Eliciting Care Plan & Treatment Goals in ADRD from Latino Caregivers: A Chicago-Based Pilot Study

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Background

- Alzheimer’s disease or a related dementia (ADRD) is a progressive, multifaceted disease that can require constant care for 6 to 12 years of life and has a huge impact on caregivers and families.
- Recent studies indicate that the Latino community is 1.5 times more likely to develop ADRD than White non-Hispanics.
- Patient care plans often require input from these family caregivers, yet are often assessed by health care professionals, and very little is known about treatment outcomes in underrepresented groups.
- Preference elicitation methods such as best worst scaling (BWS) allows the assessment of trade-offs for competing treatment and care plan options as well as an understanding of what might be negotiable for family caregivers.

Study Goal and Aims

Overall Goal:
Understand how Latino caregivers (CG) value the benefits and harms of care management options for persons with Alzheimer’s disease and related dementias (ADRD) in the Latino community.

Study Aims:
1. Test the feasibility and implementation of a family-centered, Spanish-translated BWS instrument in a community-based setting with Latino caregivers.
2. To identify priorities in care management options from Latino caregivers.
3. Use both to inform caregiver decision making throughout ADRD care management.

Methodological Approach

Qualitative Foundation:
- In depth interviews and focus groups were conducted from July-November 2015 to identify, rank, and refine concepts that are important in the care management process for non-Hispanic white family caregivers (n=29).
- Two frameworks emerged from the focus groups discussions, one related to care plan and treatment priorities, the other related to overall care plan.
- The frameworks were used to inform caregiver decision making throughout ADRD care management.

Design:
Cross-sectional paper and pencil-based survey with a best worst scaling (BWS) experiment.

Sample:
Hispanic family caregivers (n=24) were recruited from the Chicago area in October 2018.

Data Collection:
- In depth interviews and focus groups were conducted from July-November 2015.
- A best worst scaling (BWS) experiment was conducted in the Latino community in Chicago.

BWS Sample Question

When selecting a care plan for your loved one, you will have several options. When you think about these goals, if the 8 items are shown, which are the most (W=1, 0=not important to your current care goals) and which are the least important (B=1, 0=not important to your current care goals)?

BWS Relative Ranking

\[ BWS = \sum (N_i - W_i) / N_i + T \]

8 = number of times attribute was chosen as best
W = number of times attribute was chosen as worst
N = number of times attributes appeared in BWS (7)
T = Total number of participants (16)

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Contact Information

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References


Future Directions

- Although a current survey for non-Hispanic whites has been conducted with caregivers (n=250) nationally using this BWS instrument, next steps may be varied with Latino caregivers.
- Translation, refinement, and expansion of the current BWS instrument is underway in various pilot sites around the United States in collaboration with UsAgainstAlzheimer’s.
- Current results from this study will be shared with national advocacy groups, local providers, and non-profit organizations who serve the Latino ADRD population in the United States.

Conclusions

- Although several challenges exist in engaging the Latino caregiver population, it is possible to adapt current BWS instruments into Spanish to begin to explore priorities in treatment outcomes in this population.
- Relative ranking of the statements presented indicated that Latino caregivers felt that behavioral modifications and interventions surrounding them in a community were more important than lifestyle modifications such as changes in living environments.
- Differences exist between non-Hispanic White caregivers, who comparatively felt medication was less important than social and living situation factors such as support and type of community.