Interventions to Help Caregivers of Dementia Patients

Mark E. Kunik, MD, MPH
Houston VAMC, Dept of Psychiatry, Houston HSR&D CoE
Nancy L. Wilson, MA, LMSW
Department of Medicine, Section of Geriatrics, Houston HSR&D CoE
Texas Consortium of Geriatric Education Center: HCOA

Funders: Dept. of Veterans Affairs, Health Services Research & Development, SCMIRECC
Robert Wood Johnson Foundation
Alzheimer’s Association
Alzheimer’s disease and other dementias

• In 2011, 5.4 million Americans had Alzheimer’s disease.

• Incidence of Alzheimer’s disease and other dementias is expected to double by 2050.

• Common symptoms
  - Memory loss that disrupts daily life.
  - Challenges in planning or solving problems; decreased judgment.
  - Difficulty completing familiar tasks at home, at work or at leisure.
  - Confusion with time or place.
  - Problems with speaking, writing, visual images or spatial relationships.
  - Changes in mood and personality.

• 80% of care for persons with dementia is provided at home by a family caregiver-1 in 3 families involved, 51% 50+, 60% female.

2012 Alzheimer’s Disease Facts and Figures
Cognitive Impairment and Caregiver Health

- Population-based survey compared outcomes of caregivers of persons with dementia (PWD) to caregivers of persons with cognitive impairment, not dementia (CIND)

- Caregivers of PWD
  - Spent more time providing care (9 vs 4 hrs, p=.001)
  - Experienced more emotional strain (74% vs 64%, p=.06)
  - More often exhibited symptoms of depression (40% vs 27%, p=.03)
  - Caregiver rewards similar in both groups (99%)

- Behavioral problems predicted emotional strain in both groups

Patient and Caregiver Interaction

Caregiver

Demographics

Illness

Depression

Stress

Strain

Quality of Life

Health Status

Caregiver & Care Receiver Relationship Satisfaction

Caregiver Burden

Disease Management

Care Receiver

Demographics

Illness

Depression

Stress

Strain

Quality of Life

Health Status

Adapted from Trivedi, Piette, Fihn, & Edelman, 2011

Prognosis (Mortality, Hospitalization)
Are you addressing everyone impacted by cognitive impairment/dementia?

- Do you routinely identify the primary caregiver(s) of your patients/clients with dementia?
- Do you inquire about the caregiver’s health/needs?
- Do you ask your middle age/older patients about stresses like caregiving?
- Do you talk with caregiver(s) about community services and supports? Prepare them for roles as care coordinators, hands-on providers?
When my wife became ill, her experience of illness and mine of caring for her added further complexity to my understanding: it clarified for me the moral processes central to caregiving. Real things were at stake for us. What mattered most — work, family, our lives together, our fears and aspirations — became central to the giving and receiving of care. And caregiving, I learned, was about not only triage and tinkering with medication, but also being taken up in the mundane, burdensome, yet meaning-infused practices of assisting with activities of daily living — bathing, toileting, feeding, ambulating — as much as protecting, supporting, and just being there. Mundane practices created and sustained meaning, not the other way around. The things at stake were powerfully emotional and moral. Not just ours alone, they influenced our clinical relationships. In turn, we recognized that what mattered most to clinicians — in emotional and moral, not just cognitive, terms — was not necessarily the same as what mattered to us. Those contrasting stakes came to define our journey and that of the clinicians we encountered. If they'd been better equipped to bridge this divide, I think our difficult journey would have been eased. Arthur Kleinman, M.D.

Variety of Caregiver Interventions

- Education (workshops, materials, individual consultation)
- Support Groups
- Skill Training/Psychoeducational programs
- Psychotherapy for more complex problems, distress
- Environmental Modifications to improve safety/function
- Care Management for coordinating multiple services
- Respite Care for a break from caregiving
- Multi-component programs draw from several of these
Synthesis of Caregiving Research

- Numerous reviews unable to identify the one best approach to alleviate caregiver stress and outcomes of person with dementia (Goy et al, 2012; Schulz et al, 2005)

- Most effective CG interventions tend to be individually tailored and resource intensive
  - Behavior Management Training
  - Individual Skills Training: Targeting delivery of ADLs, home environment
  - Group Skills Training

- Multi-component Interventions have strongest support for positive outcomes for caregivers
  - More comprehensive, intensive and individually tailored
REACH II -

- Multi-site trial with follow-up replications in VA/elsewhere
  - 9 in home, 1.5 hour sessions
  - 3 telephone sessions, one-half hour each
  - 5 structured telephone support groups

- Delivery by certified Interventionist (e.g., psychology, social work) using specific protocol

- Focuses on multiple domains: burden, depression, managing behavior problems

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

Collaborative Care Management: Aging Brain Model

- Care Management led by nurse case practitioner working with patient’s caregiver and Primary Care MD
- Focus on non-pharmacologic management of symptoms
  - Personal care, sleep, mobility, depression, agitation/aggression, caregiver health-written protocols and handouts
- Medication management & Access to specialty input
- Tracked outcomes and quality indicators for dementia
  - Improvements in behavioral symptoms (NPI)
  - Decreased Caregiver Stress

Callahan et. al., JAMA 2006
Gaps in Dementia Care

- Need for comprehensive care for Veterans and their caregivers
- Little attention to addressing emotional and behavioral needs of patient
- Impact of dementia on other medical problems overlooked
- Inadequate attention to caregivers’ and Veterans’ need for information, skills, emotional support
- Need chronic care model of care (linkage between community and medical resources and attention over time)
- Patients and caregiver find it difficult to negotiate health care system and the many transitions across settings ranging from home to hospice
Background: Partners in Dementia Care (PDC)

- **Five-year research investigation**
- **Delivers Care Coordination via partnership:**
  VA medical center and Alzheimer’s Association Chapter
- **Version of the evidence-based “BRI Care Consultation”**
- **Improve continuity of care by linking:**
  - Primary health care
  - Specialty health care
  - Community health and social services
  - Information and support services
PDC Research Design

- Recruited community-dwelling veterans with dementia diagnosis and their primary informal caregivers
- 12-month study intervention period
- Comparison-site: received educational materials on dementia and usual care
- Intervention-site: received PDC Care Coordination and educational materials on dementia
- Data Collection:
  - VA service utilization and cost data
  - Three structured research interviews with veterans and caregivers
PDC Participants

• **Intervention sites:** Houston and Boston
• **Comparison sites:** Oklahoma, Providence and Beaumont

• **Sample:**
  - 508 U.S. Veterans age $\geq 60$ with diagnosed dementia
  - 486 Primary family caregivers of veterans
Characteristics of PDC Care Coordination

- For all stages of dementia
- Equal attention to Veterans and their primary caregivers
- Guided by the preferences and priorities of Veterans and caregivers
- Long-term relationship with Veterans and caregivers
- Main types of assistance:
  - Health-related information/education
  - Linkages to services and other resources
  - Emotional support
  - Assistance to the network of family members and friends
Features of PDC’s Care Coordination Intervention

- **Build bridge between medical care and community-based services**

<table>
<thead>
<tr>
<th>VA Medical Center</th>
<th>Alzheimer’s Assoc. Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient-focused</td>
<td>• Family-focused</td>
</tr>
<tr>
<td>• Health &amp; medical services</td>
<td>• Consumer advocacy</td>
</tr>
<tr>
<td>• Diagnostic assessment</td>
<td>• Information &amp; support</td>
</tr>
<tr>
<td>• Primary care and disease management</td>
<td>• Volunteers &amp; professionals</td>
</tr>
<tr>
<td></td>
<td>• Messages of help &amp; hope</td>
</tr>
</tbody>
</table>
Features of PDC’s Care Coordination Intervention

• **A key staff member in each partner organization:**
  - 50% time of VA Dementia Care Coordinator and 50% time of Community Partner Care Coordinator (1.0 FTE)
  - Caseload 75-120 dyads

• **Work as a team with one shared care plan**

• **Delivered by telephone and computer (long-distance and rural friendly)**

• **Standardized and manualized protocols focused on prevention as well as practical solutions for concerns**
Components of PDC Intervention

For each veteran-caregiver dyad:

- **Triggers and Assessment**
  - 24 care receiver and 14 caregiver domains

- **Action Plan:**
  - Goals
  - Action Steps
  - Individualized to needs and preferences of dyad
  - Consumer empowerment philosophy

- **On-Going Monitoring of Action Plan**
- **Reassessment**
Key features of PDC

- Provide disease and issue-related information/education.
- Offer emotional support and coaching.
- Linkage to other services and resources in the VA systems, Alzheimer’s Chapter, & community.
- Mobilize the network of family and friends.
- VA DCC is primary for medical domains;
- Alz. Chapter CC is primary for non-medical domains and caregiver domains.
## Intervention Domains

### Veteran Domains
- Cognitive Symptoms
- Behavioral symptoms
- Co-existing medical conditions
- ADL and IADL dependencies
- Medications
- Sensory Issues
- Pain

### Caregiver Domain
- Capacity to Care

### Veteran & Caregiver Domains
- Health Information
- Communicating with Providers
- Legal/Financial
- Anxiety
- Depression
- Safety
- Care-Related Strain
- Social Isolation
- Informal Support
- Formal Support Services
- Sleep
Care Coordinator Contact

- **VADCCs**: eight contacts, range 0-52
- **AACCs**: six contacts, range 0-24
- **Average total contacts**: 14, range 1-57
- **Total contacts**: 4,438
  - Telephone: 78%
  - Regular mail: 11%
  - E-mail: 8%
  - in-person: 3%
## Triggered Domains for Veterans (n=294)

<table>
<thead>
<tr>
<th>% Veteran Triggered Domains</th>
<th>% Veteran Triggered Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>Sensory Issues</td>
</tr>
<tr>
<td>25.9%</td>
<td>44.9%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Risk of Falling</td>
</tr>
<tr>
<td>25.2%</td>
<td>33.3%</td>
</tr>
<tr>
<td>Depression</td>
<td>Personal Care</td>
</tr>
<tr>
<td>25.2%</td>
<td>31.3%</td>
</tr>
<tr>
<td>Understanding Benefits</td>
<td>Pain</td>
</tr>
<tr>
<td>23.8%</td>
<td>30.3%</td>
</tr>
<tr>
<td>Legal/Financial Planning</td>
<td>IADL</td>
</tr>
<tr>
<td>22.8%</td>
<td>29.3%</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>Home Safety</td>
</tr>
<tr>
<td>16.7%</td>
<td>27.6%</td>
</tr>
<tr>
<td>Financial Concerns</td>
<td>Medications</td>
</tr>
<tr>
<td>15.0%</td>
<td>26.9%</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>Difficult Behaviors</td>
</tr>
<tr>
<td>12.6%</td>
<td>24.1%</td>
</tr>
<tr>
<td>Formal Services</td>
<td>Nutritional Status</td>
</tr>
<tr>
<td>12.2%</td>
<td>18.4%</td>
</tr>
<tr>
<td>Informal Support</td>
<td>Co-existing Medical Conditions</td>
</tr>
<tr>
<td>9.9%</td>
<td>10.5%</td>
</tr>
<tr>
<td>Health Information</td>
<td>Cognitive Status</td>
</tr>
<tr>
<td>9.5%</td>
<td>4.1%</td>
</tr>
<tr>
<td>Dyadic Relationship Strain</td>
<td></td>
</tr>
</tbody>
</table>
## Triggered Domains for Caregivers

<table>
<thead>
<tr>
<th>% Caregiver Triggered Domains</th>
<th>% Caregiver Triggered Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sleep</strong></td>
<td><strong>32.7%</strong></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td><strong>38.4%</strong></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td><strong>32.7%</strong></td>
</tr>
<tr>
<td><strong>Understanding Benefits</strong></td>
<td><strong>25.5%</strong></td>
</tr>
<tr>
<td><strong>Legal / Financial Planning</strong></td>
<td><strong>32.7%</strong></td>
</tr>
<tr>
<td><strong>Social Isolation</strong></td>
<td><strong>40.5%</strong></td>
</tr>
<tr>
<td><strong>Financial Concerns</strong></td>
<td><strong>21.8%</strong></td>
</tr>
<tr>
<td><strong>Emotional Support</strong></td>
<td><strong>22.1%</strong></td>
</tr>
<tr>
<td><strong>Formal Services</strong></td>
<td><strong>22.8%</strong></td>
</tr>
<tr>
<td><strong>Informal Support</strong></td>
<td><strong>30.6%</strong></td>
</tr>
<tr>
<td><strong>Health Information</strong></td>
<td><strong>24.5%</strong></td>
</tr>
<tr>
<td><strong>Dyadic Relationship Strain</strong></td>
<td><strong>24.8%</strong></td>
</tr>
<tr>
<td><strong>Capacity to Provide Care</strong></td>
<td><strong>35.0%</strong></td>
</tr>
<tr>
<td><strong>Physical &amp; Emotional Strain</strong></td>
<td><strong>34.0%</strong></td>
</tr>
<tr>
<td>Content of Action Steps</td>
<td>Percent</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Accessing VA Benefits and Services</td>
<td>78.2%</td>
</tr>
<tr>
<td>Accessing non-VA and non-Alzheimer’s Association Services</td>
<td>75.5%</td>
</tr>
<tr>
<td>Accessing Alzheimer’s Association Services</td>
<td>58.8%</td>
</tr>
<tr>
<td>Helping Cope and Providing Informal Support</td>
<td>57.1%</td>
</tr>
<tr>
<td>Managing Symptoms</td>
<td>40.1%</td>
</tr>
<tr>
<td>Accessing Non-VA Benefits</td>
<td>39.5%</td>
</tr>
<tr>
<td>Interacting with Healthcare Providers</td>
<td>33.3%</td>
</tr>
<tr>
<td>Addressing Safety Issues</td>
<td>29.3%</td>
</tr>
<tr>
<td>Assessing Problems</td>
<td>25.2%</td>
</tr>
<tr>
<td>Managing Co-existing Medical Conditions</td>
<td>22.4%</td>
</tr>
<tr>
<td>Altering Living Arrangements</td>
<td>15.6%</td>
</tr>
<tr>
<td>Managing Medications</td>
<td>8.5%</td>
</tr>
</tbody>
</table>
Case Example

- **Mr. F-83 years old lives with 75 year old spouse, Mrs. F**
  - Moderate dementia
  - One son and grandson living nearby – limited understanding of dementia
  - Issues identified: driving safety, gun safety, relationship strain, (“hypersexuality”), urinary incontinence,

- **Action Plan(s): telephone time of about 7 hours over 12 mo.**
  - Loaded gun disarmed and hidden
  - Plan to stop driving discussed and used-options for outings discussed
  - Incontinence Briefs and bed mat
  - Mr. F. enrolled in Medic-Alert safe return
  - Wife joined caregiver support group & counseled on response to husband

- **AA/VA Partnership involved VA MD, MSW, APS**
  - AA Care Consultant: Caregiver stress plan, safety response
  - VA DCC communicated to get incontinence supplies, involve MD as needed
Tested Hypotheses

- **Less** negative psychosocial outcomes for Veterans and caregivers
- **Less** facility-based service use by Veterans
- **More** VA outpatient service use by Veterans
- **Lower** VA healthcare cost for Veterans
- **Greater** benefits for Veterans and caregivers who had more difficulties at enrollment
- **Greater** benefits when Veterans are more impaired
### Impact of PDC on Caregiver Psychosocial Outcomes After 6 Months

<table>
<thead>
<tr>
<th>Caregiver Outcomes</th>
<th>Significant Difference after 6 Mos.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmet Needs</td>
<td>↓ When cognitive impairment higher at baseline</td>
</tr>
<tr>
<td>Role Captivity</td>
<td>↓ When role captivity higher at baseline</td>
</tr>
<tr>
<td>Physical Health Strain</td>
<td>↓ When more behavior problems at baseline</td>
</tr>
<tr>
<td>Support Service Use</td>
<td>↑ For all caregivers</td>
</tr>
<tr>
<td>Support Service Knowledge</td>
<td>↑ When knowledge lower at baseline</td>
</tr>
<tr>
<td></td>
<td>↑ When cognitive impairment higher at baseline</td>
</tr>
<tr>
<td># Informal helpers for CG</td>
<td>↑ When fewer helpers at baseline</td>
</tr>
<tr>
<td></td>
<td>↑ When behavior problems higher at baseline</td>
</tr>
<tr>
<td>Depression</td>
<td>↓ For all caregivers</td>
</tr>
<tr>
<td>Satisfaction with VA</td>
<td>↑ When cognitive impairment higher at baseline</td>
</tr>
</tbody>
</table>
# Impact of PDC on Caregiver Psychosocial Outcomes After 12 Months

<table>
<thead>
<tr>
<th>Caregiver Outcomes</th>
<th>Significant Difference Mos. 7-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship Strain</td>
<td>↓ When personal care dependency higher at month 7</td>
</tr>
<tr>
<td># Informal helpers for Caregiver</td>
<td>↑ When fewer helpers at month 7</td>
</tr>
</tbody>
</table>

Improvements in outcomes at month 6 were maintained through month 12.
# Impact of PDC on Veteran Psychosocial Outcomes After 6 Months

<table>
<thead>
<tr>
<th>Veteran Outcomes</th>
<th>Significant Difference at 6 Mos.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmet Dementia Needs</td>
<td>↓ When more memory problems or personal care dependency at baseline</td>
</tr>
<tr>
<td>Knowledge Community Services</td>
<td>↑ When less knowledge at baseline</td>
</tr>
<tr>
<td>Number Informal Helpers</td>
<td>↑ When more cognitive impairment at baseline</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>↓ For all Veterans</td>
</tr>
<tr>
<td>Isolation</td>
<td>↓ When less cognitive impairment at baseline</td>
</tr>
<tr>
<td>Relationship Strain</td>
<td>↓ When more personal care dependency, memory problems, or cognitive impairment at baseline</td>
</tr>
<tr>
<td>Depression</td>
<td>↓ When more memory problems at baseline</td>
</tr>
</tbody>
</table>
Impact of PDC on Veteran Psychosocial Outcomes After 12 months

<table>
<thead>
<tr>
<th>Veteran Outcomes</th>
<th>Significant Difference Mos. 7-12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmet Dementia Needs</td>
<td>↓ When more personal care dependency at month 7</td>
</tr>
</tbody>
</table>

Improvements in outcomes at month 6 were maintained through month 12 (with the exception of Embarrassment about Memory Problems)
## Impact of PDC on Veteran Healthcare Service Use Outcomes

<table>
<thead>
<tr>
<th>Service Use Outcomes</th>
<th>Change in Service Use (n=354)</th>
</tr>
</thead>
<tbody>
<tr>
<td>VA and non-VA Hospital Re-admissions</td>
<td>↓ Number of re-admissions when Veterans had more behavior problems at baseline</td>
</tr>
<tr>
<td>VA and non-VA Nursing Home Admission</td>
<td>↓ Likelihood of admission when more cognitively impaired at baseline</td>
</tr>
<tr>
<td>Outpatient VA Mental Health</td>
<td>↑ Likelihood and number of visits when no prior mental health visits before PDC</td>
</tr>
<tr>
<td>Outpatient VA Primary Care</td>
<td>↑ Number of visits when less functionally impaired at baseline</td>
</tr>
<tr>
<td>Outpatient VA Surgery</td>
<td>↑ Likelihood of surgery</td>
</tr>
<tr>
<td>Outpatient VA Telephone Care</td>
<td>↑ Likelihood of contact</td>
</tr>
</tbody>
</table>
Impact of PDC on Veteran VA Healthcare Costs

• Cost-data for only VA services, included inpatient services, emergency department visits, all types of outpatient services, and pharmacy

• Intervention- compared to comparison-group Veterans were not significantly different in total VA healthcare costs for 12-month study period

• PDC Care Coordination was cost neutral despite 80% of families having Action Steps related to overcoming problems accessing VA services and benefits
Overall Findings

- PDC helped most Veterans and caregivers access VA benefits and services
- Most psychosocial outcomes significantly improved after 6 months
- Improved psychosocial outcomes were maintained but not increased during months 7 to 12
- Most psychosocial outcomes improved when Veterans had more severe impairments or difficulties at enrollment
- Some reduction in use of facility-based services: hospital re-admissions and likelihood of nursing home placement
- Most VA outpatient services increased
- No difference in VA healthcare costs during the 12 month study period despite assistance with service access
Lessons for your Practice

• Dementia care requires collaboration with other providers/disciplines

• Patients and Caregivers need resources and encouragement to address their own needs. (safety, support, activity, respite)
  - 713.314.1313 or 800.272.3900

• Care Consultation available through social agencies and private geriatric care managers (http://www.caremanager.org/)

• VA has National Caregiver Support Program (http://www.caregiver.va.gov/)

• See handout for more resources--
Ways to Assess Caregiver Distress

- How emotionally distressing do you find (patient’s) behavior?
- How often in the past six months, have you felt like screaming or yelling at (patient) because of the way he/she behaved?
- In the past month or so has caregiving made you feel overwhelmed or extremely tired?
- In the past month, have you felt depressed, sad, had crying spells or felt like you often needed to cry?
Services available for caregivers

- 70+ chapters provide local services across the country
- National Helpline 24/7
- Robust website
- Education programs
- Safety services
- Family care consultation
- Support groups
- Early-stage engagement
www.taketimetexas.org

Melanie Harrison
mharrison@txregionalcouncil.org

Joyce Pohlman
Joyce.pohlman@dads.state.tx.us

www.facebook.com/taketimetexas