

# Advancing Veteran-Centric Care for Veterans, Families, and Caregivers

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#### Partners in Dementia Care (PDC): Implementing and Evaluating Coordinated VA and Alzheimer's Association Services



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## Dementia Diagnosis is Increasing in Veterans



- 500,000 total current Veterans.
- 300,000 Veteran current enrollees.
- The number of Veterans with dementia will peak in 2018.

### **Dementia Characteristics**



- Impairs cognition -- primarily memory but also language, insight, judgment, ability to plan.
- Affects ability to care for self, including managing own medical care.
- Triggers behavioral and psychological problems.
- Creates strain on caregivers.

### Impact on Caregiver



- Negatively affects family caregivers because of:
  - Intensity of needed care
  - Stresses and strain of care giving
  - Changes in the relationship with the person with dementia
  - Lengthy and progressive course of the disease

#### Results in:

- Caregiver stress and strain
- Depression
- Poor medical health

### **Gaps in Dementia Care**



- Diagnosis often missed
- Ongoing comprehensive care lacking after diagnosis
- Impact of dementia on medical care overlooked
- Caregivers rarely receive needed attention
- Need for comprehensive care for Veterans and their caregivers

### **Partners in Dementia Care**



- Four year research & demonstration study.
- Controlled trial Five sites (Houston, Oklahoma City, Boston, Providence and Beaumont).
- Tests effectiveness of a Telephone-based Care Coordination Intervention that provides:
  - Health-related information/education
  - Linkages to services and other resources
  - Emotional support
  - Mobilize family and friends
- Focuses on U.S. Veterans with dementia and their family caregivers.

### Who participates in PDC?



- Intervention Providers
  - Dementia Care Coordinators in VA medical centers
  - Care Consultants in Alzheimer's Association chapters

#### Sites

- Houston (Intervention site)
- Boston (Intervention site)
- Oklahoma City (Education only Comparison site)
- Providence (Education only Comparison site)
- Beaumont (Education only Comparison site)

### Sample

- U.S. Veterans age ≥ 60 with diagnosed dementia
- Family caregivers (mainly spouses)

### What is the goal of PDC?



#### Test effectiveness of PDC Care Coordination Intervention.

- To improve the quality of care.
- To improve primary health care.
- To improve information and support for Veterans & families.
- To improve the continuity of care by linking:
  - Primary health care
  - Specialty health care
  - Community health and social services
  - Information and support services

### What prior studies led to PDC?



#### Cleveland Alzheimer's Managed Care Demonstration

- Cleveland Alzheimer's Association
- Kaiser Permanente of Ohio
- Tested efficacy of Care Consultation
- Recognized by Agency on Aging as Evidence Based Intervention

#### Chronic Care Networks for Alzheimer's Disease Initiative

- Partnered health care organizations and Alzheimer's Association chapters
- 10 communities across the U.S. (VA in Upstate NY)
- Tested feasibility of dementia identification and diagnostic tools for primary care
- Tested feasibility of partnerships

http://www.alz.org/professionals\_and\_researchers\_coordinated\_care.asp

# **Expected outcomes of the PDC Care Coordination Intervention?**



- Reduce health care service use by Veterans with dementia:
  - Hospital admissions
  - Emergency department visits
  - Nursing home days
  - Specialty physician visits
- Reduce cost of Veterans' health care services.
- Improve psychosocial well-being of Veterans & caregivers:
  - Decrease depression
  - Improve perceived adequacy/satisfaction with care
  - Reduce caregiver-related strain
  - Improve informal social support

# What are the design features of PDC research?



- Recruit new and previously diagnosed communitydwelling Veterans.
- Comparison sites receive primary care training and comparison patients/caregivers receive educational materials.
- Intervention sites receive same as comparison intervention + Care coordination.
- Three structured telephone research interviews six months apart – Veteran and caregiver followed for 12 months.
  - Measures: health and functioning, care-related strains, satisfaction & adequacy of care, formal and informal support

# What are the features of PDC's Care Coordination Intervention?



- Partnerships between VA medical centers and Alzheimer's Association Chapters
- Capitalizes on complementary skills of partner organizations

#### **VA Medical Center**

- Patient-focused
- Health & medical services
- Diagnostic assessment
- Primary care and disease management

#### Alzheimer's Assoc. Chapter

- Family-focused
- Consumer advocacy
- Information & support
- Volunteers & professionals
- Messages of help & hope

# What are the key features of PDC's Care Coordination Intervention?



- A key staff member in each partner organization:
  - Dementia Care Coordinator (VA DCC)
  - Care Consultant (Alz. Chapter CC)
- Two key staff members share coordinating responsibilities.
- Work as a team with one care plan.
- Predominantly, a telephone-based intervention.
- Uses a standardized set of protocols for PDC implementation.

# What domains does intervention address for Veterans/caregivers?



#### **Patient Domains**

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

### **Patient & Caregiver Domains**

- Health Information
- Communicating with Providers
- Legal/Financial
- Anxiety
- Depression
- Safety
- Care-Related Strain
- Social Isolation
- Informal Support
- Formal Support Services
- Sleep

# What are the components of PDC's Care Coordination Intervention?



- For each Veteran-caregiver dyad:
  - Triggers: Shortcuts for determining the need for assessment
    - 19 patient and 11 caregiver domains
  - Assessment: Structured questions to identify & evaluate potential problems
    - 19 patient and 11 caregiver domains
  - Implementation & Development of Care Plan:
    - Goals: Intervention objectives that address problem areas through education, emotional support and/or referral linkages.
    - Action Steps: Concrete, manageable tasks to address problems.
    - Individualized Action Plan: Outlines intervention tasks for Veteran and caregiver.
  - On-Going Monitoring of Care Plan

# A Veteran's and Caregiver's Experiences



- Hubert McCarty, Veteran
- Wanda Shedd, Caregiver

### **Initial Findings**



- Recruited 504 Veterans and caregivers
- Average age of Veteran study participant is 81
- 70% of caregivers are wives
- Veterans in PDC have wide variability in dementia severity
- On average, Veterans had more than five medical problems
- Veterans have considerable difficulty with instrumental activities of daily living (eg., managing finances and medical care), and much less difficulty with personal care tasks (eg., bathing and dressing)

### **Initial Caregiver Findings**



- 50% of caregivers have clinical depression
- Caregiver strain relatively low, but there was social isolation and emotional strain occurred in more than 15% of caregivers
- Nearly 50% of caregivers felt unmet needs for:
  - Understanding memory problems
  - Gaining service access
  - Understanding VA benefits

### **Next Steps**



- Does PDC reduce costs and service use?
- Does PDC improve psychosocial well-being of Veterans & caregivers?

#### **Answers in Fall 2010!**

 If results are positive, plans are in place to roll out in VHA by 2012



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