Interventions to Ease Burden and Stress of Caregiving (The Reach II Project)

Alan B. Stevens, PhD
Professor, Department of Medicine
Vernon D. Holleman-Lewis M. Rampy
Centennial Chair in Gerontology
Scott & White Memorial Hospital
The Texas A&M University System Health Science Center
# Symptoms and Stages of Progressive Dementias

<table>
<thead>
<tr>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Terminal</th>
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<tbody>
<tr>
<td>Memory</td>
<td>Aphasia</td>
<td>Resistiveness</td>
<td>Bedfast</td>
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<td>Personality</td>
<td>Apraxia</td>
<td>Incontinence</td>
<td>Mute</td>
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<td>Spatial</td>
<td>Confusion</td>
<td>Eating</td>
<td>Dysphagia</td>
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<td>disorientation</td>
<td>Agitation</td>
<td>difficulties</td>
<td>Intercurrent</td>
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<td>Insomnia</td>
<td>Motor</td>
<td>infections</td>
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<td>MMSE &lt; 15</td>
<td>impairment</td>
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<td>MMSE &lt; 10</td>
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Volicer L., JAMA 2001
Care Needs of the Patient and Family

- Medical treatments are necessary but not sufficient
  - Tacrine, Donepezil, Rivastigmine, Galantamine
    (Lingler et al., 2005, Raskind et al., 2005)
  - Memantine
    (Reisberg et al., 2003; Doody et al., 2004)
  - Typical and atypical antipsychotics
    Martin-Cook et al., 2005, Profeno and Tariot, 2004; Woolterton, 2002; FDA Advisory, 2005, Schneider et al, 2006
  - Antibiotics
    Van der Steen et al, 2005, artificial nutrition
    Ritchie and Kvale, 2005
Care Needs of the Patient and Family

- Informal caregivers provide the most significant treatment – supervision and daily care
  - 70% of dementia patients are living in the community with family caregivers
  - Physician instructions are carried out by the caregivers
  - Patient quality of care and quality of life is inextricably linked to the caregiver

- The burden of care is defined by both “work” and “worry” and places the caregiver at risk for negative health and well-being outcomes
Consequences of Caregiving

- Nearly 50% of caregivers report symptoms of depression and high levels of anxiety. Teri et al., 1997; Sansoni et al., 2004

- Caregivers who placed their relative reported depressive symptoms and anxiety to be as high as they were while in-home caregivers. Schulz, Belle, Czaja, McGinnis, Stevens, and Zhang, 2004, JAMA
  - No change in antidepressant use
  - Significant increase in anxiolytics
Negative Health Effects Result From Care

- Caregivers consistently rate their health as significantly worse than non-caregivers

- Evidence suggests poorer health care utilization and immune functioning in caregivers

  Vedhara et al., 1999, Kiecolt-Glaser et al., 1995
Self Care is Affected by Caregiving

At any point since you have been providing care, have you...

- Not gone to the doctor as often as you should: 72%
- Missed any doctors' appointments: 55%

$n=528$

Evercare, 2006
Caregiving and Mortality

- Spouses who provided care and experienced caregiving stress had 63% higher risk (relative risk, 1.63, 95% confidence interval, 1.00-2.65)

- Spouses who provided care but did not experience stress and disabled spouses who did not provide care had mortality rate similar to control

Schulz and Beach, JAMA 282:2215-12219, 1999
Interventions to Improve Patient Functioning

*Primary Stressor*

- **Increased functional/meaningful engagement**

- **Decreased patient depressive symptoms**
  - Teri et al., 1987, Stevens et al., 2005

- **Decreased patient problem behaviors**
  - Burgio et al, 2003, Teri et al., 1987, Stevens et al., 2005
Multi-component Interventions Focused the Caregiving Experience

- Decreased caregiver burden and depressive symptoms  
  Burgio et al., 2003, Eisdorfer et al., 2003, Middelman et al., 2004

- Increased social support  
  Middelman et al., 1995

- Delayed institutionalization of patient  
  Reach II, Middelman et al., 1996, Middelman et al, 2006
The REACH II Study
Resources for Enhancing Alzheimer’s Caregiver Health

- Second in a series of multisite research program to develop and test effective caregiver interventions

- Sponsored by the National Institutes of Health (NIH), National Institute on Aging (NIA), National Institute of Nursing Research (NINR)
REACH II Study

- One intervention tested at 5 sites: Birmingham, AL, Memphis, TN, Miami, FL, Palo Alto, CA, and Philadelphia, PA

- Ethnically Diverse Sample of 642 Care Recipient/Caregiver dyads

- Carefully defined eligibility requirements ensured sample was composed of family caregivers of person with dementia who were experiencing caregiving related burden
REACH II Study

- Randomized, two group design for each of the ethnic and race samples
  - Hispanic or Latino: control 106, intervention 106
  - White or Caucasian: control 106, intervention, 113
  - Black or African American: control 107, intervention 104

- Control group received packets of educational materials and two brief “check in” calls

- Standardized assessments at baseline and at a 6-month follow

- Interviewers were blind to group assignment
REACH II Intervention

- Number of therapeutic contacts
  - 9 in home, 1.5 hour sessions
  - 3 telephone sessions, one-half hour each
  - 5 structured telephone support groups

- Delivered by Interventionist certified in the treatment protocol
  - Bachelor or Master’s in social science disciplines (e.g., psychology, social work)
  - Computerized telephone system placed in the home to support intervention delivery

- Intervention strategies allowed tailoring of the intervention to meet specific needs of the caregiver
Target Areas of Intervention

- Depression
- Burden
- Self-care and healthy behaviors
- Social support
- Problem behaviors

Risk assessment was used to identify the unique needs of each caregiver
Treatment Strategies for Depression

- Teach and practice strategies for engaging in pleasant events
- Teach and role play strategies for mood management and use of thought record
- Establish schedule of pleasant events
Treatment Strategies for Burden

• Teach and practice three stress management techniques – breathing exercises, music, and stretching

• Refer to stress management feature on computerized telephone system
Treatment Strategies for Self-care and Healthy Behaviors

- Demonstrate and review use of health passport
- Teach healthy behaviors and compliance with preventative health behaviors
- Refer to healthy living feature of computerized telephone system
Treatment Strategies for Social Support

• Teach how to access community resources

• Practice role-play strategies to enhance communication with health care providers and family members

• Reinforce participation in telephone support groups

• Refer to resource guide and communication and respite features of computerized telephone system
Treatment Strategies for Problem Behaviors

• Engage in structured problem solving and brainstorming of strategies

• Provide written behavioral prescription that specifies step-by-step strategies to manage troublesome behaviors

• Demonstrate and practice specific strategies using role-play
Objectives of the Intervention

• Assess risks and needs
• Present and teach educational information
• Tailor content of each of the five target areas to the unique risks and needs of caregiver
• Practice and role play strategies
• Integrate strategies of the five target areas via a supportive therapeutic relationship with a trained interventionist
REACH II Outcomes

- 5 Measures central to caregiver’s quality of life and closely linked to intervention components modeled into a single primary outcome
  - Depression
  - Caregiver burden
  - Self-care
  - Social Support
  - Problem Behaviors of the CR
- Clinical Depression
- Institutional Placement of CR at 6 months
REACH II Primary Outcome

- Intervention group displayed significant improvement on the multidimensional Quality of Life Variable for Hispanic or Latino, $p<.001$, White or Caucasian, $p=.032$, but not Black or African American, $p=.23$

- Improvement from baseline to the 6 month assessment met the study criterion of clinical significance by exceeding .5 SD for Hispanic or Latino and White or Caucasian caregivers

- A significant improve was found for African American spouse, that is, intervention x spouse interaction, $p=.008$

REACH II Secondary Outcomes

- **Clinical Depression**
  - The overall prevalence for clinical depression at follow was significantly greater among caregivers in the control group than in the intervention group, p=.001

- **Institutional Placement**
  - Groups differences were not significant, 7.2% in control, 4.3% in intervention
REACH II Implications

- Intervention had a meaningful impact on quality of life and rates of caregiver depression were halved
- However,
  - “The REACH study offered a level of caregiver support that few clinicians will be equipped to offer to their patients.”
  - “…much of the care that patients with dementia and their caregivers need cannot be delivered in the office setting. The usual fee-for-service works poorly for dementia care.”

How Do We Respond?

- Policy and Systems Change
  - Translational research and demonstration projects
  - Scott & White Memorial Hospital Family Support Program
    - A program to identify and assess the needs of family caregivers during a hospitalization of the care recipient
    - Funded by Johnson & Johnson and Rosalynn Carter Institute Caregiver Program
How Do We Respond?

- Partner with the Community
  - Area Agency on Aging of Central Texas
    - Support Teams for Caregivers, Funded by Johnson & Johnson and Rosalynn Carter Institute Caregiver Program
  - Capital of Texas Alzheimer’s Association
    - Support Teams for Caregivers
Support Teams for Caregivers

• Support Teams for Caregivers merges a nationally recognized volunteer program, the Support Team Network, with the REACH II intervention

• Support Teams serve as the delivery system for the intervention components included in REACH II

• Intervention components are delineated in the Caregiver Guidebook

• A Family Profile tailors intervention components based on findings from a standardized risk appraisal of the caregiving family
Questions

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