

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. A-LIST surveys gather data and personal insights to better understand and share the collective experience of living with this disease and caring for a loved one. We call it the "science of us."



The Pulse of the Community

What Matters Most

The mission of the A-LIST is to use data to make life better for the Alzheimer's and dementia community. UsAgainstAlzheimer's shares anonymous findings with policymakers, researchers, health care providers, public health officials, drug developers, insurers and others who serve this community to ensure they consider these insights when making decisions affecting people living with the disease and their caregivers.

Latino Caregiver Study

The A-LIST is committed to researching what matters most to all of those affected by Alzheimer's. Recently we had the opportunity to recruit participants for a study focused on Latino family caregivers. This study was conducted by Jaime Perales-Puchalt, PhD, MPH of the University of Kansas Alzheimer's Disease Research Center. Dr. Perales-Puchalt wanted to learn whether caregiver support delivered through text messaging might address some barriers for Latino family caregivers.

Latinos are 1.5 times more likely than non-Latino whites to develop Alzheimer's disease, due in part to increased incidence of risk factors for Alzheimer's such as high blood pressure, heart disease, diabetes and stroke.

Family caregivers for people with dementia often experience an emotional, physical, and financial toll. Latino caregivers typically experience higher levels of depression and poor health, and less access to support and resources because of barriers like unreliable transportation, high costs and language.

Dr. Perales-Puchalt tested a bilingual intervention program called "CuidaTEXT." The main questions he wanted to answer were:

- Does delivering caregiver support through a text-based program work?
- Would the program be effective in lowering depression and stress, and help caregivers feel more prepared?
- Is it worthwhile to conduct a larger study on this intervention program?

Study participants received daily text messages and could ask for information on specific topics or text live with a support provider.

Sample texts:

Check out this video that explains how to do mindfulness meditations to relax.

What 3 things are you grateful for today? Better small than big things. Example: feeling the breeze, eating a food you like or being with your loved one.

Findings

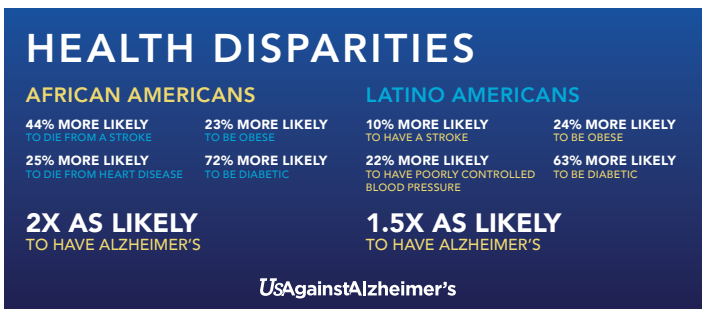
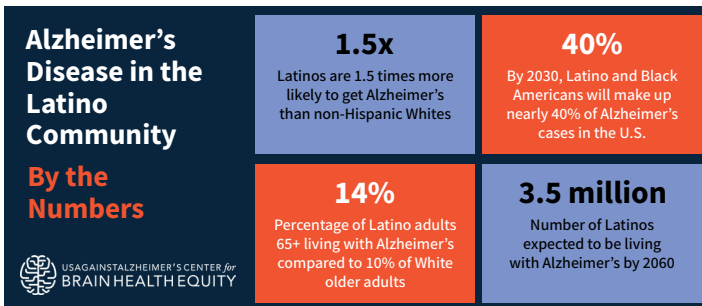
The study found that CuidaTEXT is:

- Feasible
- Leads to high levels of satisfaction and perception of helpfulness, and holds promise in improving caregiver outcomes
- More research should be done on the program

Click [here](#) to see the poster Dr. Perales-Puchalt presented at the 2022 Alzheimer's Association International Conference.

Alzheimer's Disparities

Alzheimer's disease disproportionately affects Latino peoples, as well as African American people and women. As our nation ages and becomes more diverse, UsAgainstAlzheimer's is accelerating efforts to promote brain health across lifespans through culturally-tailored, data-driven public health strategies and partnerships.



The A-LIST strives to build a diverse cohort, reflective of the real-life population of those with Alzheimer's and those who care for them, and offers research on what matters most to patients and caregivers.

And UsAgainstAlzheimer's has two key programs that champion health equity and access for those who are disproportionately impacted by the disease.

UsAgainstAlzheimer's Center for Brain Health Equity

The [UsAgainstAlzheimer's Center for Brain Health Equity](#) is a hub for collaboration focused on:

- Educating and mobilizing minority-serving health providers
- Making culturally-tailored brain health resources accessible to people of color
- Empowering community partners and policymakers with public health data on brain health inequities

This work is in partnership with the National Association of Hispanic Nurses and National Black Nurses Association. It is made possible by a cooperative agreement with the Centers for Disease Control and Prevention's Healthy Brain Initiative.

NADEX

The [National Alzheimer's Disease Index™ \(NADEX\)](#) is a public health tool that aggregates Medicare data to enable the field to visualize and analyze Alzheimer's health statistics by geography and demographics. Guided by an interdisciplinary working group of experts, the tool will help catalyze the health system change needed to advance health equity in Alzheimer's research and health services.

These two data-driven initiatives have narrowed equity gaps in access to brain health education, health services, research and care, and raised the visibility of the impacts of brain health inequities on families and communities.



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