Evidence-Based Community Support Programs for Early Stage Dementia

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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.
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
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<th>Administration</th>
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<td>Nursing Home: Mod to Severe</td>
<td>Observation</td>
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<td>QOL-D (Albert, 1996)</td>
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<td>DQOL (Brod, 1999)</td>
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<td>QOL-AD (Logsdon, 1999)</td>
<td>Community: Mild to Mod</td>
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<td>DEMQOL (Smith, 2005)</td>
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<td>Observing QOL in Dementia (Fulton, 2006)</td>
<td>Residential/Day: Mild to Severe</td>
<td>Observation</td>
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Quality Of Life-AD


- 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
2. What factors influence QOL in dementia?
Longitudinal Study (N=155)


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
(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
- Hoe, et al, 2005
- Logsdon, et al, 2005
- Selwood, et al, 2005
- Snow, et al, 2005
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

- 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


**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)

National Alzheimer’s Association (IIRG # 0306319) & National Institute on Aging (R01AG23091-2)
Quality of Life Outcome

Better

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

Logsdon, et al, 2010
Depression Outcome

Participant Depression (GDS: $\beta = -1.34$, $p < .01$)

Logsdon, et al, 2010
Benefits of Early Stage Groups

Social Support
Information About AD
Decreased Isolation
Emotional Support
Legal Information
Community Resources
Caregiving Advice

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**
- Lazowksi, et al, 1999
- 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
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


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

Community-residing AD patients
Mean Age = 78
Mean MMSE = 17
56% exercising 60+ minutes at baseline

ITT: Pre-Post <.01
Change in Daily Activities

ITT: Pre-Post p<.01
Change in Depression

ITT: Pre-Post
p< .05
Longitudinal
p=.05
HDRS, Pts >6 on Cornell at baseline
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


**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

Pre-Post p<.05
Longitudinal p<.02
Caregiver Burden: SCB

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<td>Post</td>
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<td>Follow-up</td>
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Pre-Post $p<.01$
Longitudinal $p<.03$
Care Recipient QOL-AD

Pre-Post p<.05
Longitudinal p<.03
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.