

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 outcome preferences 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:

- Test the feasibility and implementation of a family-centered, Spanish-translated BWS instrument in a community-based setting with Latino caregivers.
- To identify priorities in care management options from Latino caregivers.
- 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 trade-offs (not shown) and one related to goals for the care plan and treatment options for family caregivers' loved ones.
- In order to understand care plan and treatment priorities, the goals framework was integrated into a pilot paper and pencil survey that was translated into Spanish and tested in the Latino community in Chicago.

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.
- Translated surveys were delivered via paper and pencil at a caregiver workshop and were collected at the end. Of the 24, 16 had useable, complete data.

BWS Analysis:

- Mean importance scores for each of the goal statements identified were calculated using the equation below, where:

$$B\overline{W}_i = \frac{\sum B_i - \sum W_i}{N_i * T}$$

B = number of times attribute was chosen as best
 W = number of times attribute was chosen as worst
 N_i = number of times attribute i appeared in BWS (7)
 T = Total number of participants (16)



Where Loving-Kindness Lives

Demographic Characteristics

Basic Demographics	N (16)	%
Relationship to Person with Dementia		
Child/Step-Child	8	50
Spouse/Partner	3	18.75
Grandchild	1	6.25
Other Relative	4	25
Age (years)		
<25	3	20
25-34	3	20
45-54	5	33.33
55-64	3	20
>65	1	6.67
Gender		
Male	3	18.75
Female	12	75
Other	1	6.25
Race		
Hispanic	16	100
Not Hispanic	0	0

Socioeconomic Demographics	N (16)	%
Education Level		
High School	5	31.25
College	9	56.25
Postgraduate	1	6.25
Other	1	6.25
Work Status		
Employed full-time	9	56.25
Employed part-time	0	0
Not Employed	4	25
Retired	1	6.25
Other	2	12.5

Table 1: Demographic and socioeconomic characteristics of caregivers are displayed (N=16).

BWS Sample Question

When selecting a care plan for your loved one, you may have several goals. When you think about these goals, of the 9 items show here, which is the MOST and LEAST important to you?

	Most Important	Least Important
They are not aggressive	<input type="radio"/>	<input type="radio"/>
They live at home with you	<input type="radio"/>	<input type="radio"/>
They live in a community specializing in memory care	<input type="radio"/>	<input type="radio"/>
They are able to have a daily routine	<input type="radio"/>	<input type="radio"/>
They live in a community with caregiving support	<input type="radio"/>	<input type="radio"/>
They take medication for their cognitive symptoms	<input type="radio"/>	<input type="radio"/>
They do not wander	<input type="radio"/>	<input type="radio"/>
They are able to sleep through the night	<input type="radio"/>	<input type="radio"/>
They participate in occupational and physical therapy	<input type="radio"/>	<input type="radio"/>

Figure 2: An example of a Case 1 BWS question is displayed. The BWS included 15 statements derived from prior qualitative work. Participants completed 15 questions, each displaying 7 statements at one time. They were asked to select ONE most important to their current care goals and ONE least important to their current care goals.

BWS Relative Ranking

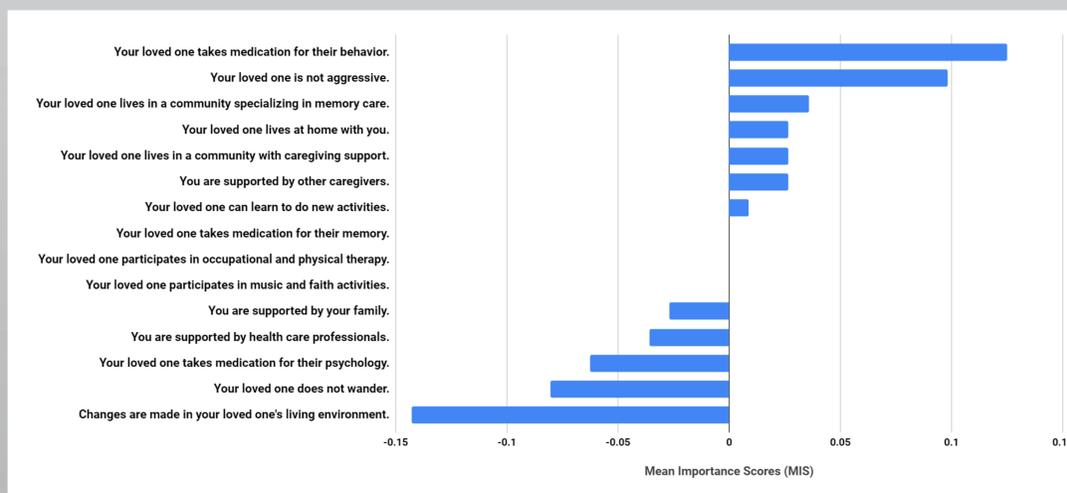


Figure 2: Mean Importance Scores (MIS) are displayed for each of the care plan goals for Latino caregivers who participated in the pilot study (N=16).

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.

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 survey will be shared with national advocacy groups, local providers, and non-profit organizations who serve the Latino ADRD population in the United States.

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Contact Information

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