Let’s Talk About Alzheimer’s: Knowledge, Attitudes and Behaviors of Caregivers
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Presenter Disclosures
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(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.

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Program Outcomes

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

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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
• 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.

Health Care Providers
Primary care, general medicine, family medicine, or internal medicine
At least one practicing:
• 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

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