

Caregiving a concern as Hispanic community in U.S. ages faster

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Caregiving has been part of María Aranda's life since she was a young



girl, when her Puerto Rican grandmother and namesake lived with her family in the Los Angeles area. She remembers watching her mother and other family members care for her grandmother for years before she died of heart disease.

"Ever since, I always found myself gravitating towards working with older adults," said Aranda, executive director of the Edward R. Roybal Institute on Aging at the University of Southern California Suzanne Dworak-Peck School of Social Work. She and her sister are now caring for their 91-year-old mother, who also has heart disease.

For many Hispanic/Latino people in the U.S., caregiving is a natural part of family life. Among Mexican Americans, for example, family caregiving has been a cultural norm even under extreme circumstances. However, research suggests that sense of familism may be fading as younger generations become more acculturated or individualistic due to personal circumstances such as work obligations.

Ensuring caretakers and recipients of care have the resources they need is a concern: A recent census report shows the Hispanic community aged at a faster rate than the rest of the U.S. population between 2010 and 2020.

In 2020, the Hispanic community in the U.S. reached a median age of 30, up 2.7 years from 2010 and 4.2 years from 2000. The non-Hispanic population's median age was older, around 41, an increase of just 1.5 years from 2010.

The number of Hispanic adults 65 and older has nearly tripled since 2000 to about 4.9 million in 2020. By 2060, that number is projected to quadruple.

"I actually have a sign outside my office that says, 'If aging is not your



issue, it soon will be," said Adriana Pérez, an associate professor of nursing and the Anthony Buividas Term Chair in Gerontology at the University of Pennsylvania in Philadelphia.

What a Latino caregiver looks like

The U.S. Latino community faces unique challenges when it comes to caring for older <u>family members</u>. Latino caregivers are an average 43 years old, younger than other racial and <u>ethnic groups</u>, according to a National Alliance for Caregiving report. Typically, the person they care for is about 67 years old with more than one medical condition.

Latino caregivers report more financial and personal strain and often have full- or part-time jobs, "so juggling the responsibilities of caregiving and work is a tightrope," Aranda said. Many of them are simultaneously caring for children under 18 and thus face the compounded challenges of the "sandwich caregiver."

The challenges mean it's less likely Latino caregivers know what resources are available to help them, Aranda said. The NAC report shows Latinos use the fewest sources of caregiving help or information of any demographic.

"One of the main challenges (for Latino caregivers) is the lack of outreach," Pérez said. Resources often aren't always available in Spanish. Lower income and a lower rate of medical insurance put health services even further out of reach, she said.

The alphabet soup of programs and services to help older adults and their caregivers are often under-resourced and overwhelmed by the number of people who need care, Pérez said.



Caregivers and dementia

Caring for someone with dementia can be taxing, Aranda said. That person may be easily agitated and restless or dealing with delusions or hallucinations, she said. These symptoms can be particularly stressful for a family caregiver who's less likely to have the knowledge or training to manage these types of behavior.

Older Latino adults are 1.5 times more likely to have dementia than their white counterparts, according to the Centers for Disease Control and Prevention.

As dementia advances, the person loses executive function—the ability to learn, plan and manage everyday tasks, including decision-making. Caregivers may find themselves with added responsibilities such as decision-making about health care and finances for that person.

The lack of representation in <u>clinical research</u> is another barrier to properly addressing dementia. Aranda and Pérez were co-authors of a 2023 report published in Alzheimer's & Dementia: Translational Research & Clinical Interventions that showed the Latino community has been severely underrepresented in <u>clinical studies</u> for Alzheimer's disease and related dementias because of inadequate outreach, including a lack of funding and bilingual workforce.

Census data shows the Hispanic community makes up nearly 20% of the total U.S. population. Yet they make up just 6% of participants in U.S.-based clinical trials that reported ethnicity data, according to a 2022 study in The Lancet Regional Health-Americas.

It's not just because of a lack of outreach and higher uninsured rates. It's also a result of higher distrust of <u>clinical trials</u> within the Latino community, research shows.



Connection and community

Caregivers and the people they care for will need community bonds as Latinos age more quickly than others, Aranda and Pérez said.

In the 1980s, Aranda founded the first Spanish-speaking support group for families affected by Alzheimer's disease and has developed services to address their clinical, social and resource needs. Caregivers voice their challenges, share advice and techniques, and learn about additional resources available to them.

"It's like night and day," she said. "The caregiver realizes they are not alone, and that other people are going through a similar situation. That is empowering."

Aranda, who also is the Margaret W. Driscoll/Louise M. Clevenger Professor of Social Policy and Administration at USC, is currently testing a caregiver psychoeducational intervention in English and Spanish for family caregivers of people living with dementia.

In Philadelphia, Pérez is in the middle of a study to track cognitive health, heart health and sleep health among older Latino adults. The Tiempo Juntos study is looking at the effect of regular exercise on Latino people 55 and older who aren't physically active. Group walks and subsequent health checks provide both community and vital information on health outcomes, she said.

In July, the U.S. Department of Health and Human Services unveiled a new model that aims to relieve the strain on unpaid caregivers. Called Guiding an Improved Dementia Experience, the program intends to provide care coordination and management, <u>caregiver</u> education and support, and respite services. Pérez said she hopes GUIDE will focus on diverse populations—the Latino community in particular with the least



access to resources.

"In order for us to address the inequities that exist in health care, the burden can't just be on Latino scientists or Latino <u>health care</u> providers," Pérez said. "It's a responsibility for everyone."

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