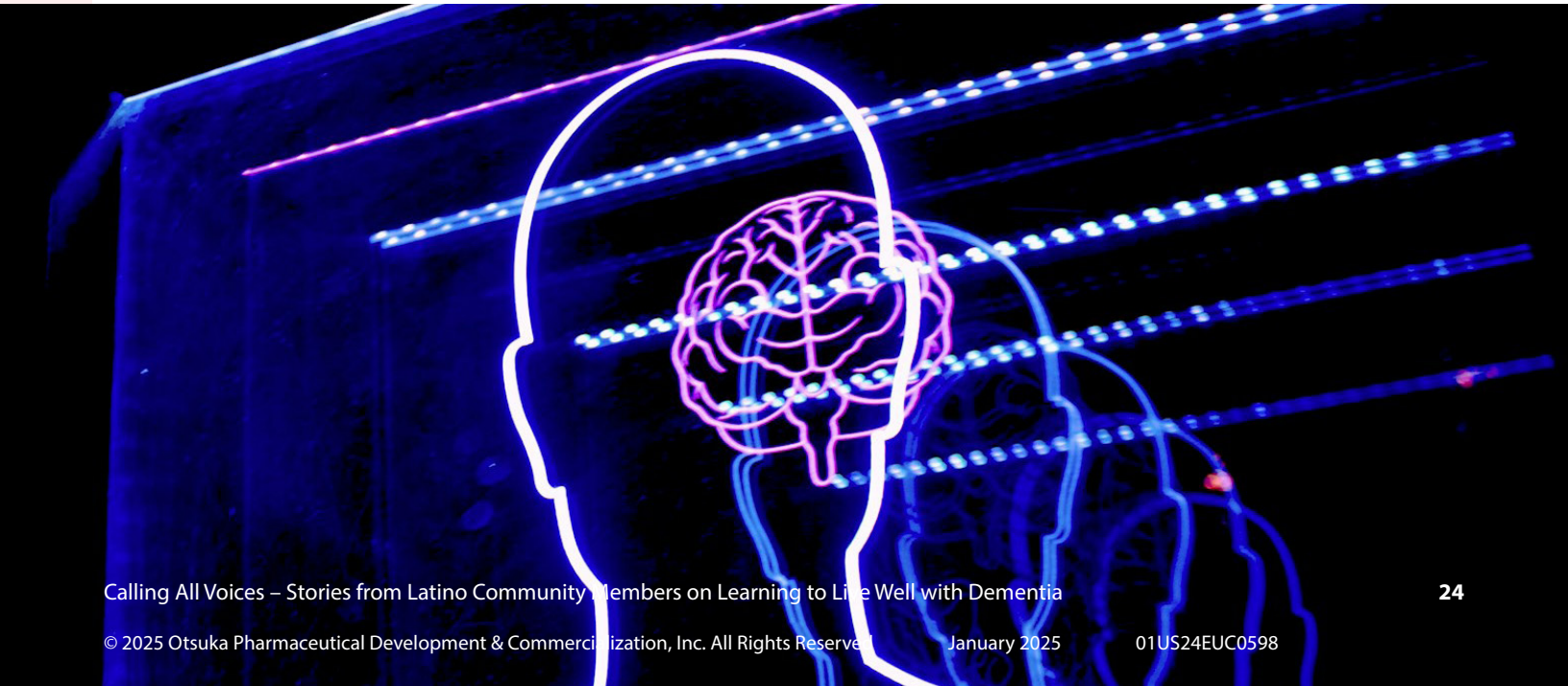
There are some days when I have my meltdowns. I cry a lot sometimes. I get frustrated."

- Yoli Alvarez-Bell, living with dementia

When my mom starts to sundown* she'll say she wants to leave, that she is not home. In her mind, she lives in the old days, on the ranch in Mexico with my grandmother and my grandfather. She hallucinates things as well. She will say that she sees men at the window, or some children and she'll ask for the girl."

- Mayra Gonzales, care partner

*"Sundowning" is a term commonly used to describe a situation in which someone living with dementia becomes confused, anxious, or agitated in the late afternoon and into the night[29]. While sundowning is often thought to be a fixed or inevitable symptom of dementia, its expressions can be correlated with a buildup of stress throughout the day[30]. Proactive measures to reduce stress can help mitigate these experiences[31].



January 2025 01US24EUC0598

Overcoming the Barriers: Harnessing Community, Planning, and Purpose to Live Well with Dementia

Finding Community Through Support Groups

As individuals and their families contend with the plethora of challenges that can accompany the dementia journey, many have found support from their peers. Community members consistently share that support groups provide them opportunities to process feelings, give and receive advice, cultivate lasting friendships, and find validation in their journeys.

> ***"I'm very active with the Alzheimer's Association where I'm in a support group that is absolutely wonderful. We are all in similar stages, we all have stories - sometimes sad sometimes funny, and we help each other. It's really important to have people who understand what you're going through, without judgment, and for them to acknowledge that this is real."***
>
> - Myra Garcia Solano, living with dementia

> ***"I attend about six caregiver support groups now. Some are weekly, some are bi-weekly, some are monthly. I learn techniques, what does work, what doesn't work? I'm able to give feedback, support others, build relationships, and vent when I need an outlet."***
>
> - Carols Olivas III, care partner

> ***"We run a daycare program. It helps the person with dementia feel like they're still independent. They get to hang out with others like them in an environment that's culturally competent. Then, at the end of the day, they go back home to their families."***
>
> - Ana Castanda, Elderly Programs Manager, United Community Center

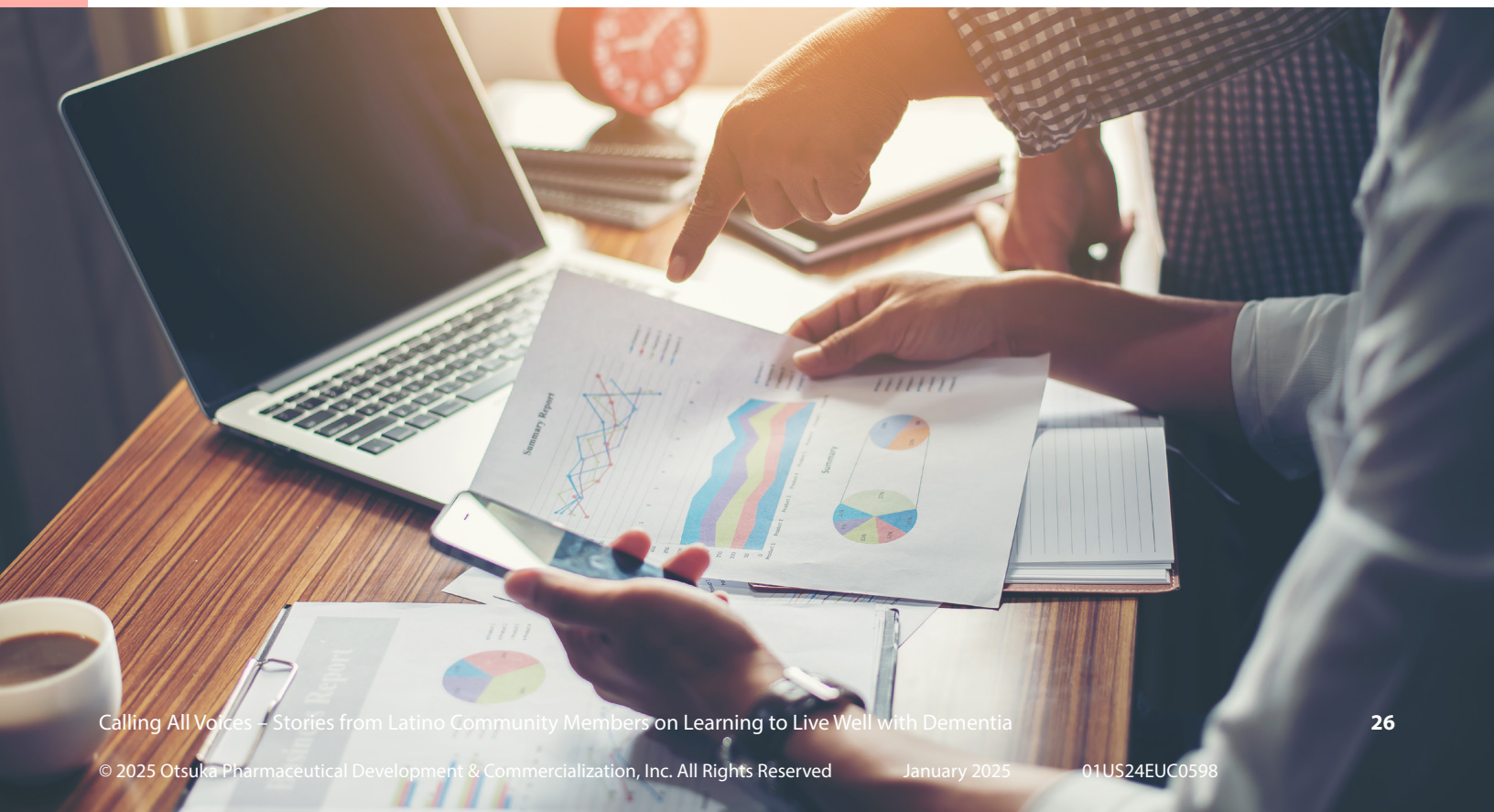
> ***"Thanks to Dementia Action Alliance, I feel like I've had plenty of support and I've built great friendships. It's helped me realize that there are other people on the same journey, having the same problems. I realized that I wasn't alone. They pull you in and they hold on to you."***
>
> - Yoli Alvarez-Bell, living with dementia

Financial Planning

The financial burden of dementia for many families is undeniable, but there are some measures that can help reduce the impact. Individuals discuss the value of long-term care insurance, financial planning, and saving money where possible.

> ***We're doing our best to save money and be as frugal as possible because we know what's going to come eventually and we don't want to be a burden to our children. Fortunately, way before I had the diagnosis, I think it was because of my aunt's dementia, I insisted to my husband that we have long-term care insurance. My husband would say 'It's such a waste of money, we're too young, we don't need to do this.' But I felt very strongly that we needed to be prepared."***
>
> - Myra Garcia Solano, living with dementia

> ***Early on I set up an appointment with my dad's attorney to review his documents and affairs. That led me to the insurance agent who helped determine what benefits were covered under the long-term care insurance my dad had established early on. That insurance has been a great relief for us – we are able to have a paid caregiver come into the house and provide companionship when we are not around. It's also enabled me to have a steady part time job, and some respite time."***
>
> - Carols Olivas III, care partner



 January 2025 01US24EUC0598

Responding to Difficult Experiences Associated with Dementia

In response to difficult experiences associated with dementia, many families have found compassionate strategies to help their loved ones cope.

> ***We're at a point now where we understand mom's behavior is very common, we can recognize it and know how to get around it. For example, 'mom is doing this, but let's not hyper focus on it, let's work around it and move on.' Recently, we've been walking a lot and the added activity and sun has been helpful."***
>
> - Alma Valencia, care partner

> ***If my son sees that I'm agitated, or confused, or mad, he'll try calm me down and comfort me or distract me."***
>
> - Yoli Alvarez-Bell, living with dementia

> ***I've been able to key in on a strategy of male bonding to keep the environment light, and avoid anxiety, negativity, and strain. I've had to be very adaptive and it's a skill that I have to practice over and over again, but it helps."***
>
> -Carols Olivas III, care partner

Finding Joy and Meaning in the Journey

Latino community members share that, just as they have experienced challenges in the dementia journey, from behavioral symptoms to trauma resurfacing, they have also found joy and meaning alongside them. Some share that the journey has created more space for art and hobbies, others say it has brought their families closer together and afforded them precious time for enjoying one another's company.

> ***"One of our routines is waking dad up, getting him in the shower, and then heading off to our favorite bakery. From the bakery, we go to a park that's along the river. We sit there together and enjoy a donut, just being at peace."***
>
> - Carols Olivas III, care partner

> ***"I volunteer in three different choirs. Anything I can do to keep myself viable. I do physical exercises with a Peloton bicycle - that's my morning routine. I cook, take care of the house, and I enjoy going to the movies, I go by myself and it's my me time."***
>
> - Myra Garcia Solano, living with dementia

> ***"Mom and I are closer now more than ever since the diagnosis. She even says I love you; she never said that before. A nicer side has come out of her and she's such a loving grandmother."***
>
> - Susan Delgado, care partner

> ***"I sit here all the time and work on my art. I have all the colors here. I imagine pure water, in the middle of the ocean when the sun is going down."***
>
> - Carlos Olivas II, living with dementia

> ***"We like to take short walks together, we'll sit and enjoy the animals and the birds. Mom loves to dance, so I'll put on music, and we'll have our own little dance party."***
>
> - Kimberly Scott, care partner

Call to Action

This paper shares a set of challenges facing the Latino community impacted by dementia and it highlights stories of how they are responding with compassion, activism, and persistence. We would be remiss, however, to suggest these are their burdens to shoulder alone. Rather, it is the duty of the broader dementia community to step up, advocate, and push for change, in allyship with the Latino community. Based on our interviews with community members, we offer three calls to action for how the broader community can get involved. These outline ways each one of us can support members of the Latino community impacted dementia and, together, work toward a better, more equitable future.

1. Improve Cultural Humility in Care Systems

a. Educate yourself on what it means to be culturally humble and the unique challenges and needs of Latino community members.

b. Advocate for efforts that bolster inclusivity within local health and care settings including Spanish fluency and culturally relevant activities, food, music, programming, etc.

c. Collaborate with and support Latino community organizations that are working to advance cultural competency in health and care settings.

> **Even something as simple as having Hispanic music or food they are familiar with - things that contribute to a comfortable, culturally appropriate environment. Having those things gives them a better quality of life. They can feel like they're at home, and not just thrown in a strange place."**
>
> **Ana Castanda,**
> Elderly Programs Manager,
> United Community Center

2. Expanded Dementia Awareness, Particularity Amongst Youth

a. Support organizations that provide education or resources around dementia or mental health in the Latino community
b. Organize, participate in, and promote initiatives that target youth education on dementia
c. Leverage social media to share information and resources on dementia
d. Promote the dissemination of inclusive informational material about dementia in the Latino community through your networks (schools, neighborhoods, employers, etc.).

> **Most of us have to learn about dementia in the middle of a crisis. I think people should learn about dementia in grade school. This conversation needs to start early. If we come into it with more understanding of what's happening, we will have more patience, we will have more understanding."**
>
> **Juan Carlos Zaldivar,** care partner

3. Fill the Resource Gap

a. Volunteer your time or resources to organizations that prioritize dementia care within the Latino community.
b. Advocate for increased funding for dementia resources in Latino communities through local, state, and federal channels. Attend town hall meetings, write letters to your representatives, and support initiatives that prioritize these needs.
c. Provide pro bono services if you have relevant skills or expertise. Offer legal advice, healthcare counseling, or event planning, to organizations that focus on dementia care in the Latino community.

> **It would be nice to have someone walk you through the process - where you should go, what resources are available, how to navigate medication, etc."**
>
> **Kimberly Scott,** care partner

Resources

Websites

Alzheimers.gov
https://www.alzheimers.gov/es
An official website from the United States Government providing Alzheimer's related information and support.

Alzheimer's Association | Español
https://www.alz.org/inicio?lang=es-mx
A leading voluntary health organization in Alzheimer's care, support, and research.

Alzheimer's Los Angeles
https://www.alzheimersla.org/
A non-profit organization increasing awareness, delivering programs and services, providing support and advocating for quality care and a cure for Alzheimer's and dementia.

LatinosAgainstAlzheimer's | UsAgainstAlzheimer's
https://www.usagainstalzheimers.org/networks/latinos
A network of UsAgainstAlzheimer's promoting brain health equity and uniting Latino-serving organizations and leaders to stop Alzheimer's.

National Hispanic Council on Aging (NHCOA)
https://nhcoa.org/
The National Hispanic Council on Aging (NHCOA) is a leading national organization working to improve the lives of Hispanic older adults, their families, and caregivers.

Salud America!
https://salud-america.org/
A national Latino-focused organization that creates culturally relevant and research-based resources to inspire people to start and support healthy changes.

Valdosta Latino Association
https://valdostalatino.org/
A non-profit corporation supporting Hispanic and Latino residents in the South Georgia community.

Resource Hubs

Caregiver Resources in Spanish | U.S. Department of Veterans Affairs

https://www.caregiver.va.gov/pdfs/CaregiverResourcesEnglish-LinksInSpanish.pdf
A list of caregiver resources in Spanish

Health Topics/Temas de salud | National Institute on Aging

https://www.nia.nih.gov/espanol
A list of research-based, peer reviewed health information to learn about healthy aging and health conditions that frequently occur in older adults

Caregiver Resources | United Community Center

https://www.unitedcc.org/community-services/latino-geriatric-center/caregiver-resources/
A list of resources to support caregiving for older adults living with Alzheimer's or other forms of Dementia

Books

El manual para el cuidado de la demencia | Judy Cornish

https://thedawnmethod.com/manual-para-el-cuidado-de-la-demencia/
Introduces the DAWN Method approach to dementia care that is kind, person-centered and based on the person's strengths

Works Cited

1. Diaz-Santos, Mirella, et al. "Alzheimer's Disease in Bilingual Latinos: Clinical Decisions for Diagnosis and Treatment Planning." Journal of Health Service Psychology, 2021, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8507357/
2. "Hispanic Americans and Alzheimer's." Alzheimer's Association, https://www.alz.org/help-support/resources/hispanics-and-alzheimers
3. "Alzheimer's Disease and Related Dementias in the Hispanic/Latino Community." Dementia Friendly America, https://www.dfamerica.org/spotlight/2021/9/2/alzheimers-disease-and-related-dementias-in-the-hispaniclatino-community
4. "Latinos and Alzheimer's Disease." Us Against Alzheimer's, https://www.usagainstalzheimers.org/networks/latinos
5. "Promising new Alzheimer's drugs may be less effective for Black patients." NBC News, 2023, https://www.nbcnews.com/news/nbcblk/alzheimers-drugs-leqembi-donanemab-may-benefit-black-people-less-rcna97298
6. "Care and Caregiver Programs." Latino Alzheimer's and Memory Disorders Alliance, https://www.latinoalzheimersalliance.org/care-caregiver-programs
7. "How to Raise Awareness About Dementia in Hispanic/Latino Older Adults." MHP Salud, 2021, https://mhpsalud.org/dementia/
8. Spichak, Simon. "In These 10 U.S. Counties, 1 in 6 People Over 65 Have Alzheimer's Disease." Being Patient, 2023, https://www.beingpatient.com/in-these-10-u-s-counties-1-in-6-people-over-65-have-alzheimers-disease/
9. Cabrera, L. Y., et al. "Knowledge and Attitudes of two Latino Groups about Alzheimer Disease: a Qualitative Study." Journal of cross-cultural gerontology, 2021, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8421275/
10. Lin, P. J., Emerson, et al. "Racial and Ethnic Differences in Knowledge About One's Dementia Status." Journal of the American Geriatrics Society, 2020, https://doi.org/10.1111/jgs.16442
11. Martinez, I. L., et al. "The Experience of Alzheimer's Disease Family Caregivers in a Latino Community: Expectations and Incongruences in Support Services." The journals of gerontology, 2021, https://doi.org/10.1093/geronb/gbab170
12. Sehar, U., et al. "Comprehensive Understanding of Hispanic Caregivers: Focus on Innovative Methods and Validations." Journal of Alzheimer's disease reports, 2023, https://doi.org/10.3233/ADR-220094
13. "Special Report: Race, Ethnicity and Alzheimer's in America." Alzheimer's Association, 2021, https://alz.org/media/Documents/alzheimers-facts-and-figures-special-report-2021.pdf
14. Quiroz, Y. T., et al. "Addressing the disparities in dementia risk, early detection and care in Latino populations: Highlights from the second Latinos & Alzheimer's Symposium." Alzheimer's & dementia: the journal of the Alzheimer's Association, 2022, https://doi.org/10.1002/alz.12589
15. Velasco-Mondragon, et al. "Hispanic health in the USA: a scoping review of the literature." Public health reviews, 2016, https://doi.org/10.1186/s40985-016-0043-2
16. Lin, P. J., et al. "Dementia Diagnosis Disparities by Race and Ethnicity." Medical care, 2021, https://doi.org/10.1097/MLR.0000000000001577
17. Balch, Bridget. "The United States needs more Spanish-speaking physicians." Association of

American Medical Colleges, 2023, https://www.aamc.org/news/united-states-needs-more-spanish-speaking-physicians/

18. "Latinx/Hispanic Communities and Mental Health." Mental Health America, https://www.mhanational.org/issues/latinxhispanic-communities-and-mental-health/
19. "Communication and Long-Term Care: Technology Use and Cultural Barriers among Hispanics." Associated Press-NORC, 2018, https://apnorc.org/projects/communication-and-long-term-care-technology-use-and-cultural-barriers-among-hispanics/
20. "Up to 85% of people living with dementia may not receive post-diagnosis care – World Alzheimer Report reveals." Alzheimer's Disease International, 2022, https://www.alzint.org/news-events/news/up-to-85-of-people-living-with-dementia-may-not-receive-post-diagnosis-care-world-alzheimer-report-reveals/
21. Gamboa, Suzanne. "Americans way off on number of Latinos they think are undocumented, poll finds." NBC News, 2021, https://www.nbcnews.com/news/latino/americans-way-number-latinos-think-are-undocumented-poll-finds-rcna2464
22. Balakrishnan, A., Jordan, N. "The Undocumented Elderly: Coverage Gaps and Low Health Care Use." Journal of health care for the poor and underserved, 2019 https://doi.org/10.1353/hpu.2019.0062
23. Aranda, M. P., et al. "Impact of dementia: Health disparities, population trends, care interventions, and economic costs." Journal of the American Geriatrics Society, 2021 https://doi.org/10.1111/jgs.17345
24. Skaria, Anita. "The Economic and Societal Burden of Alzheimer Disease: Managed Care Considerations." American Journal of Managed Care, 2022, https://www.ajmc.com/view/the-economic-and-societal-burden-of-alzheimer-disease-managed-care-considerations
25. Creamer, John. "Poverty Rates for Blacks and Hispanics Reached Historic Lows in 2019." United States Census Bureau, 2020, https://www.census.gov/library/stories/2020/09/poverty-rates-for-blacks-and-hispanics-reached-historic-lows-in-2019.html#
26. Tyson, Alec., Lopez, Mark. "5 facts about Hispanic Americans and health care." Pew Research Center, 2023, https://www.pewresearch.org/short-reads/2023/10/30/5-facts-about-hispanic-americans-and-health-care/#
27. Janssen, Scott. "Trauma-Informed Dementia Care." Social Work Today, https://www.socialworktoday.com/archive/exc_0218.shtml#
28. "What is Posttraumatic Stress Disorder (PTSD)?" American Psychiatric Association, https://www.psychiatry.org/patients-families/ptsd/what-is-ptsd#
29. "Sleep Issues and Sundowning." Alzheimer's Association, https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning#
30. Smith, Marianne., et al. "History, Development, and Future of the Progressively Lowered Stress Threshold: A Conceptual Model for Dementia Care." Journal of the American Geriatrics Society, 2004, https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/j.1532-5415.2004.52473.x
31. Smith, Marianne., et al. "Application of the Progressively Lowered Stress Threshold Model Across the Continuum of Care." The Nursing clinics of North America, 2005, https://pubmed.ncbi.nlm.nih.gov/16492454/
32. Kovach, Christine., et al. "A Model of Consequences of Need-Driven, Dementia-Compromised Behavior." Journal of Nursing Scholarship, 2005, https://sigmapubs.onlinelibrary.wiley.com/doi/10.1111/j.1547-5069.2005.00025_1.x
33. "Managing Triggers". Research Institute for Aging, 2007, https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Managing-Triggers_AODA.pdf
34. Cohen-Mansfield, Jiska., et al. "Which unmet needs contribute to behavior problems in persons with advanced dementia?" Psychiatry Research, 2015, https://www.sciencedirect.com/science/article/abs/pii/S0165178115002012?via%3Dihub#