


Let's Talk About Alzheimer's: Knowledge, Attitudes and Behaviors of Caregivers

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Magdalena Castro Lewis
Vice President for Programs



Presenter Disclosures

Magdalena Castro Lewis

(1) The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

“No relationships to disclose”




THE NATIONAL ALLIANCE FOR HISPANIC HEALTH (THE ALLIANCE)

Vision: Strong healthy communities whose contributions are recognized by a society that fosters the health, well-being, and prosperity of all its members.

Mission: Improve the health of Hispanic communities and work with others to secure health for all.

We are unique:

- Since 1973 represent all Hispanic groups.
- Dedicated to community-based solutions.
- No funds from tobacco or alcohol companies.



The Initiative: Let's Talk About Alzheimer's

GOAL:

To develop a culturally and linguistically appropriate strategic framework and resources that will effectively reach Hispanic consumers with messages and materials to increase understanding of Alzheimer's Disease



Program Outcomes

- Conducted environmental scan and review of resources
- Conducted Community panel discussions (CPD)
 - Caregivers
 - Health care providers
- Developed Resources





Environmental Scan Results

- Hispanics are 1.5 times more likely to develop AD.
- Literacy level affects tests.
- Hispanics experience more severe clinical symptoms at the start of the disease.
- Reviewed inventory of existing AD resources for Hispanics.



CPD - Methodology

- **Instrument**
- **Data Collection:**
 - Recruitment and Screening
 - Caregiver Profile/Exit Survey
 - Clinician Profile and Survey
- **Site Selection:**
 - Miami, FL
 - San Ysidro, CA
 - Philadelphia, PA






CPD – Methodology (cont.)

Hispanic Caregivers	Health Care Providers
<ul style="list-style-type: none"> • Self-identify as Hispanic • Speak, write, and read Spanish • Be at least 18 years of age • Be the caregiver of a family member • Be an unpaid family member or friend • Not know the other participants. 	<p>Primary care, general medicine, family medicine, or internal medicine</p> <p>At least one practicing :</p> <ul style="list-style-type: none"> • Neurology • Geriatrics • Psychiatry • Geriatric psychiatry

Results: Caregivers

- Have heard of AD, but learn at diagnosis.
- Tendency to ignore/denial symptoms.
- Misconception that memory loss is a normal part of aging.
- Negative opinion on care out of home.
- Main concerns:
 - Health of person with AD
 - Mental Health of caregiver
 - Financial issues

Results: Caregivers (Cont.)

- Adequate diagnostic testing in Spanish
- Not enough resources in Spanish
- Favored the Internet as a source of information
- Recognized the need for multiple formats to reach all audiences
- Messages should emphasize taking proactive steps to get the person checked by a HCP



Results: Providers

- Lack of knowledge about AD and its progression
- Tendency to ignore possible AD symptoms
- Misconception that memory loss is a normal part of aging
- Care out of home is not an option
- Adequate access to diagnostic tests in Spanish
- Emphasis on caregivers' own care
- Communication in a variety of forms



Recommendations

Strategic framework should target:

- General population
- Persons engaged in providing care
- Health care providers



Recommendations for Messages to General Population

- Basic Information about AD and its stages
- Promote detection of early signs and early diagnosis
- Signs and symptoms
- Memory loss misconceptions and denial
- Action steps
- Information you need to share with the HCP



Recommendations for Messages and Outreach

- Internet, television, and radio.
- Resource on local support groups
- Available in English and Spanish
- Written on 6th-8th grade reading level
- Concise
- Attractive layout



 National Alliance
for Hispanic Health
www.nahh.org

Recommendations from Caregivers

Content for caregivers should focus on:

- AD stages
- AD treatments
- Questions for providers
- Caregiving tips in each stage
- Coping with effects of AD on family
- Caregivers' health
- Out-of-home care
- End-of-life matters



