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**Círculo de Cuidado (Circle of Care):  
A Randomized Controlled Trial to  
Assess the Benefits of a Cognitive  
Behavioral Group Intervention for  
Latino Families Coping with Dementia**

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I would also like to acknowledge the other members of the Boston University Research Team—

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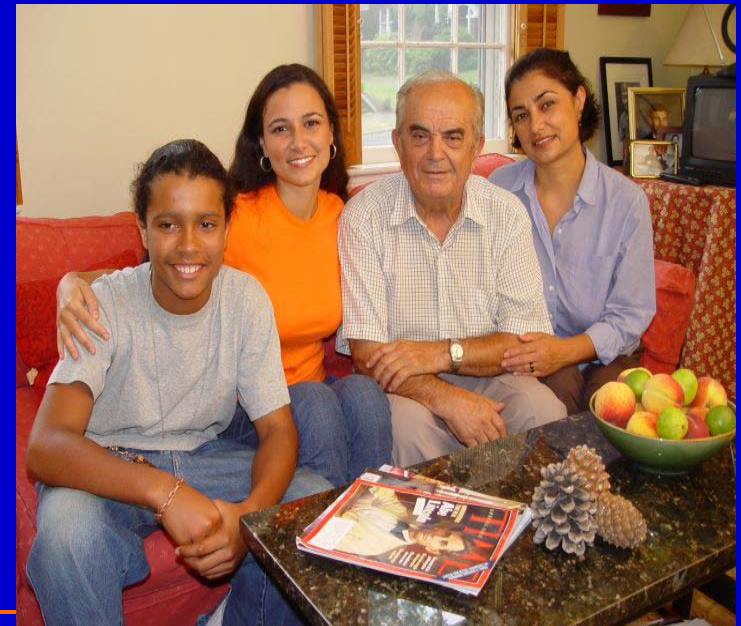
We are especially thankful to the family caregivers who participated in this research project.



# *Study Rationale & Importance:*

## *Why focus on Latino Alzheimer's (AD) caregivers?*

- Latinos are the fastest growing racial/ethnic group in the US older population. By 2050, the older Latino population will constitute 20%—or one out of every five—of the nation's seniors.
- Dementia rates are projected to increase more than six-fold among Latinos to 1.3 million by 2050.
- Research suggests that Latinos not only have a higher rate of AD than Anglos but they also experience an earlier average age of onset—about age 68 vs. age 73.
- Latino elders are more likely to live with other family members than Anglo elders; 80% of elderly Latino women live with relatives.



- Despite these statistics, many Latino elders and their family members are currently not receiving services to reduce their risk or manage their dementia—and Latinos are underrepresented in AD research studies.
- Llanque & Enriquez's (2012) literature review found only 10 intervention studies published between 2000-2011 specifically targeting Latino AD caregivers.
- 7 of the 10 studies were part of the NIH multi-site REACH Study; most were conducted in CA and FL, in large urban areas—primarily long-established Mexican or Cuban American communities.
- Yet, there are now 16 states with at least a half million Latino residents—many of these states have relatively newer established Latino communities.
- The U.S. Latino population is very heterogeneous; it is comprised of individuals of different racial backgrounds which come from more than 20 different countries.

## *Why focus on neuropsychiatric (NP) symptoms?*

- ❑ NP symptoms (i.e., apathy, depression, irritability, agitation, delusions) occur in more than 80% of individuals with AD.
- ❑ NP symptoms are major contributors to distress among family caregivers; they have been shown to be associated with caregiver burden.
- ❑ NP symptoms have been found to be a leading precipitant to nursing home placement.



## *Why test a short-term targeted cognitive behavioral intervention?*

- Systematic reviews of AD caregiver intervention studies suggest that targeted, multi-component interventions may be more effective than broader psychoeducational interventions.
- We were particularly interested in testing a shorter-term intervention as the duration of many research interventions often exceeds families' and agencies' resources—limiting their translation to the “real world.”
- In our prior research, we found that a 5-week CBT group targeting NP symptoms with Anglo caregivers improved their well-being. Thus, we wanted to extend this work to Latino caregivers.
- Importantly, in developing Circulo de Cuidado, there was an explicit objective to build the intervention on the cultural strengths that Latino families possess.
- To increase the relevancy to Latino families, modifications were made in recruitment approaches, curriculum content and delivery methods.

# *Study Design*

- The study was conducted in urban MA communities, a region in which the predominant Latino populations are from Puerto Rico & the Dominican Republic, 2 groups underrepresented in caregiver intervention studies.
- Through block randomization, 67 caregivers were assigned to 1 of 2 study arms: the cognitive behavioral treatment (CBT) experimental condition or the psychoeducational (PED) control condition.
- Participants were interviewed in Spanish in their homes by trained interviewers prior to the start of the group intervention (Time 1), at the end of the group (Time 2,) and three months later (Time 3) to assess the interventions' effects.



# *Five Core Hypotheses*

- Post-test and follow-up, it was predicted that CBT participants, as compared to PED participants, would report:
  - lower levels of neuropsychiatric symptom severity in their AD relatives [H1];
  - lower levels of caregiver neuropsychiatric symptom distress [H2];
  - a greater sense of caregiver self-efficacy [H3];
  - lower levels of caregiver depressive symptoms [H4]; and
  - [lower levels of caregiver anxiety [H5]





## *Methods- Outcome Measures*

The core outcomes were assessed with Spanish-language versions of the following standardized instruments:

- *Neuropsychiatric Symptom Inventory (NPI)* (Cummings et al., 1994)  
2 scales—Level of NP Impairment & Level of Caregiver Distress
- *Revised Scale for Caregiving Self Efficacy (RSCSE)* (Steffen, McKibben, Zeiss, Gallagher-Thompson, & Bandura, 2002)  
3 subscales scales—**Obtaining Respite**, Responding to Disruptive Behaviors & Controlling Upsetting Thoughts
- *Center for Epidemiological Studies-Depression Scale (CES-D)* (Radloff, 1977; Robinson, Gruman, Gazambide & Blank, 2002).
- *State Anxiety Inventory-State (STAI-S)* (Spielberger, et al, 1970).

## *Methods- Interventions*

- The structure of the 2 conditions—experimental & control—were identical. The groups ran over the course of 5 weeks, with each group meeting once a week for 90 minutes.
- Groups were small in size; dialogue, discussion & sharing were blended in throughout the session. There were refreshments to create a more “comfortable, sharing environment.”
- The manualized group interventions were conducted in Spanish by bilingual MSW social workers. Each participant also received a Spanish-language caregiver manual which had the 5-session content. [Attention was paid to language, stigma and literacy levels in creating the manuals]
- In the last session, each participant received a certificate honoring their completion of the group.
- The group leader followed up with 10-15 minute “coaching/check-in telephone calls” to the participants—3 wks, 6 wks, 9 wks & 12 wks post-group to reinforce the group’s focus/content.

# *CBT Intervention*

- The **cognitive behavioral intervention** had 3 core components: *behavioral management training, pleasant events training, and relaxation techniques.*
- In terms of **behavioral management training**, a significant amount of time was devoted to teaching caregivers the rationale and use of the A-B-C (antecedents-behaviors-consequences) problem-solving approach to behavior change.
- Caregivers learn to set reasonable goals and practice behavior modification or activation techniques to make successive approximation to larger goals.
- Although delivered in a group setting, the particular behavior focus was individualized or tailored to the specific concerns of each caregiver. For example, a caregiver might choose to focus on reducing agitation around bathing.

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- Increasing caregivers' and care recipients' engagement in pleasant activities and improving communication was also an important component of the intervention.
  - Once again, the type of pleasant activities was individualized and defined by the participant. And again, the focus was on setting reasonable goals. Examples, included doing home manicures together, listening to old radio novellas, and even driving the car to a spot to watch planes take off and land.
  - The third focus was on offering caregivers guidance in ways to better assess and manage their own levels of distress. Weekly sessions always end with the use of relaxation techniques or exercises.
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- The group leader used Bandura's 4 identified self-efficacy enhancing strategies to reinforce caregivers' sense of mastery of skills:
  - mastery experience
  - modeling
  - social persuasion, and
  - altering of emotional/somatic states.
- In addition to the group experience, participants had weekly assignments to practice the new skills/techniques at home and report back to the group on their experiences.



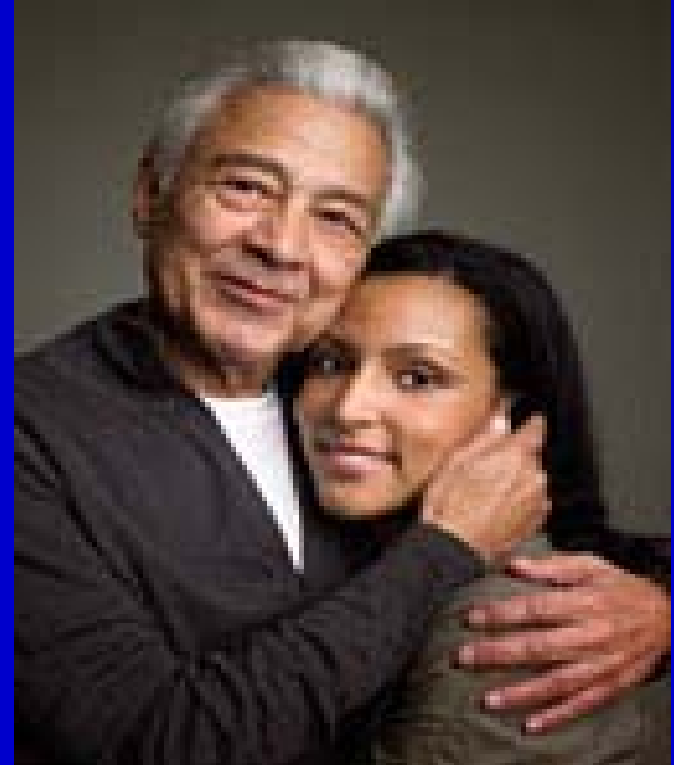
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# *PED Intervention*

- PED group was chosen to be the control condition. As the most commonly available resource for AD families, it was viewed as best representing the routine or standard group intervention.
  - It matched the CBT group in terms of structure, however, the sessions focused on educating caregivers about broad topics such as memory loss and the progression of AD, tips to finding community resources, home safety issues, and communication in the context of AD.
  - Weekly home assignments include tasks such as constructing an up-to-date list of the AD relative's medications
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# *Methods-Participant Eligibility*

- ***Participant Criteria were:***
  - The family member (or friend) provided a weekly minimum of 5 hours of caregiving.
  - The caregiver identified their relative as having a diagnosis of AD.
  - The care recipient was experiencing at least 1 NP symptom (based on the NPI).
  - The caregiver was willing to accept random assignment.



# ***Outreach Strategies- Use of Networks & Media***

## ***Finding “Hidden Families”***

Examples:



- Spanish-language Local Cable TV
- Spanish-language Radio Programs
- Spanish-language Community Newspapers
- Posting of flyers in neighborhood Latino markets and agencies
- Senior Subsidized Housing-Presentations, Staff & Posted Flyers
- Aging Services Access Points (ASAPs)/Home Care
- Latino Community/Service Organizations



# *Methods- Analysis*

- Analysis was undertaken using SPSS v20; we chose a 2-tailed value of  $p < .05$  as the criterion for statistical significance. Our analysis is based on the 57 caregivers who completed assessments at all 3 timepoints.
- Our 1<sup>st</sup> analytic step was to examine the baseline characteristics of the caregivers and AD relatives on demographic and outcome variables (using  $\chi^2$  and ANOVA tests) to identify possible differences between the intervention group and the control group participants.
- Our 2<sup>nd</sup> analytic step, was to use multivariate repeated measures ANOVA was used to test the study's core hypotheses. We considered the condition x time interaction effects to be most important because we hypothesized significant different changes over time in outcomes for participants in the two arms of the study rather than significant main effects of condition or time.

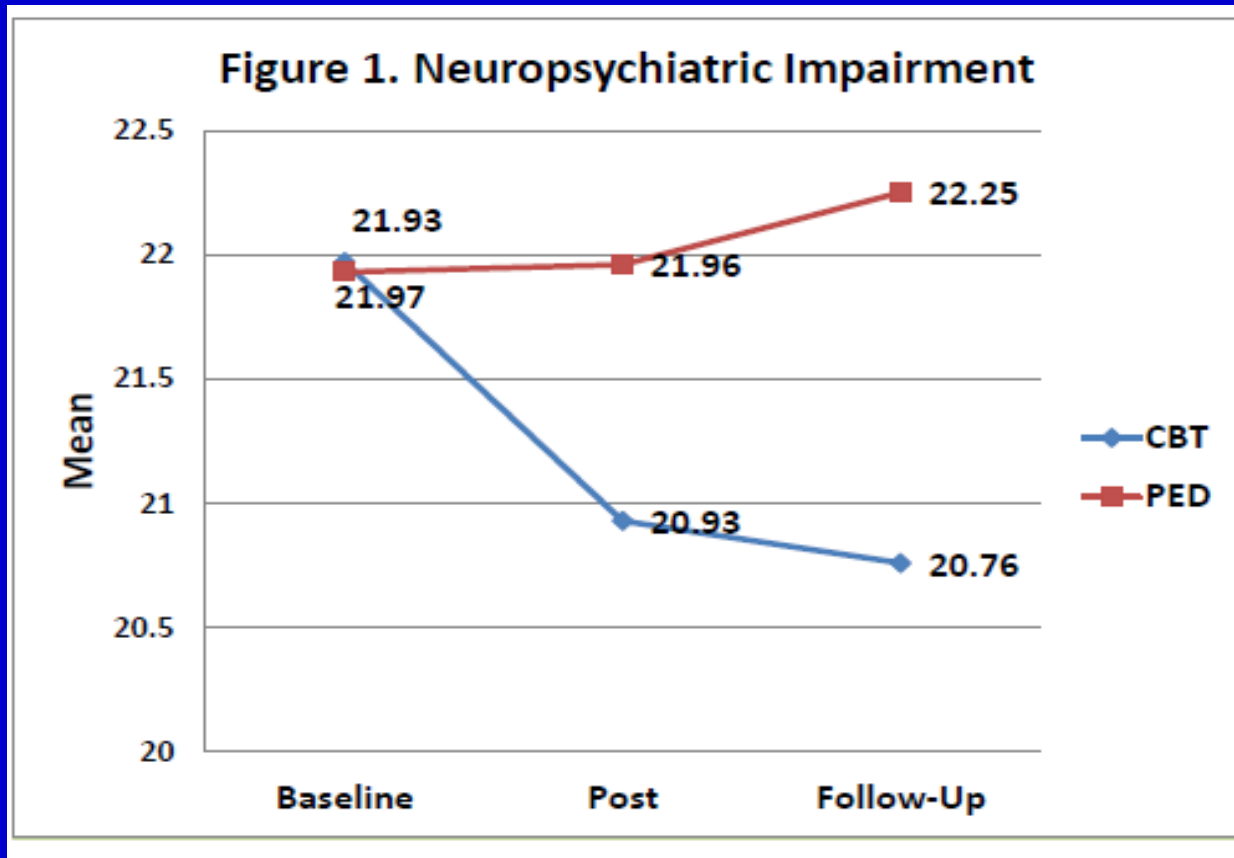
Caregiver Characteristics	% or Mean (SD)
Gender, Female	97%
Relationship	
Spouse	22%
Child	61%
Other	17%
Age, years	54.6 (3.1)
Family's Cultural Roots	
Puerto Rican	37%
Dominican	47%
Other	16%
Childhood Primarily Outside US Mainland, Yes	75%
Primary Language Spoken at Home	
Spanish	67%
Bilingual-Spanish & English	32%
English	1%
Education-Highest Degree	
Less than High School	26%
High School Degree or GED	45%
Associate or Technical Degree	23%
Bachelor Degree	5%
Annual Household Income	
Less than \$10,000	15%
\$10,000-\$20,000	26%
\$20,001-\$30,000	26%
Greater than \$30,000	33%

<b>Care Recipient Characteristics</b>	<b>% or Mean</b>
<b>Gender, Female</b>	<b>64%</b>
<b>Age, years</b>	<b>75 years</b>
<b>Childhood Primarily Outside US Mainland, Yes</b>	<b>96%</b>
<b>Primary Language Spoken at Home, Spanish</b>	<b>93%</b>
<b>Lived in Same Household as Caregiver, Yes</b>	<b>63%</b>

## Baseline Comparison of Caregivers on Outcome Measures: CBT and PED Groups

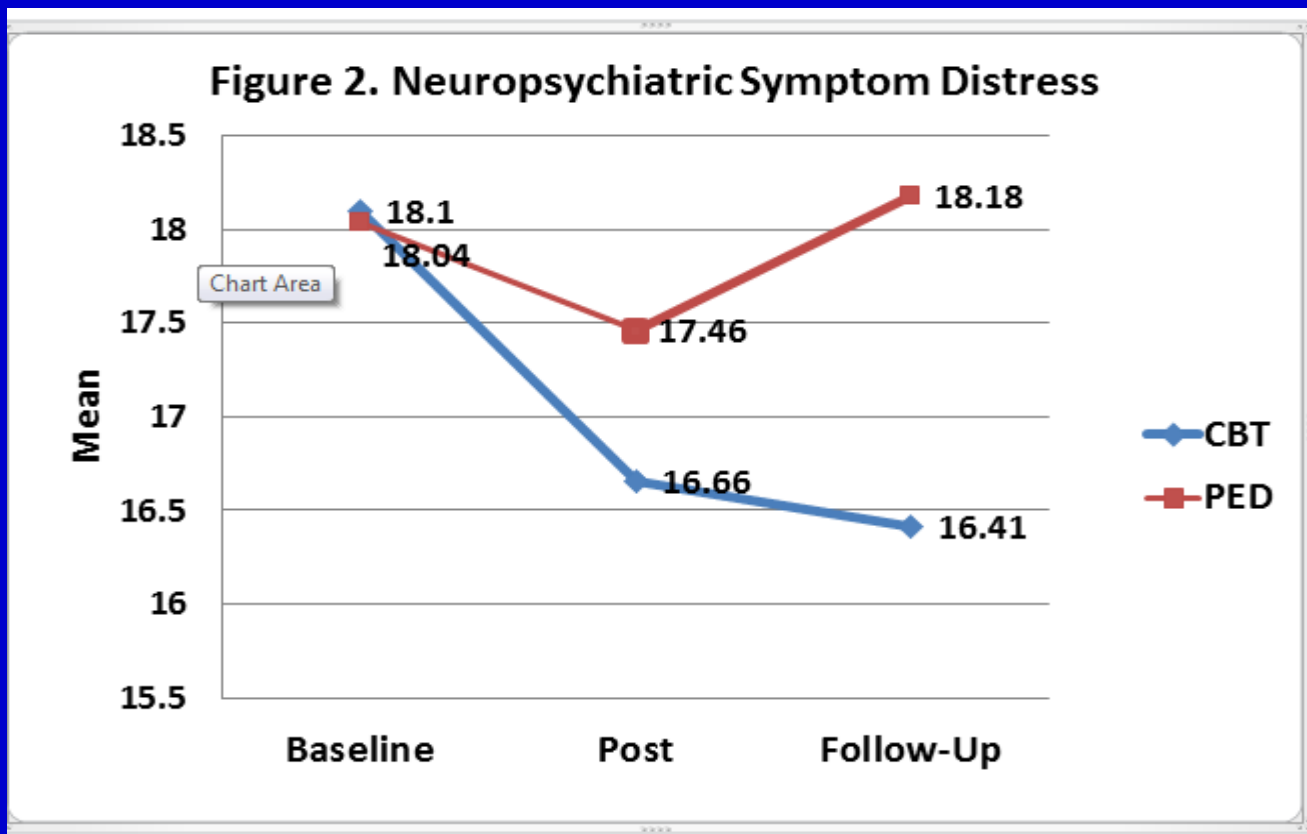
Outcome Measures	CBT (n= 29)		PED (n= 28)		t <sub>(55)</sub>
	M	SD	M	SD	
Neuropsychiatric Inventory Severity Scale (NPI-S)	21.97	7.63	21.93	8.03	-0.02
Neuropsychiatric Inventory Distress Scale (NPI-D)	18.10	7.45	18.04	7.56	-0.03
Revised Scale for Caregiver Self-Efficacy (RSCSE)	68.44	12.79	68.87	8.66	0.15
Center for Epidemiological Studies-Depression Scale (CES-D)	14.24	6.37	14.36	6.24	0.07
State-Trait Anxiety Inventory (STAI) State Scale	38.83	12.50	36.68	10.71	-0.69

**COMPARISON OF THE 2 GROUPS (CBT AND PED) AT BASELINE REVEALED NO SIGNIFICANT DIFFERENCES IN CAREGIVER AND CARE RECIPIENT CHARACTERISTICS AND OUTCOME MEASURES.**



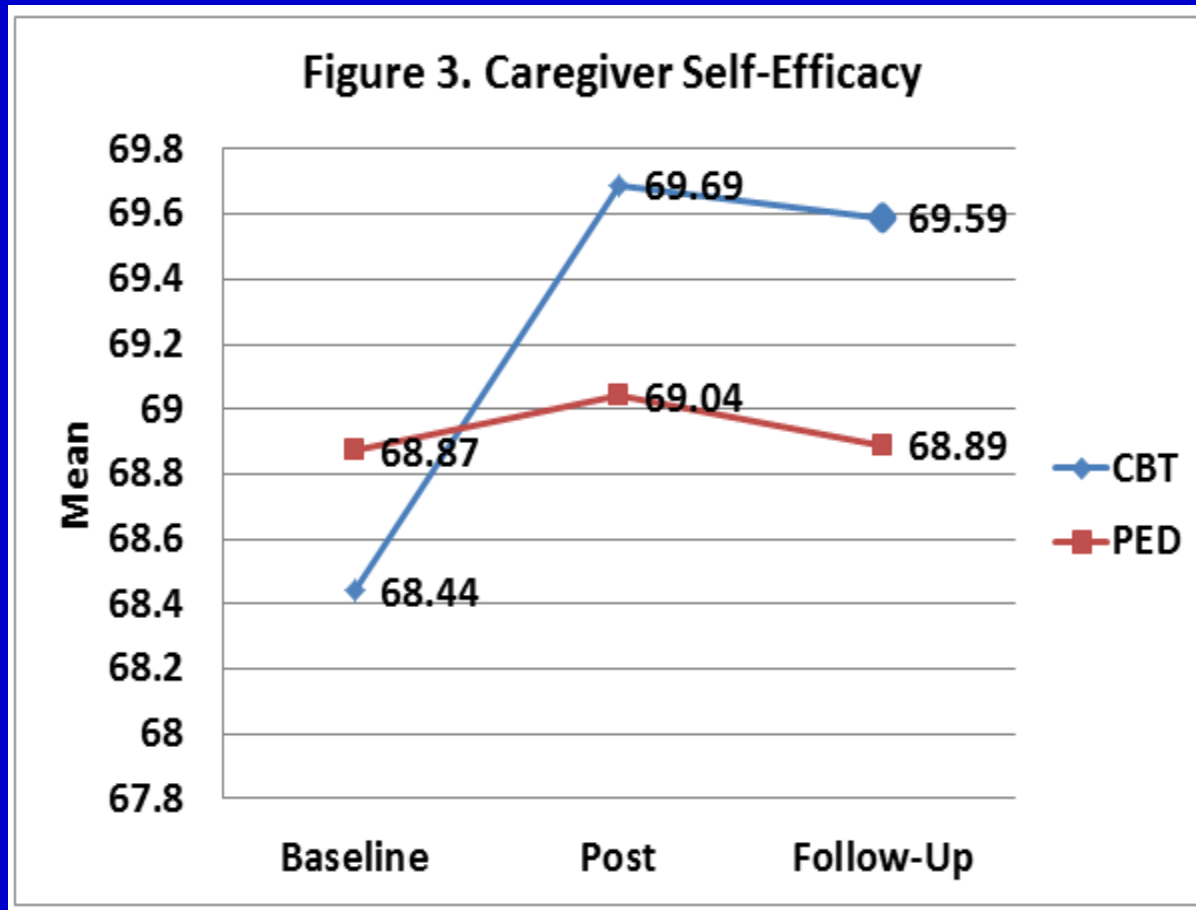
**Hypothesis 1 was supported: Over time, CBT participants, as compared to PED participants, reported significantly lower levels of NP symptom severity.**

There was a significant condition x time effect ( $F=16.51, p=.001$ ).



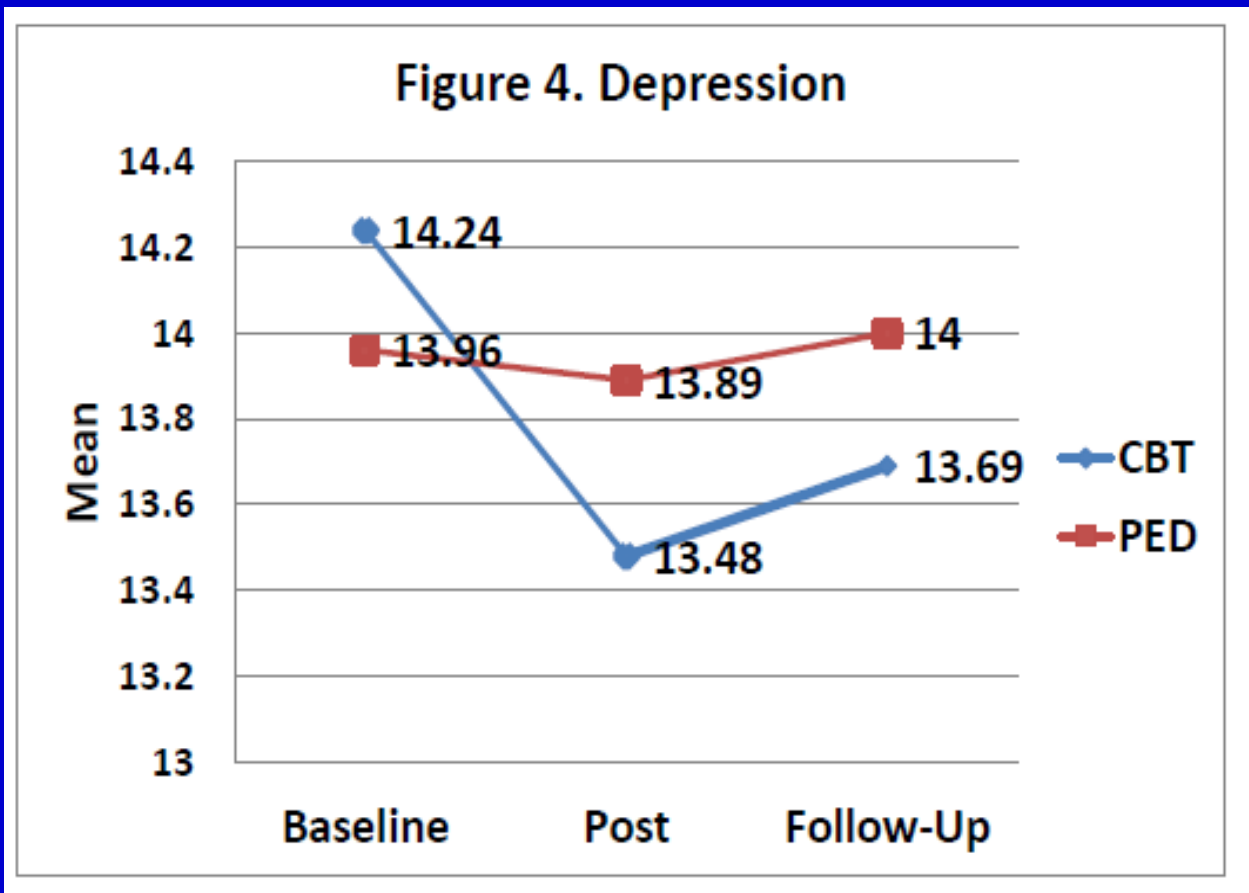
**Hypothesis 2 was supported: Over time, CBT participants as compared to PED participants, reported significantly lower levels of distress to NP symptoms.**

There was a significant condition x time effect ( $F=24.91$ ,  $p=.001$ ).



**Hypothesis 3 was supported: Over time, CBT participants, as compared to PED participants reported a significantly higher sense of self-efficacy.**

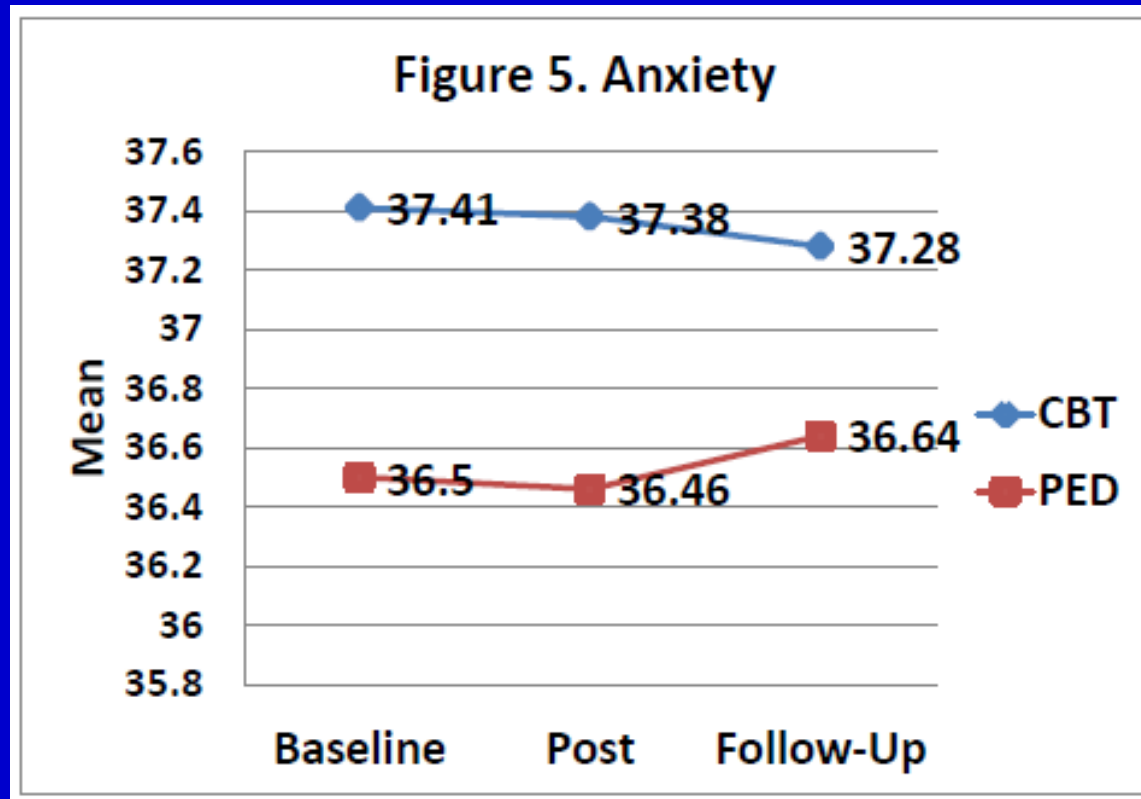
There was a significant condition x time effect ( $F=14.48$ ,  $p=.001$ ).



**Hypothesis 4 was supported: Over time, CBT participants, as compared to PED participants, reported significantly lower levels of depressive symptoms.**

There was a significant condition x time effect ( $F=5.93, p=.001$ ).





Hypothesis 5 was not supported; No significant difference was found in CBT and PED participants' anxiety levels over time ( $F=1.51, p.05$ ).

## *Conclusions*

- 2 Methodological limitations:
    - (1) the study findings are based on a relatively small sample size; and
    - (2) impact was only assessed at post-group & 3 month follow up.
  
  - Important Contributions to the Field:
    - Our study is one of a small number of scientifically rigorous evaluations of a culturally-relevant, theoretically-driven intervention with Latino AD populations.
  
    - It demonstrates that structured, multicomponent CBT interventions are superior to the more widely used PED interventions. PED interventions are relatively easy to implement; yet, our study joins a growing body of research which suggests this type of intervention offers very limited psychological benefits to caregivers.
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- Our study demonstrates that, even within a shorter-term group experience, interventions can be individualized or person-centered to address the specific concerns of each caregiver.
- Our findings support the importance of developing culturally specific interventions, which are built on the cultural strengths of Latino families, to increase their access to valuable resources, support their desire to care for their loved ones, and to alleviate the stresses associated with caregiving.

**THANK YOU!**

