



For people with intellectual  
and developmental disabilities

# “Caring for Myself”: A health promotion program for family caregivers of persons with IDD

Sandy Magaña, PhD, MSW

Miguel Morales, MPH

Judith S. Rocha, MSW, LCSW



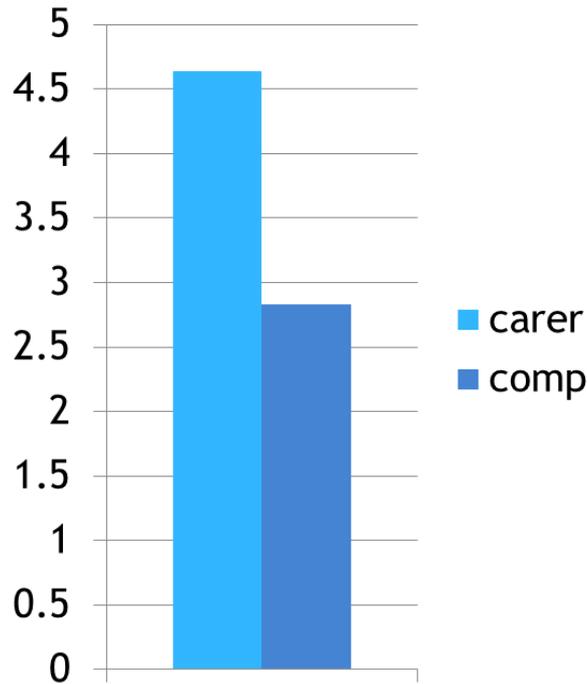
*Achieve with us.®*

**UIC** UNIVERSITY OF ILLINOIS AT CHICAGO

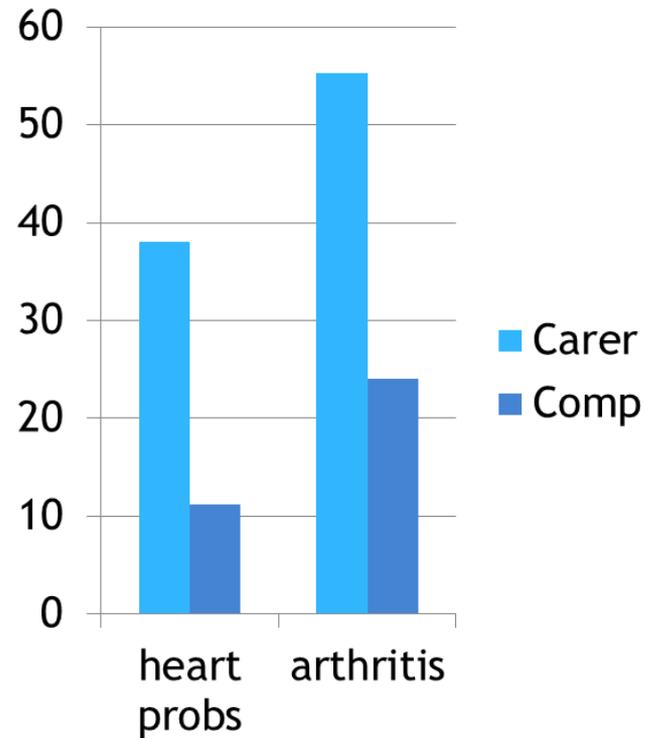
# Background

- Over half of adults with intellectual & developmental disabilities(IDD) live with families
- Latinos & African Americans with IDD are more likely to live with families
- People of color experience social, economic and cultural conditions often not shared by Whites
  - Chronic exposure to many stressors
  - Language barriers
- Health disparities – especially chronic conditions

# Previous Research: NHIS Study – Latinas and Depression



**Depressive symptoms**



**Chronic health conditions**

# Latinos and Health Care

- Latinos have lower access to care and poorer quality of care



Language barriers



Immigration status



Poverty



Discrimination



Unfavorable working conditions

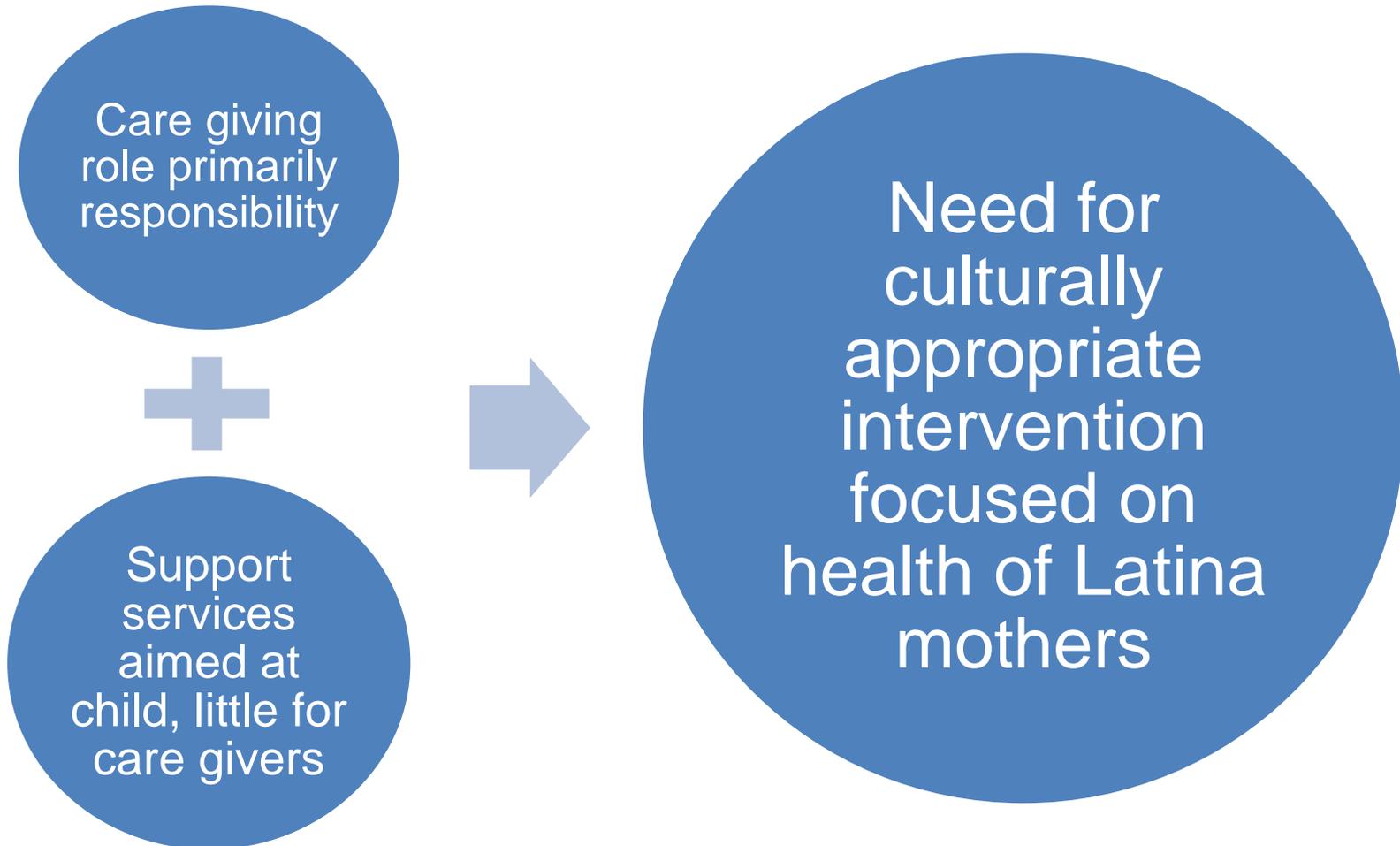


Lack of familiarity with healthcare system



Lack of Social Support

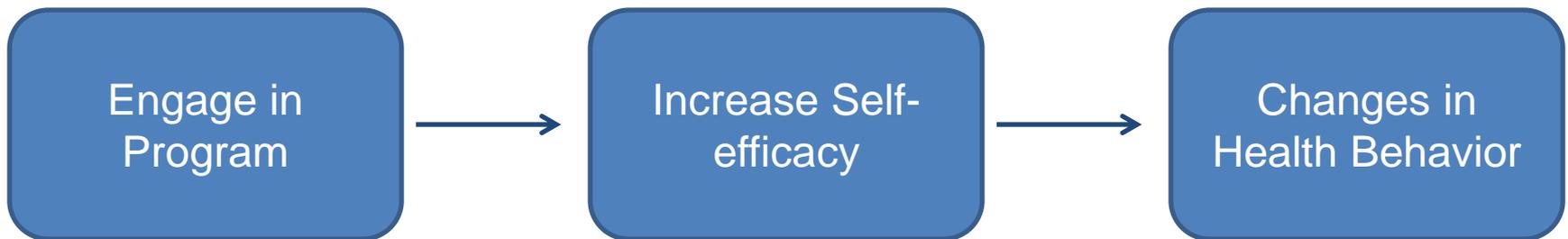
# Supportive Services for Latina Mothers of Children with IDD





# Theoretical Framework

- Self-Efficacy Theory (Bandura)
  - Engaging in health education program, participants feel more confident in carrying out behavioral changes (self-efficacy), leading to changes in health behaviors



# Research Questions



1) Do caregivers show greater increases in self-efficacy compared to control group?



2) Do they show greater improvements in health behaviors?  
3) Reductions in depressive symptoms?



4) Do older caregivers have better or worse outcomes than younger caregivers?

# By Caring for Myself Curriculum

- Eight week health education program



- **Session One:** Taking care of oneself & pre-test



- **Session Two:** Health care



- **Session Three:** Well-being activity



- **Session Four:** Nutrition



- **Session Five:** Exercise



- **Session Six:** Stress & depression



- **Session Seven:** Including others



- **Session Eight:** How to sustain growth & post-test

# Program Content

- **Manual**

- Emphasized dialogue and was culturally relevant. Example, how can we make our traditional recipes healthier



De acuerdo a MiPlato, aproximadamente la mitad de lo que usted come **en un día** deben ser frutas y verduras. A lo mejor esto le suena un poco extraño porque normalmente no comemos los alimentos de forma separada. A lo mejor de la manera que usted come se asemeja más a estos dibujos que contienen un poco de todo. Los 5 grupos que sugiere MiPlato nos ayudará a entender mejor la forma en que nos alimentamos.



# Other Cultural Elements

- Promotoras introduce topics by discussing food or exercise habits they had in their country of origin (or in the past) and how it is different now
- Several of the sessions begin with an inspirational or thought provoking story (cuento), phrase or saying (dicho)
  - This is an element that promotoras taught us as we were piloting the intervention

# Recruitment



# Methods

- Design
  - Randomized control trial
- Measures
  - Health related self-efficacy
    - Self-Efficacy Scales for Health-related Diet and Exercise Behaviors
  - Depressive symptoms
    - Center for Epidemiology Studies Depression Scale (CES-D)
  - Positive health behaviors
    - Adaptation of the Family Habits Scale

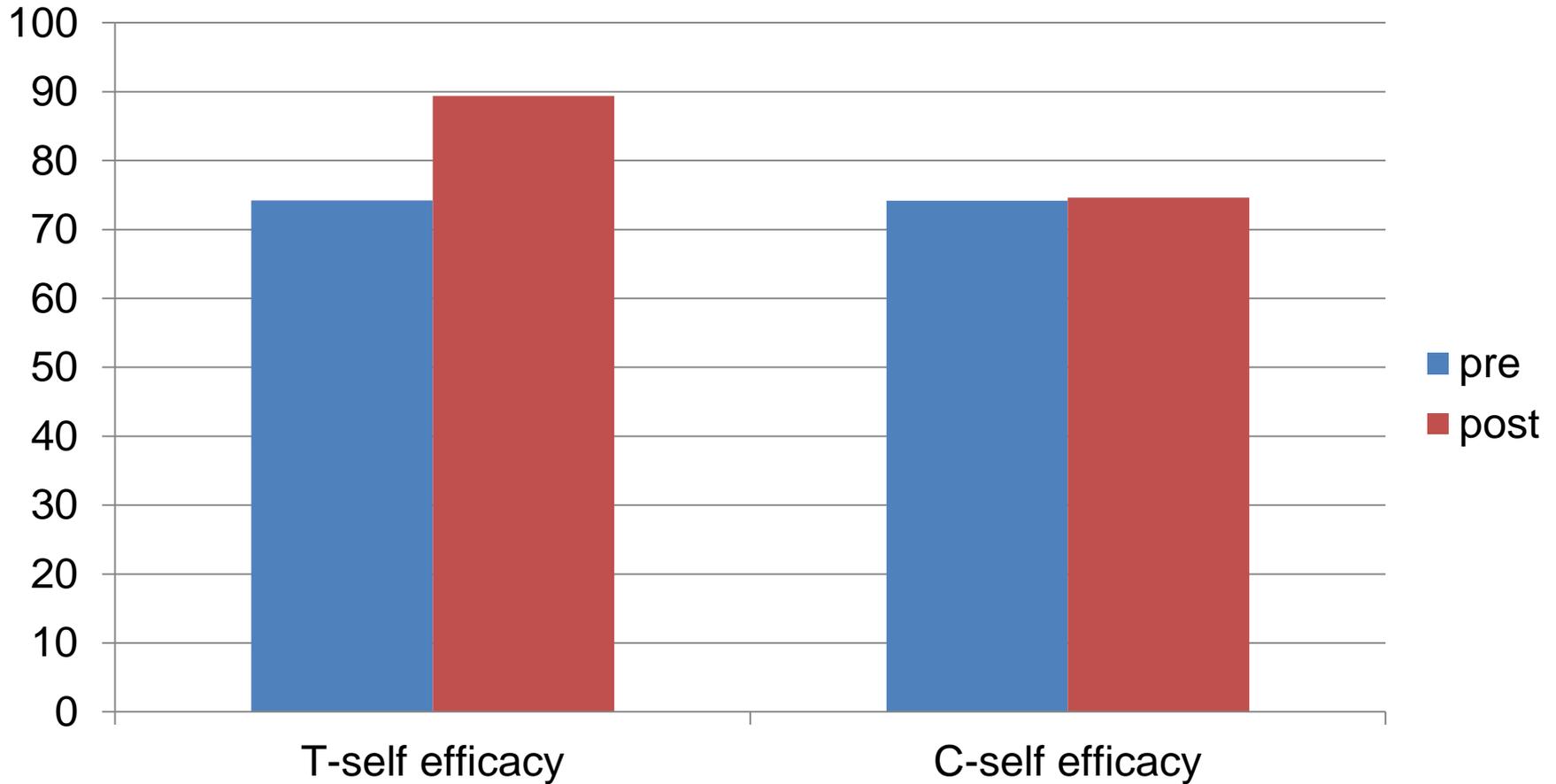
# Methods

- Quantitative analysis
  - Repeated Measures Analysis of Covariance (RM-ANCOVA)
- Qualitative Analysis
  - Focus groups audio recorded and transcribed
  - Content analysis
    - Iterative process--two people independently reviewed transcripts, came together, reread transcripts, etc.

<b>Maternal Characteristics</b>	<b>Intervention (n=42)</b>	<b>Control (n=48)</b>
Mean age (SD)	43.5 (9.3)	45.0 (7.8)
Percent 50 and older	31.0	22.9
Level of education (percent)		
less than high school	78.3	80.0
high school or more	21.7	20.0
Income (percent)		
0 to \$19,999	43.8	30.0
\$20,000 and up	56.2	70.0
Percent employed	24.5	46.9*
Percent married or living together	76.0	82.0
Percent foreign born	92.0	96.0
Ethnicity (percent)		
Mexican descent	94.0	98.0
Percent good/excellent health	38.0	22.0

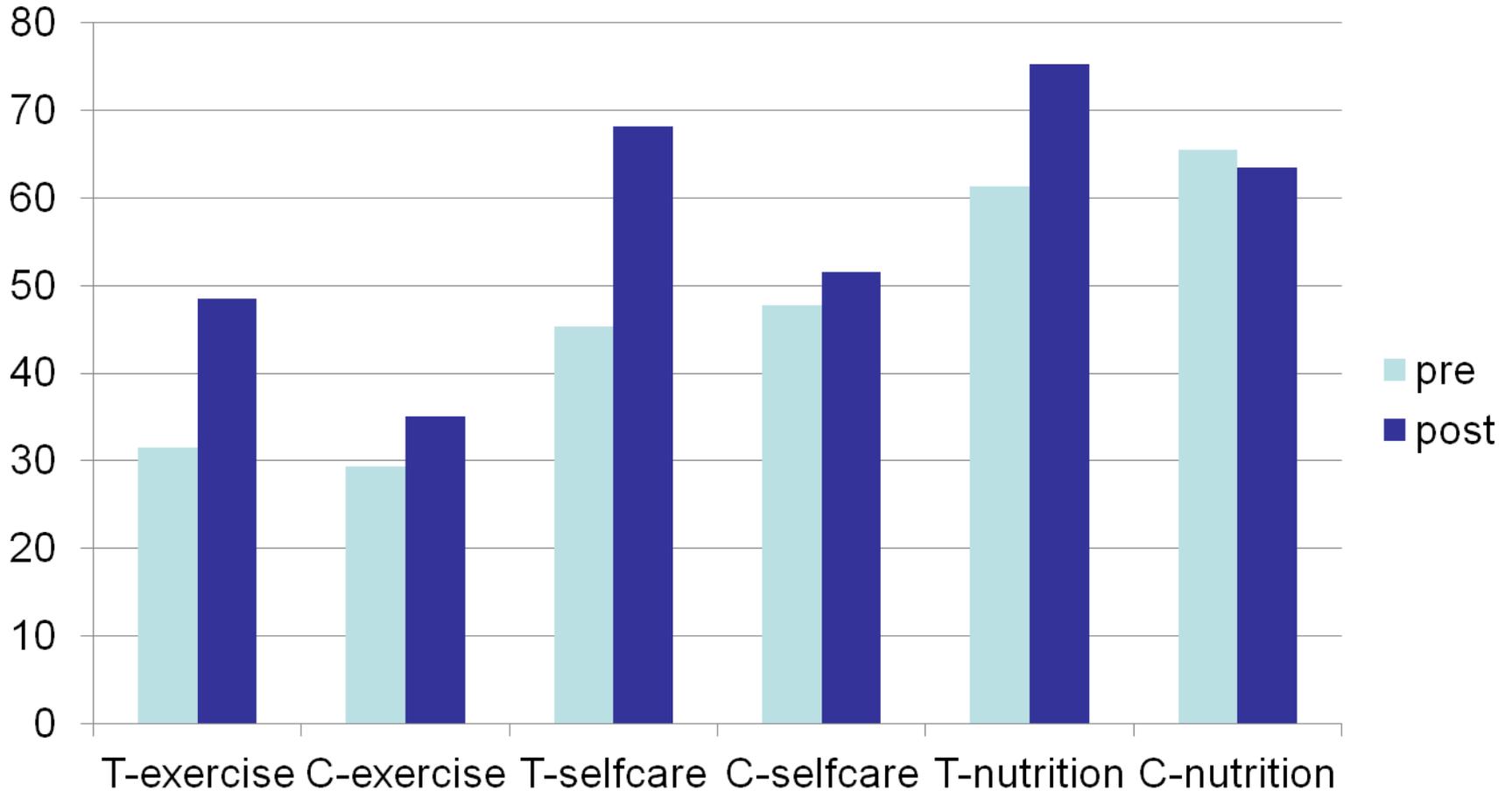
<b>Child Characteristics</b>	<b>Intervention</b>	<b>control</b>
Mean age (SD)	16.9 (7.6)	18.0 (8.8)
Percent male	58.0	64.0
Diagnosis		
Autism	28.6	19.2
Down Syndrome	16.7	26.9
Cerebral Palsy	35.7	38.5
Intellectual disability	14.3	8.3
Other	4.8	3.8

# Results: Self-Efficacy



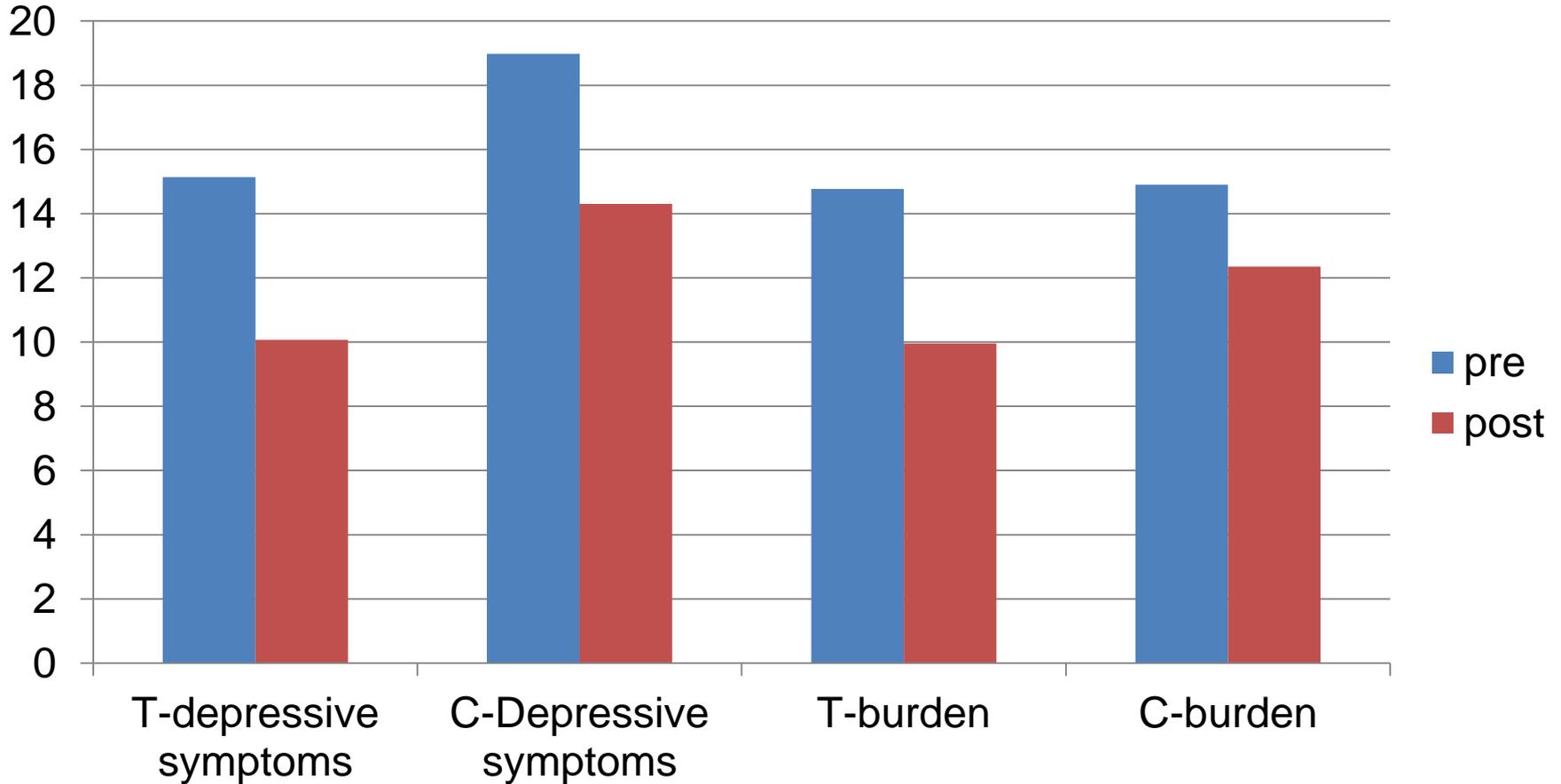
# Results: Health Behaviors

(treatment and control different except for exercise)

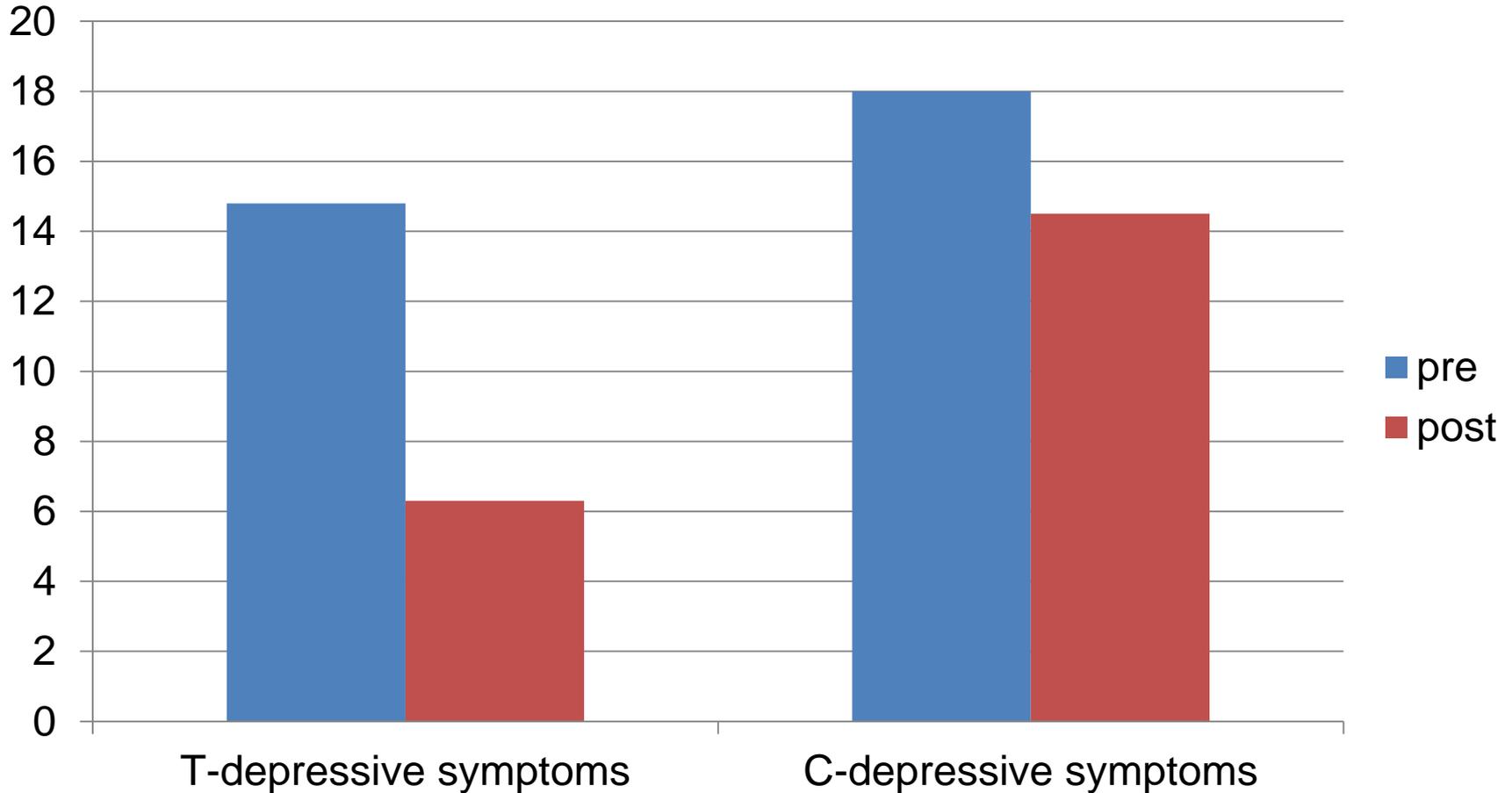


# Psychological Outcomes

(treatment and control not different)



# Findings for 50 and older



•Results in all outcomes were similar with the exception of depressive symptoms

# Qualitative Analysis

- Focus Groups with Promotoras
  - Conducted after each promotora completed a full case
- Semi-Structured Interviews with Participants
  - Conducted 6 months post baseline
  - Findings very positive, limited depth
  - Findings complement quantitative results

# Qualitative Findings

- Increase Self-Efficacy
  - *“I learned that taking care of myself doesn’t make me a selfish person. That’s something that wasn’t in my mind before. I used to think that it was selfish to think about myself” (Participant).*
  - *“From my first participant, I saw the same [pattern of change as seen in the others], that thanks to the discussions of the manual, she started looking for medical assistance” (Promotora).*

# Qualitative Findings

- Improve Health Behaviors
  - “[The participant] had never in her life paid attention to the labels and now she is already checking the labels, checking their content and nutritional value” (Promotora).
  - “We go to swim, we all go together: my husband, my children, we try to go as a family. We share moments together” (Participant).

# Qualitative Findings

- Reduce Psychological Distress
  - *I believe that [the most effective aspect of the program] was to have someone to talk to about the problems they [participants] are facing, someone who understands them and who doesn't criticize them" (Promotora).*
  - *Sometimes people forget about themselves in order to dedicate themselves to their children without sometimes concentrating on [the fact that] if we as mothers and fathers are not very well, we will not be able to take care of our children" (Participant).*

# Discussion

- **Limitations:**
  - All measures were self-report
  - Older adult sample was small, most participants were midlife
  - Could use a larger sample over all to examine different subgroups and conditions
  - No measures related to the child with IDD
- **Conclusions:**
  - Program was found to be efficacious with whole sample
  - Also found to benefit mothers 50 and over
  - Program may be especially beneficial in providing social support and reducing depressive symptoms among older adults

# Current study funded by Midwest Roybal Center

- Goal is to gear up for larger NIH study
- Additional pilot data being collected:
  - Integrating rigorous measures- 24 hour dietary recall and accelerometers
  - Integrating text messaging to reinforce health habits and provide motivation
  - Adding some child outcome measures
  - 20 families single arm pre and post test design

# Current study funded by Midwest Roybal Center

- Accomplishments to date
  - Already 10 Latina mothers enrolled in first 2 months of the study
  - Has been well received by the current participants
  - Some moms engage well in the texting interaction and comply with the accelerometer use

# Current study funded by Midwest Roybal Center

- Challenges
  - Some moms have found the food recall somewhat cumbersome
  - Accelerometer is not the most discrete so some moms have to be convinced how important it is to keep it on all the time (even while sleeping) for one week
  - It has been difficult to get a few moms to get fully engaged with the text messages (e.g. no response to questions, feedback that they are too long, etc.)

# Looking to the Future: Dissemination

- Adaptation to Latina family caregivers of persons with Alzheimer's or related dementia (ADRD)
  - Assessment and adaptation of intervention through focus groups with caregivers and stakeholders
  - Selection and training of two ADRD Latina family caregivers to implement the intervention as *Promotoras de Salud (community health workers)*
  - Pilot-test with 20 ADRD Latina family caregivers

# Looking to the Future: Dissemination

- Adaptation to African American caregivers
  - Special topics of interests (e.g. hair)
  - Culturally relevant food recipes
  - Mothers expressed approval of the name of the project being “By Caring for Myself” appreciating that they themselves were being acknowledged

# Looking to the Future: Dissemination

- Train the Trainer
  - We are developing a train the trainer program
  - If interested in implementing or adapting the program in your organization, contact me:

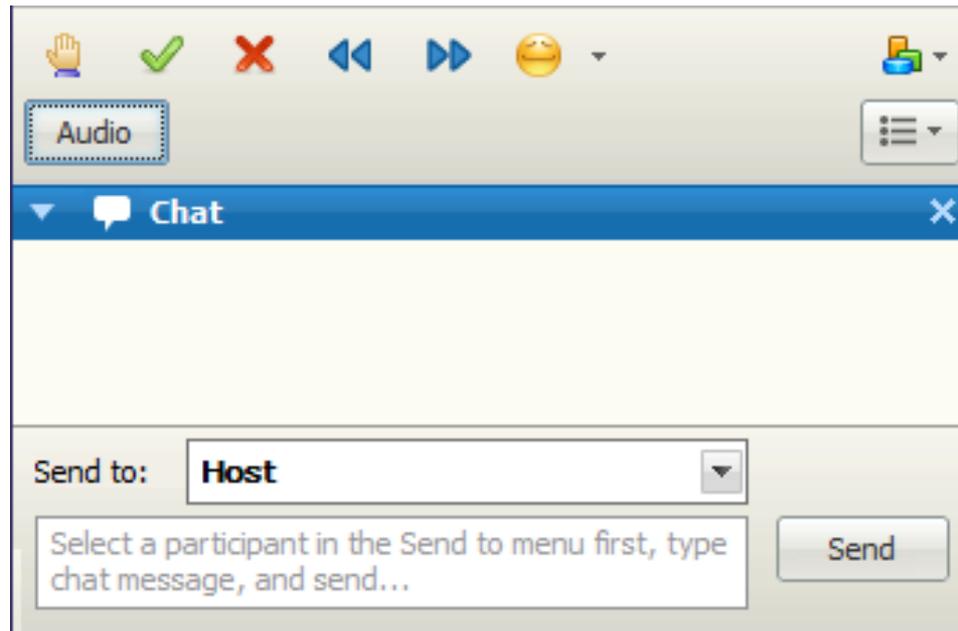
Sandy Magaña

[maganas@uic.edu](mailto:maganas@uic.edu)

312-355-4537

# Questions or Comments?

Please raise your hand and we will call on you OR type your question into the chat box.



# Acknowledgements

- Rehabilitation Research and Training Center on Health and Developmental Disabilities at the University of Illinois at Chicago (NIDILRR funding, **90RT5020-01-00**)
- Midwest Roybal Center for Health Promotion & Translation, National Institute on Aging P30 AG028849
- Students and staff: Rebecca Paradiso de Sayu, Elizabeth Miranda & Linda Serna, Henan Li, Kristen Salkas, Miguel Morales, Judith S. Rocha