

Evidence-Based Community Support Programs for Early Stage Dementia

Rebecca G. Logsdon, PhD

School of Nursing

UNIVERSITY OF WASHINGTON



Early Stage Diagnosis

Individuals who are diagnosed in the early stages will live with the disease for many years.

Positive:

- initiation of medical treatment
- legal and financial planning
- early mobilization of support services

Negative:

- anxiety about the future
- negative stereotyping
- relationship changes



Early Stage services may alter the experience of the disease & quality of life for both the diagnosed person and for those who care for him or her.

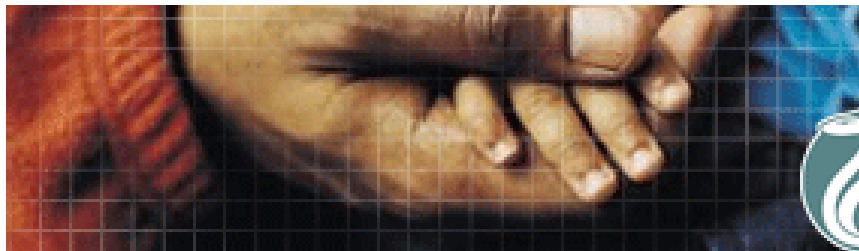


Dementia as Chronic Illness

- Individuals who are diagnosed in the early stages will live with the disease for many years.
- Focused health promotion activities may alter the experience of the disease & quality of life for both the diagnosed person and for those who care for him or her.

Quality of Life

Quality of life for older adults with **chronic illness**: a sense of well-being, satisfaction with life, and self-esteem, accomplished through the care received, the accomplishment of desired goals, and the ability to exercise a satisfactory degree of control over one's life.



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Research Questions

1. How can we measure QOL in individuals with early stage dementia?
2. What factors influence QOL in dementia?
3. What can we do to improve QOL for people with early stage dementia and their caregivers?



Research Questions

1. How can we measure QOL in individuals with early stage dementia?
 - Health Care provider ratings
 - Direct Observation
 - Caregiver/Family member ratings
 - Self Report by the individual

Assessment Tools for QOL in Dementia

Measure	Population	Administration
Affect Rating Scale (Lawton, 1996)	Nursing Home: Mod to Severe	Observation
QOL-D (Albert, 1996)	Community: Mild to Severe	Family Proxy
DQOL (Brod, 1999)	Community: Mild to Mod	Self-Report
QOL-AD (Logsdon, 1999)	Community: Mild to Mod	Self & Proxy
AD-QOL (Black, 2000)	Residential Care: Mild to Severe	Professional Proxy
QOL-NH (Kane, 2001)	Nursing Home Residents	Self-Report
Cornell-Brown QOLD (Ready, Ott, 2002)	Community: Mild to Mod	Clinician Rating
Dementia Care Mapping (Brooker, 2006)	Residential/Day: Mild to Severe	Observation
DEMQOL (Smith, 2005)	Community: Mild to Mod	Self & Proxy
Observing QOL in Dementia (Fulton, 2006)	Residential/Day: Mild to Severe	Observation



Quality Of Life-AD

Logsdon RG, Gibbons LE, McCurry SM, & Teri L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging*, 5 (1), 21-32.

- ❑ Structured interview with diagnosed individual
- ❑ Caregiver questionnaire
- ❑ 13 items assessing 4 domains of QOL: physical, psychological, environmental, behavioral/functional
- ❑ Good internal reliability (alpha = .86)
- ❑ Good test-retest reliability (.76 for patient; .92 for caregiver)

Funded by: National Alzheimer's Association FSA 95009



Research Questions

2. What factors influence QOL in dementia?

Longitudinal Study (N=155)

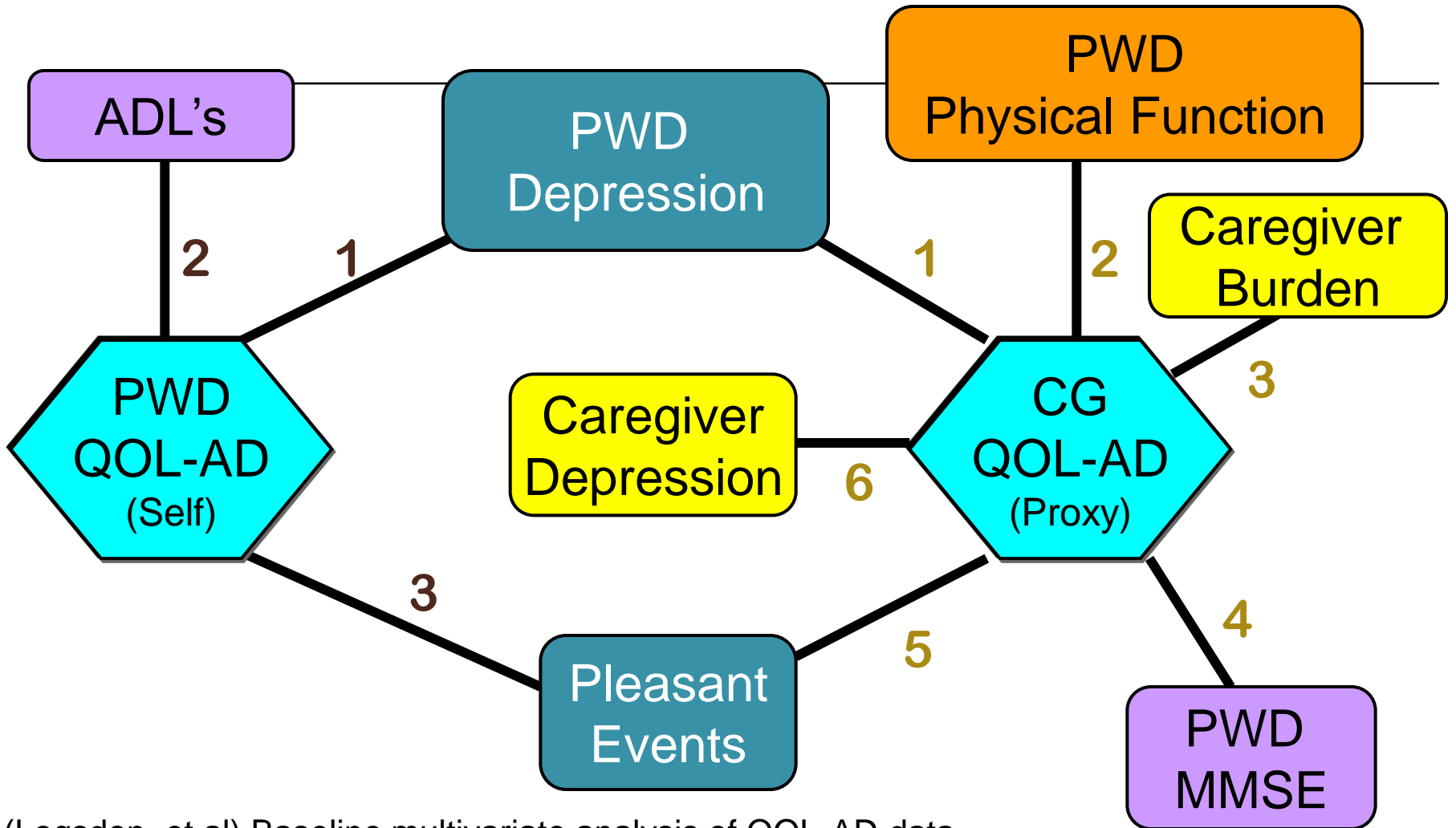
Logsdon R.G., Gibbons L.E., McCurry S.M., and Teri L. (2002) Assessing Quality of life in older adults with cognitive impairment. *Psychosomatic Medicine* 64:510-519.

**Community-residing PWD/caregiver dyads
evaluated at home every 6 months for up to 5
years**

Mean Age	77.2	(6.8)
Education	13.5	(3.5)
MMSE	16.4	(7.3)
Dementia Duration	4.5	(3.0)
Sex	57% male	
Caregiver Relationship	83% spouse	

Funded by: National Institute on Aging AG1084504

Multivariate Associations



(Logsdon, et al) Baseline multivariate analysis of QOL-AD data

Predictors of QOL Change Over 12 Months

Participants re-interviewed every 6 months for up to 5 years
PT=206 Observations
CG=253 Observations

□ PWD Self-Rating Decline

- Higher Depression
- Less Productive
Activity

□ CG Rating of PWD Decline

- Higher Depression
- More Memory Problems
- Less Physical Mobility

Confirmatory Studies

QOL in Persons with Dementia

Thorgrimsen, et al, 2003

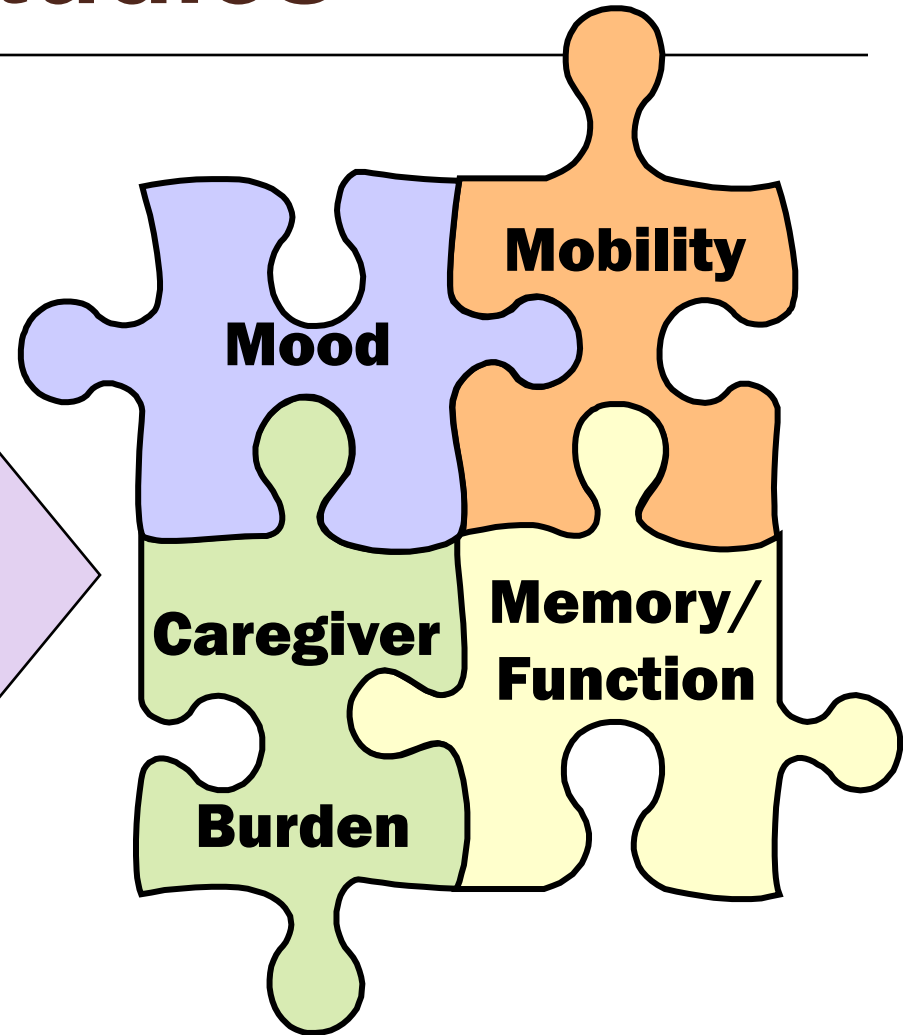
Hoe, et al, 2005

Logsdon, et al, 2005

Selwood, et al, 2005

Snow, et al, 2005

Banerjee, et al, 2006





Research Questions

3. What can we do to improve QOL for people with dementia and their caregivers?



Treatment Implications

- Maximize **social and ADL function**
- Treat **depressive symptoms** and encourage **pleasant activities**
- Improve or maintain **physical mobility**
- **Support caregivers** to reduce burden and depression

QOL & Psychosocial Intervention: RCT Evidence Base (not specific to early stage)

- ✓ Maximize **social and ADL function**
Gitlin, 2001, 03, 05; Dooley, 2004; Graff, 2006
Lowenstein, 2004; Tarraga, 2006; Spector, 2003
- ✓ Treat **depressive symptoms** and encourage **pleasant activities**
Teri, 1997, 2005; Gerdner, 1996, 2002; Huang, 2003; Lichtenberg, 2006
- ✓ Improve or maintain **physical mobility**
Lazowski, 1999; Littbrand, 2006; Rolland, 2007 (NH)
Teri, 2003; Logsdon, 2005 (Community)
- ✓ Reduce **caregiver burden and depression**
Gallagher-Thompson, 1994, 2000, 07; Schulz, 2003, 05; Mittelman, 1995, 2004; Teri, 2005

Early Stage Support Groups

- Logsdon RG, McCurry SM, & Teri L (2005). Time limited support groups for individuals with early stage dementia and their care partners. *Clinical Gerontologist*, 30(2), 5-19.
- Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010) Early stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *Journal of Gerontology: Psychological Sciences*, 65B(6), 691-97.

Active treatment:

- Early Stage Memory Loss seminar program

Control:

- Delayed treatment

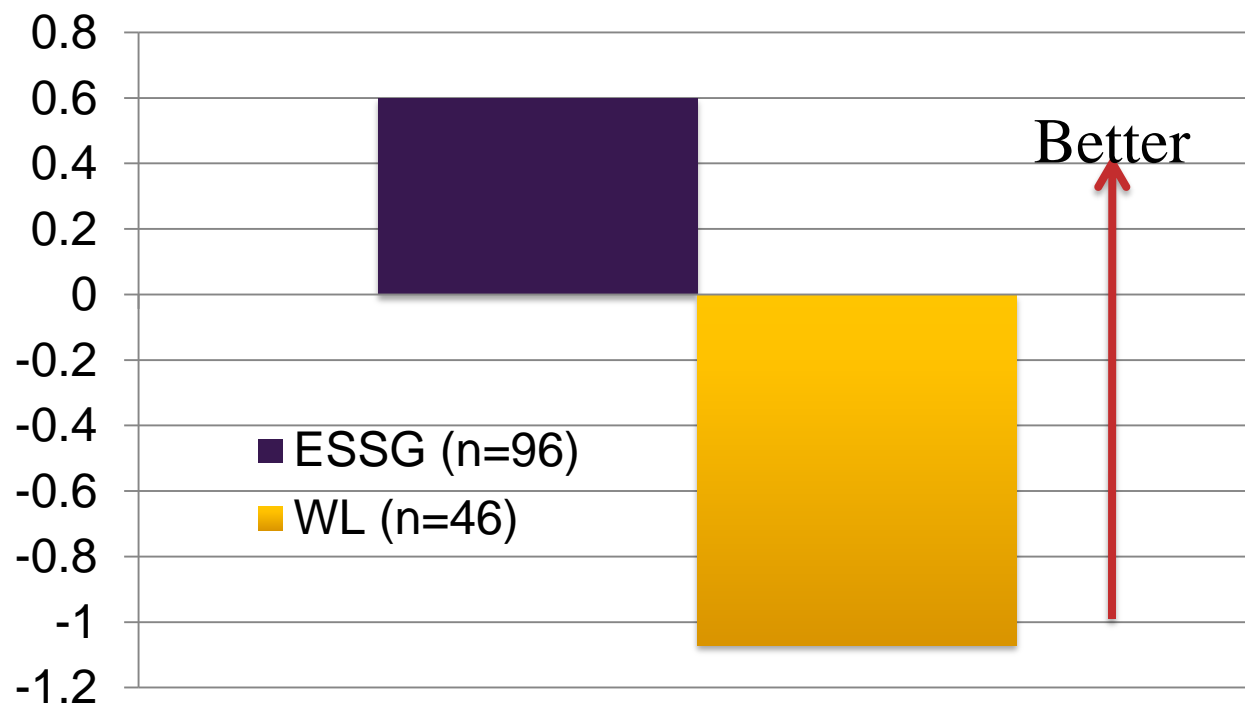
Support Group Facilitators: Master's level social workers

9 weekly sessions, participant and care partner attend together

MMSE 18-30; Mean = 24

Assessments at baseline and post treatment (2 months)

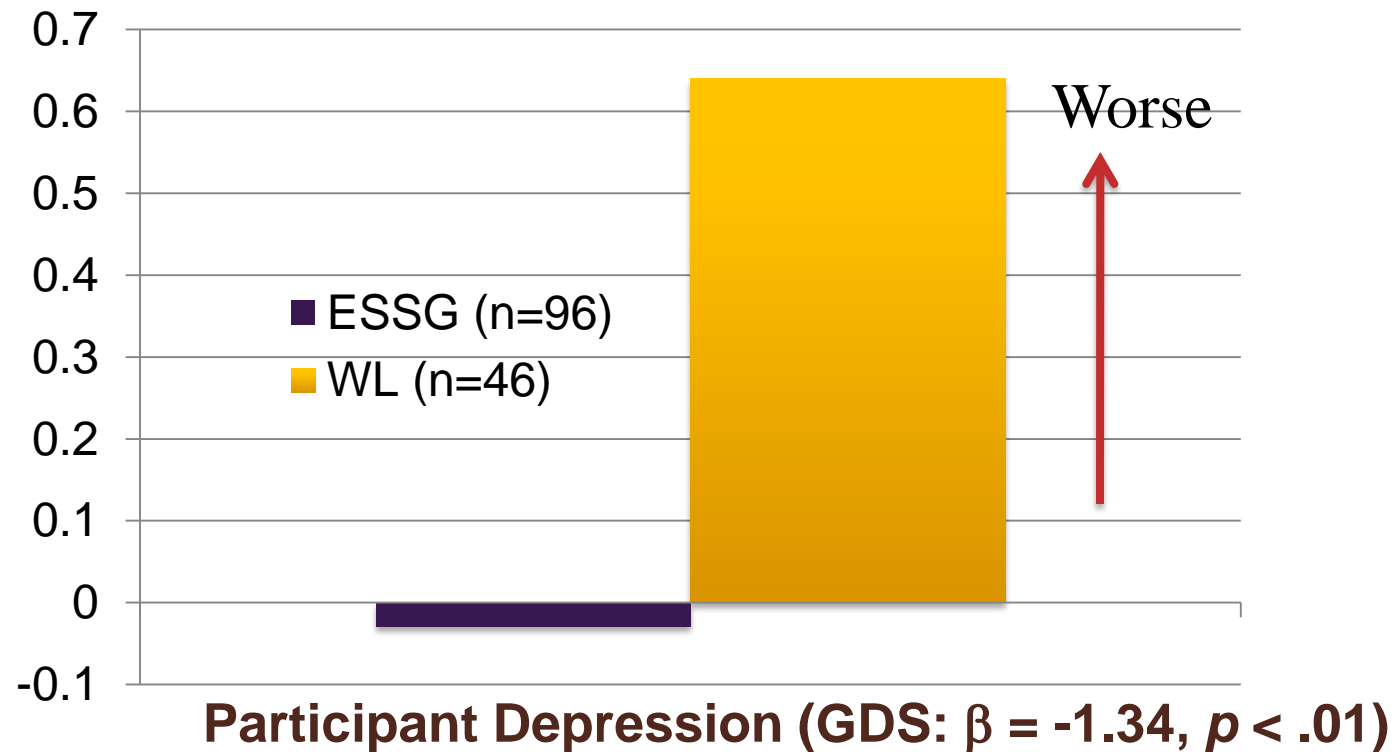
Quality of Life Outcome



Participant Quality of Life (QOL-AD: $\beta = 1.74, p < .001$)

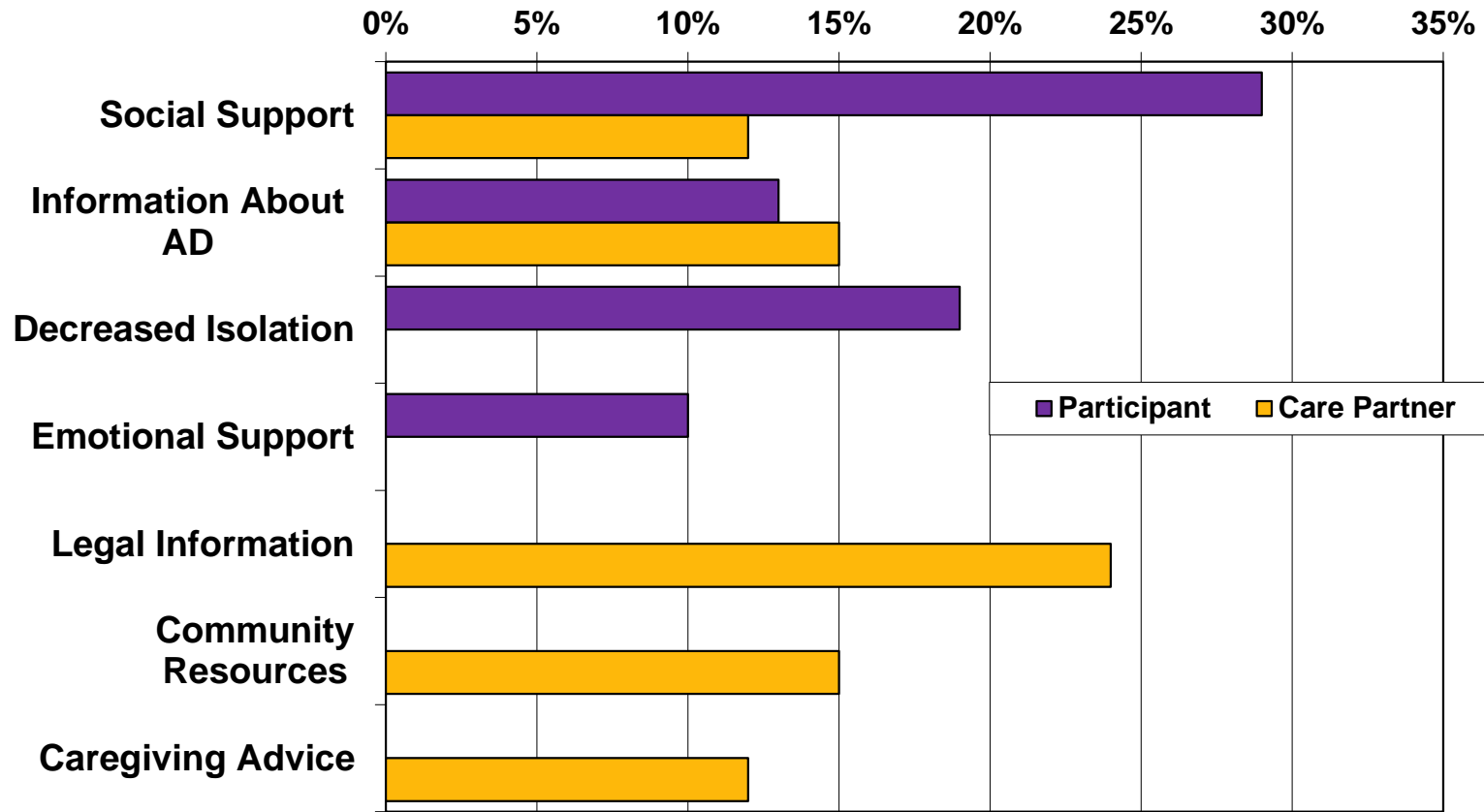
Logsdon, et al, 2010

Depression Outcome



Logsdon, et al, 2010

Benefits of Early Stage Groups



Logsdon, et al, 2006 (*Clinical Gerontologist*)

Promoting Pleasant Events


- Individuals with dementia retain many skills despite cognitive impairments.
- Interpersonal relationships are very important, and are fostered by shared pleasant activities.
- Caregiver depression and burden may be lessened by focusing on positive, rather than negative interactions.



Identify and Re-introduce Pleasant Activities



- What did the person enjoy in the past?
- What does he/she enjoy now?
- How can tasks be modified to accommodate current abilities?
- Who is available to help with these activities?



Benefits of Physical Activity for Individuals with Dementia

Improve Strength and Mobility

Lazowski, et al, 1999

Arkin, et al, 2003

Hageman, et al, 2002

Rolland, et al, 2000

Reduce Depression

Teri, et al, 2004

Decrease Behavioral Disturbances

Rolland, et al, 2000

Teri, et al, 2004

Mitigate Cognitive Decline

Rolland, et al, 2000

Emery, et al, 1998, 2003

Challenges of Exercise for Individuals with Dementia

- Reluctance to try new activities
- Difficulty learning & remembering to do exercises
- Inability to exercise independently due to safety concerns
- Family caregivers lack knowledge about exercise, already burdened by daily tasks, may be physically frail





Physical Function

Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner D, Barlow W, Kukull W, LaCroix A, McCormick W, Larson E. (2003) Exercise plus behavior management in patients with Alzheimer's disease: A controlled clinical trial. *JAMA*, 290(15); 2015-2022.

Active treatment:

- Home-based exercise – strength, balance, endurance
- Behavior therapy – communication, problem-solving

Control:

- Routine Medical Care

Therapists: Master's level home health providers (SW & PT)

12-week treatment duration, monthly follow-up 4 months

MMSE 0 to 29; Mean = 17

Assessments at baseline, 3, 6, 12, and 24 months

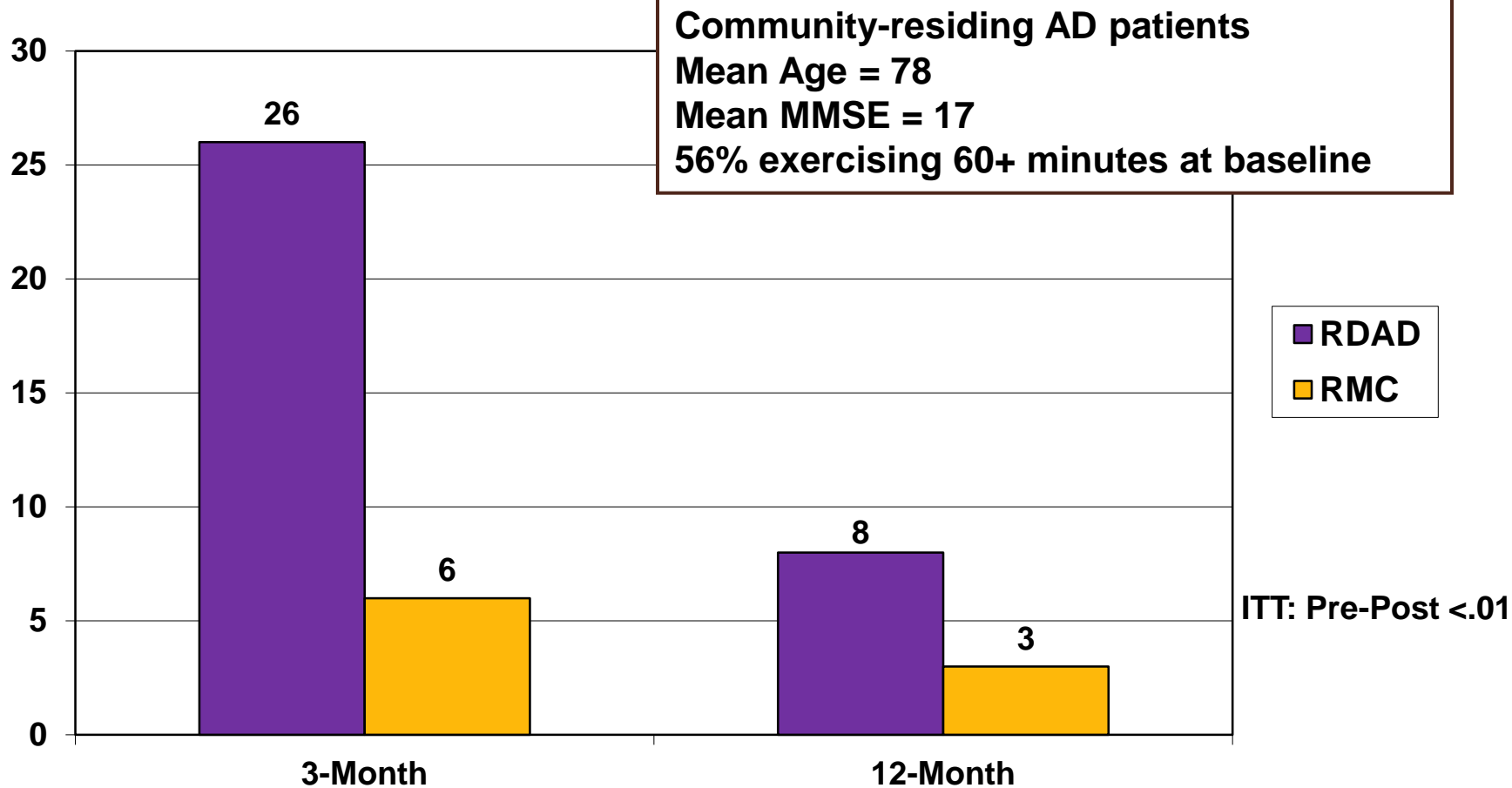
Funded by the National Institute on Aging AG10845 and AG14777



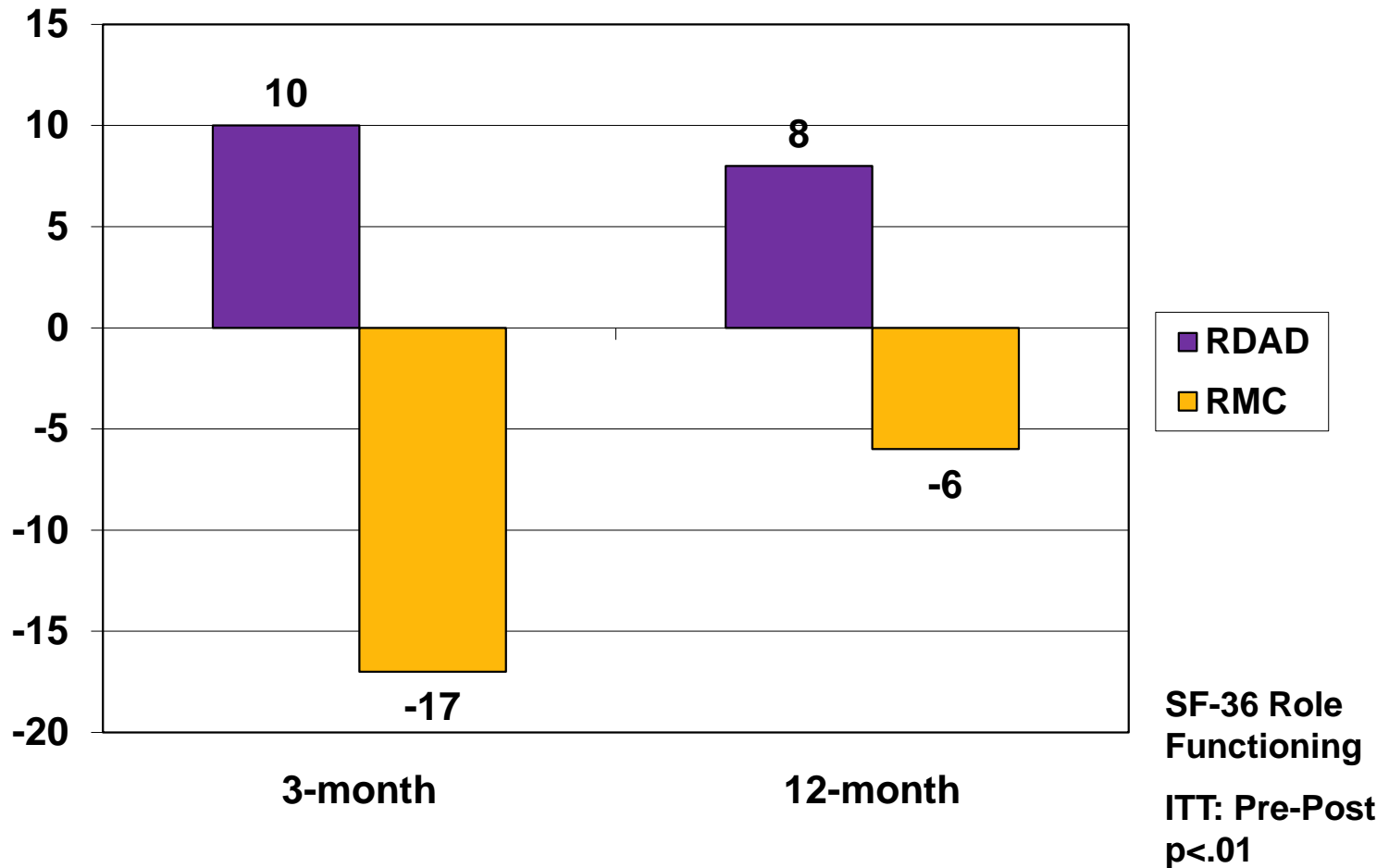
RDAD Treatment Protocol

- 12-week program
- Delivered by community home health providers (physical therapist or social worker)
- Exercise
 - Aerobic/endurance activities (walking)
 - Strength
 - Balance
 - Flexibility
- Problem-solving
 - Education about AD
 - Intervening with behavioral problems
 - Enhance caregiver resources and skills

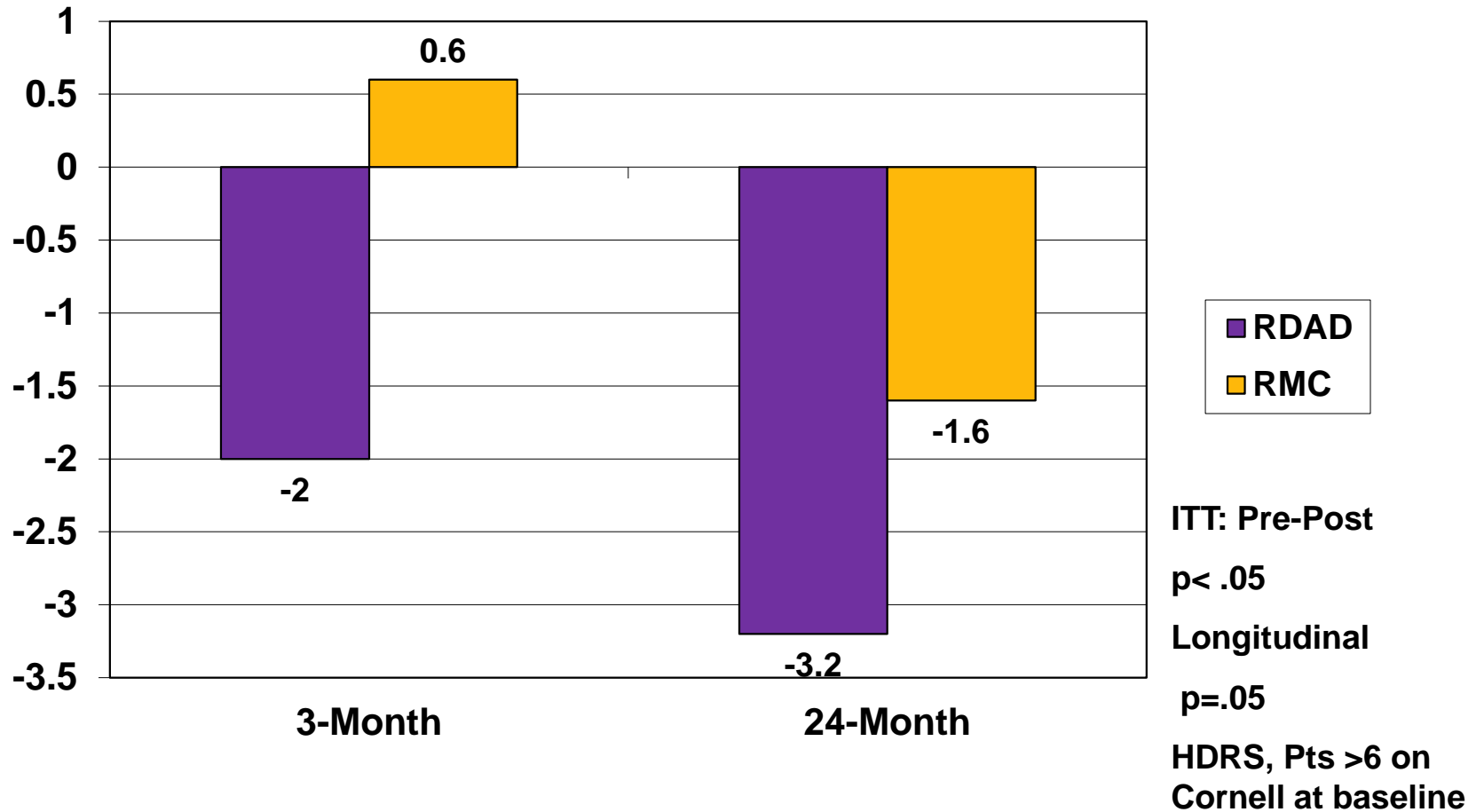
Change in Percent of Subjects Exercising 60+ Minutes a Week



Change in Daily Activities

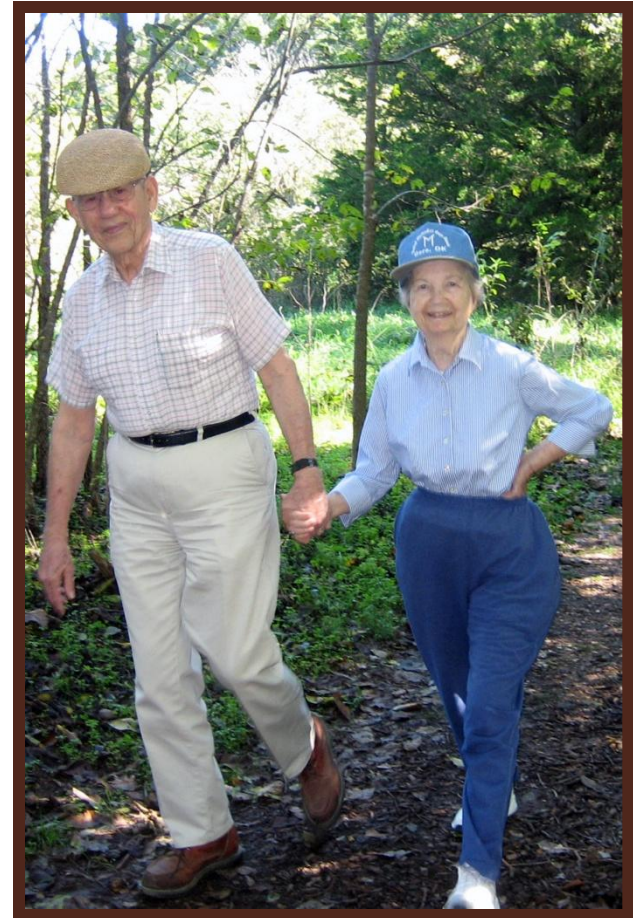


Change in Depression



Promoting Exercise for Individuals with Dementia

- What “exercise” did the person enjoy in the past?
- Provide support, assistance, lots of repetition for group programs
- Monitor for safety; simplify, avoid or closely supervise use of unfamiliar equipment
- Encourage family caregivers to incorporate a daily walk to the routine, and gradually increase the time, distance, and speed of walking
- Make physical activity a pleasant event





Caregiver Support

Teri L, McCurry SM, Logsdon RG, & Gibbons LE. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45(6), 802-811.

Active treatment:

- Seattle Protocols – communication, problem solving, pleasant events

Control:

- Routine medical care

Caregiving consultants: Master's-level mental health counselors
8 weekly sessions, monthly phone calls 4 months

MMSE 0-28; Mean = 14

Assessments at baseline, 3, 6, and 12 months

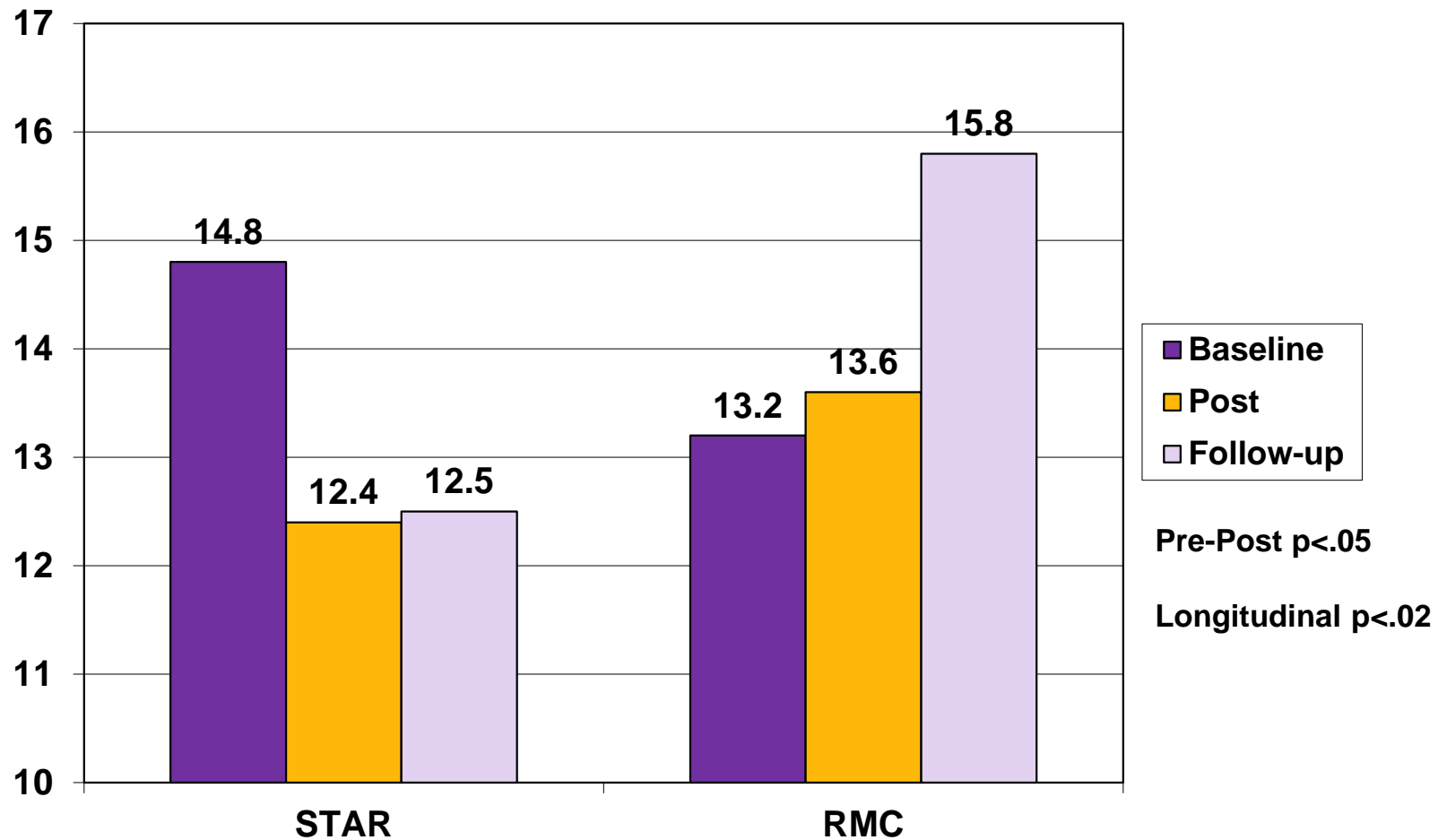
Funding: Alzheimer's Association Pioneer Grant P10-1800



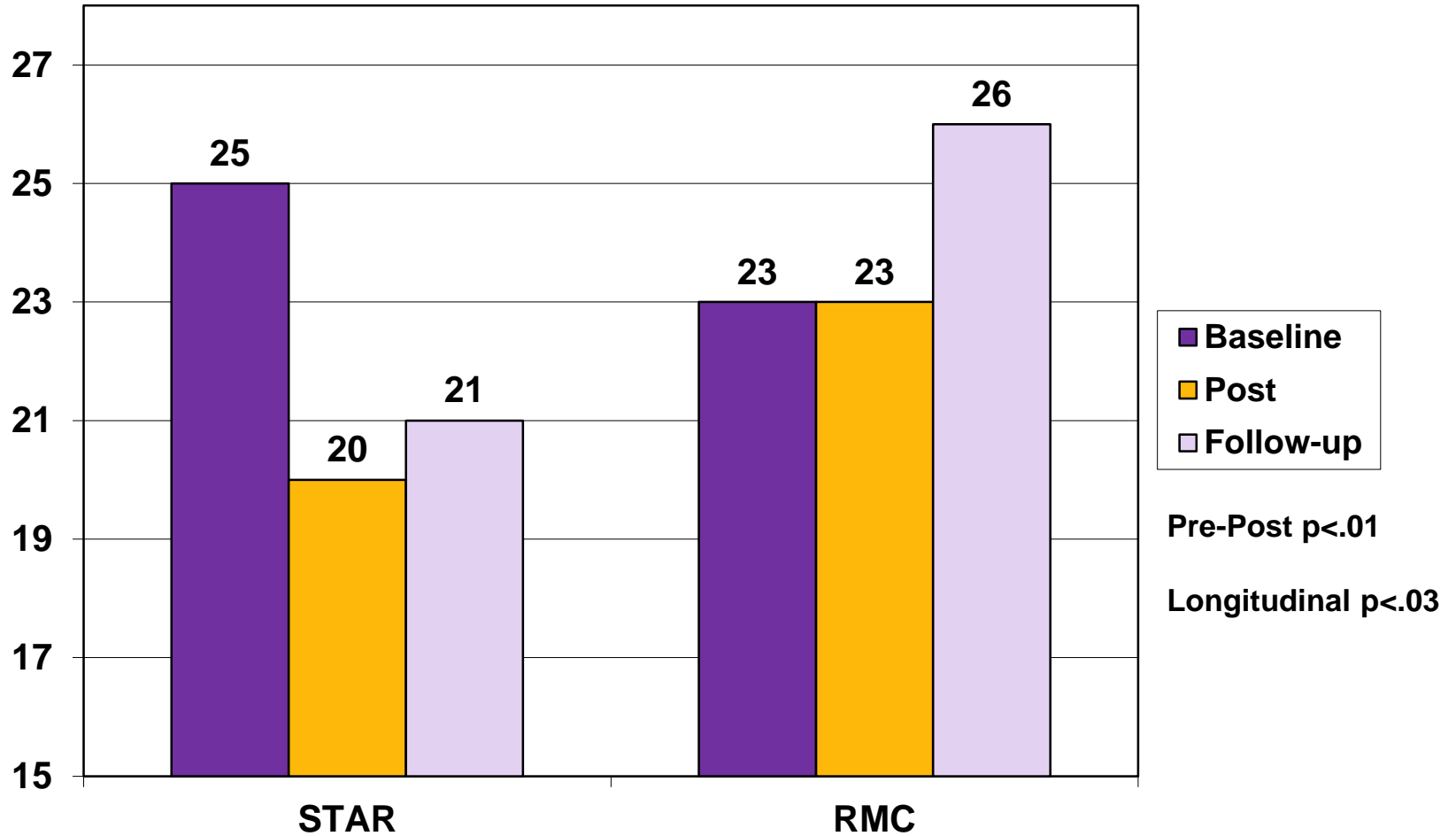
STAR Caregivers

- 8 weekly in-home caregiver counseling sessions
- Communication, problem-solving, pleasant events
- Target behaviors
 - agitation, anxiety, depression
- Provided by master's level caregiving consultants
- Companion for person with dementia if needed
- Training, ongoing supervision, and weekly monitoring of adherence to protocol by geropsychologists

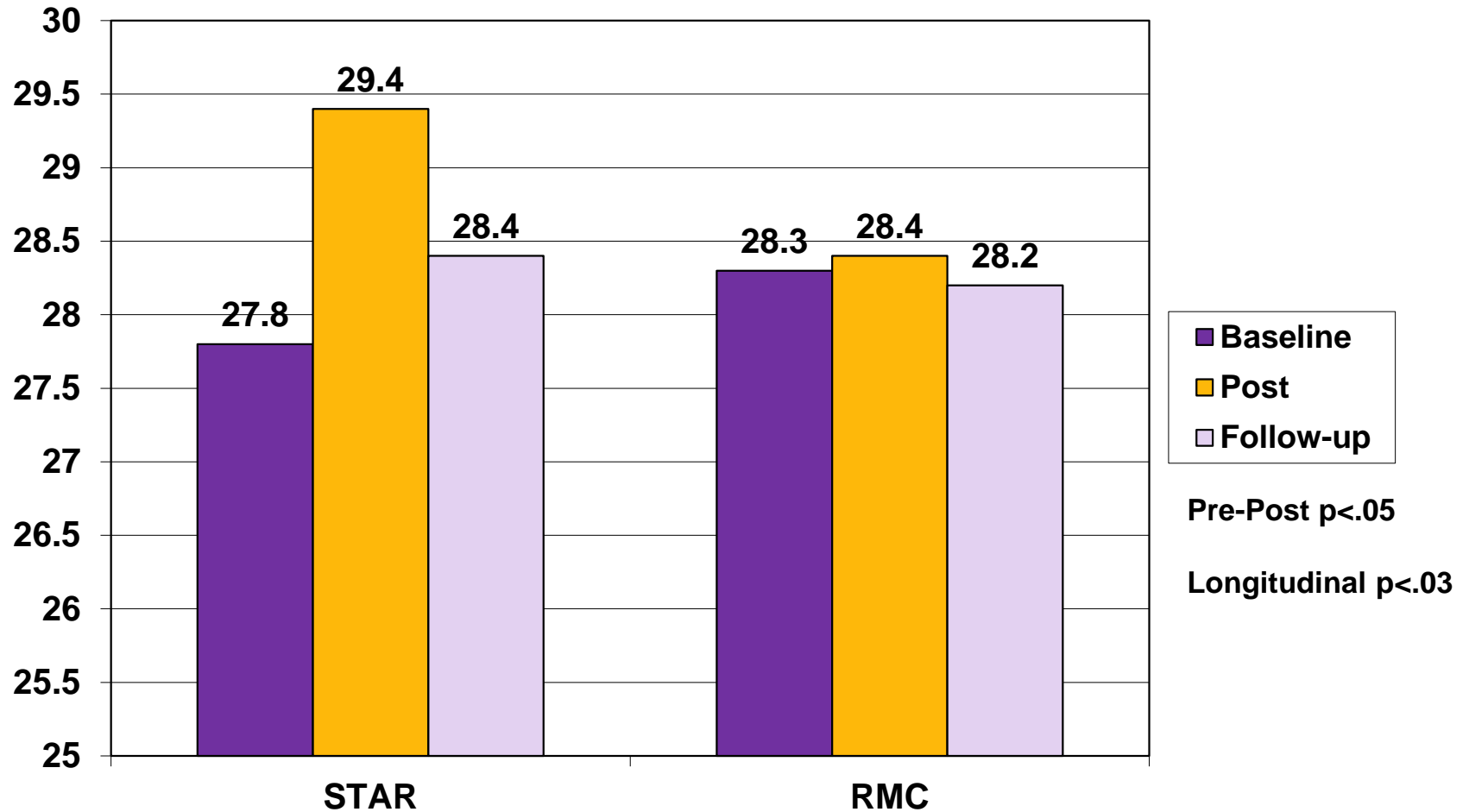
Caregiver Depression: CESD



Caregiver Burden: SCB



Care Recipient QOL-AD





Future Directions in Early Stage Memory Loss Programming

- Counseling & Support Groups: **Best Research Support**
 - Family/couples Counseling (C. Whitlatch, M. Mittelman)
 - Social/Emotional Support Groups (L. Snyder; R. Yale; R. Logsdon)
 - Cognitive Behavior Therapy (M. Stanley)
- Physical Activity: **Mixed Results**
 - Reducing Disability in Alzheimer's Disease (L. Teri, R. Logsdon, S. McCurry)
 - Improving sleep in dementia patients (S. McCurry)



Future Directions in Early Stage Memory Loss Programming

- Cognitive Rehabilitation Programs: **Mixed Results**
 - Cognitive Rehabilitation & Stimulation (L. Clare; A. Spector; M. Orrell)
 - Computer-based Training and Practice (no support from RCTs with dementia; for older adults, mixed results)
 - Results often short-lived, clinical significance unclear



Future Directions in Early Stage Memory Loss Programming

- Arts Programs: **Qualitative research support & high interest**
 - Art Museum Programs (e.g. Meet Me at MOMA-Mittelman; “here:now” programs at Frye Art Museum in Seattle)
 - Photography (e.g. PhotoVoice-Ataie)
 - Choirs (e.g. The Unforgettables-Mittelman)
 - Drama (e.g. The Penelope Project-Bastings)
 - Storytelling (e.g. TimeSlips-Bastings)
- Intergenerational Programs: **Beginning to accumulate qualitative support**
 - Partnering dementia patients and medical students (Morhardt)
 - Day care associated with assisted living (Whitehouse)



Recommendations for Early Stage Memory Loss Programming

- Provide a variety of programs
- Provide memory support by using visual aids, handouts, recordings
- Individualize programs as much as possible
- Make existing programs for older adults accessible to individuals despite increasing memory loss
- Create new social networks and opportunities
- Develop or modify volunteer programs for individuals with memory loss or other age-related changes

Take Home Messages

- Quality of life as perceived by the person with dementia does not necessarily decline due to memory loss or cognitive decline.
- Quality of life is strongly influenced by mood.
- Mood is influenced by pleasant activities, exercise, and social support.
- Family members, friends, and other caregivers can significantly impact QOL for individuals with dementia.
- What's good for the person with dementia is good for the caregiver.

