

# Engaging Family Members in the Care of Veterans with Diabetes



Ann-Marie Rosland, MD MS

PACT Research Inspiring Innovations & Self Management (PRIISM)  
Demonstration Laboratory, VISN 11

Ann Arbor VA Center for Clinical Management Research  
VA Diabetes QUERI Affiliated Investigator

September 18, 2013

VA HSR&D Cyberseminar



# Agenda

- Why Engage Family Members To Help “Able Bodied/Minded” Veterans Manage Chronic Illness?
  - Family Roles in Chronic Illness Care
  - Family Impact on Health Care and Outcomes
- What Do Involved Family Members Need (And Want) to More Effectively Support Chronically Ill Patients?
- New Programs Under Development
- Lessons Learned for PACT Teams

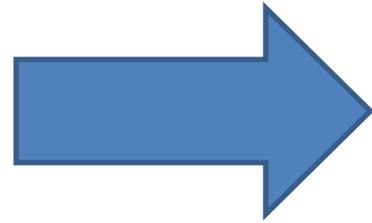
# Poll

What is your main professional role?

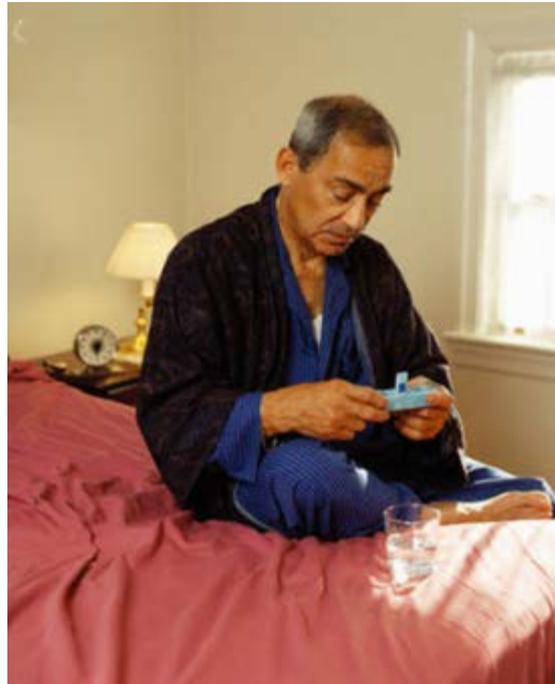
- Student, Trainee, or Fellow
- Clinician
- Researcher
- Manager or policy-maker
- Other



# Caregiver



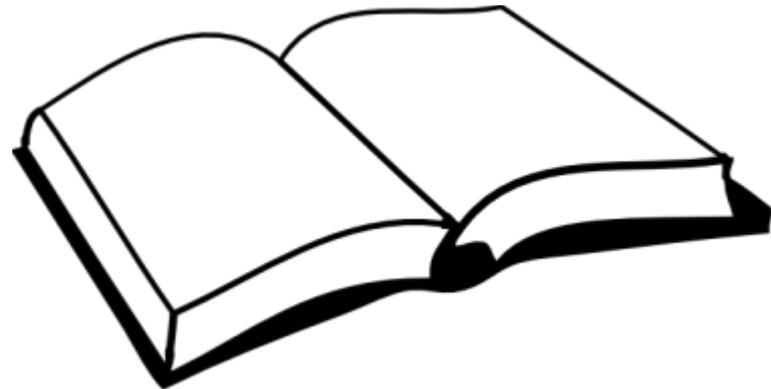
# Family Supporter



# Data Sources

- Literature Reviews
- Survey of 437 University of Michigan Primary Care Patients with Diabetes or Heart Failure
- National Internet Survey of 1722 Family Supporters of Adults with Chronic Illness
- PACE Project Survey (569 patients) and Qualitative Interviews (21 patient-family pairs) with Veterans with 'High-Risk' Diabetes

*See End for Bibliography*



# Family Roles in Chronic Illness Care

Among adults who are functionally independent:

- 50-75% of diabetes and heart failure patients have ongoing family member involvement in medical management
  - Managing and Using medications
  - Checking sugar or blood pressure at home
  - Making day-to-day decisions about self-care or illness care
  - Preparing for appointments
  - Tracking clinician recommendations and sending to other providers
  - Health system navigation

# Family Roles in Chronic Illness Care

- About half of these involved family members live outside the patient's home
- Patients with low health literacy, multiple comorbidities, and comorbid depression involve family in care more often



# Family Discussions About Health Care

<b>When you talk with your care recipient about their health, they mention that...</b> <i>% sometimes or more</i>	<b>All RECIPIENTS N=947</b>
<b>Has “bothersome symptoms”</b>	670 (72.2%)
<b>Thinks should do more to stay healthy (“such as lose weight, exercise, or stop smoking”)</b>	510 (55.1%)
<b>Concerned about medication side effects</b>	433 (46.8%)
<b>Having trouble paying for medications or health care</b>	287 (31.0%)
<b>Not getting support they need to manage health problems</b>	279 (30.2%)
<b>Confused about health care provider instructions</b>	259 (28.0%)

# Family Impact on Health Care

- Among veterans with 'high-risk' diabetes
  - 61% had a family member who regularly helped them prepare for medical appointments
  - 70% regularly discussed the medical appointment with a family member afterwards ('debriefing')
    - 27% patients not confident they are remembering the content of the visit correctly

# Family Impact on Health Care

- 50% of older adults regularly bring family members into primary care appointments
  - Information giving:
    - Facilitate discussion - prompt patient to speak and provider to listen
    - Help patient remember home events, explain symptoms
    - Provide information - clarify, expand patient history
    - Help patient understand - explain physician's instructions
  - Information seeking:
    - Help patient remember, take notes
    - Ask questions, request explanations
  - Emotional Support / Companionship
- Accompaniment to Appointments is linked to Higher Patient SATISFACTION with Primary Care



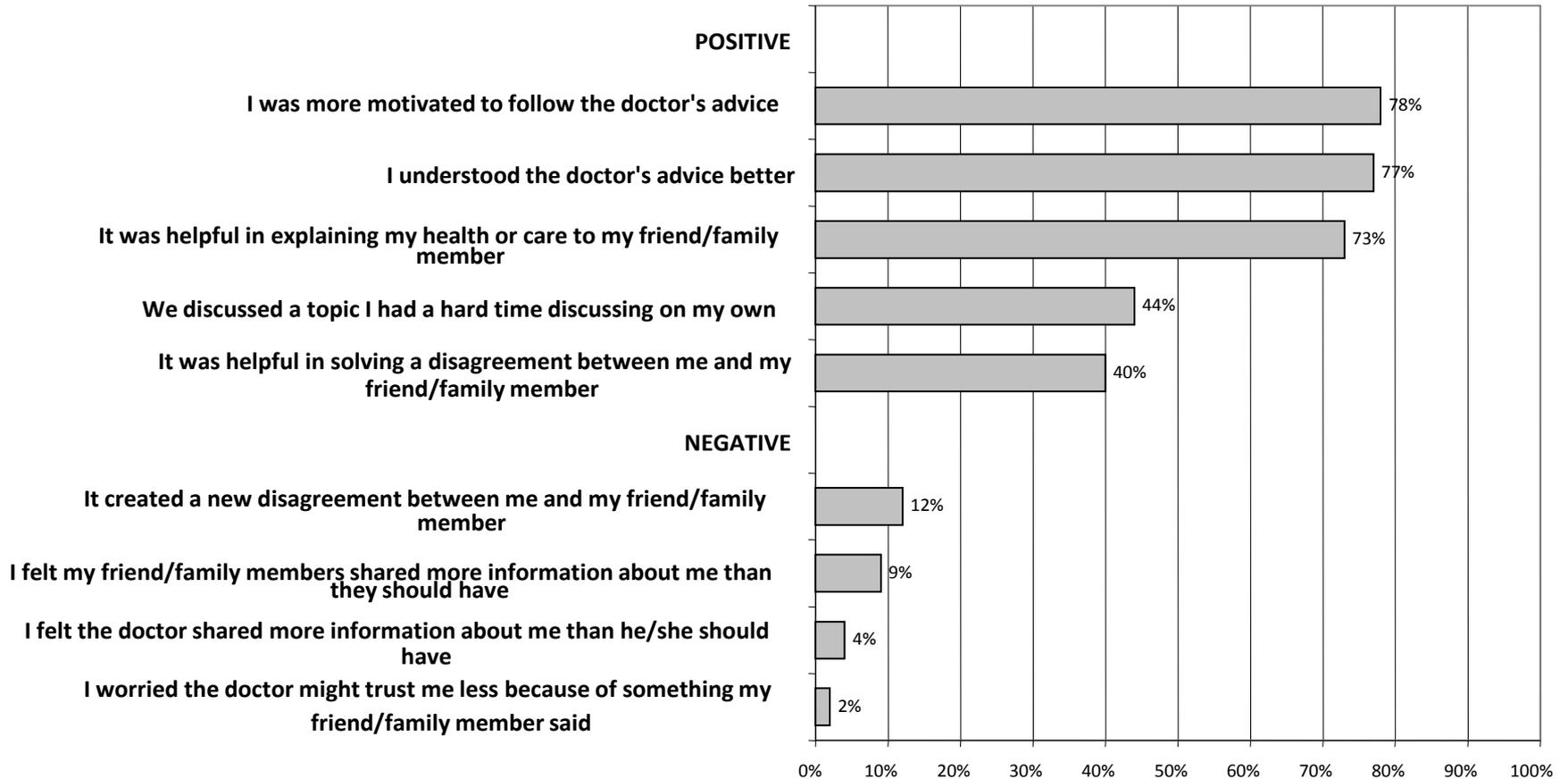
# Family Interactions with Care Team

- About 25% talked on phone with clinical team in the last year
- About 5% used email / secure messaging with patient's care team the last year
- 33% of all veterans who attended health classes or groups had family members come with them



# Patient Experiences With Family Participation In PCP Care

“When your friends or family talk to your [primary care] doctor how often have you had the following experiences?” (N=193\*)



# Support Effect on Health Outcomes

- Social support is linked to better self-management, and outcomes in chronic illness
  - Healthy Eating and Exercise
  - Glycemic Control
  - BP Control
  - Heart Failure Symptoms and Hospitalizations
  - Cardiac Events
  - Overall health status and Mortality

# Summary

## Why Involve Family Supporters in PACT?

- Supporters are already involved in medical self-care tasks and decision making
- Supporters already help patients navigate the healthcare system and communicate with clinical staff
- Supporters may help improve patient satisfaction and outcomes
- PACT goal is to engage all those helping to care for the patient in a team-based approach

# PACT and Family Supporters

- How can PACT teams engage family supporters to improve PACT care for patients with chronic illness?
- What do family members need and want to more effectively support patients?

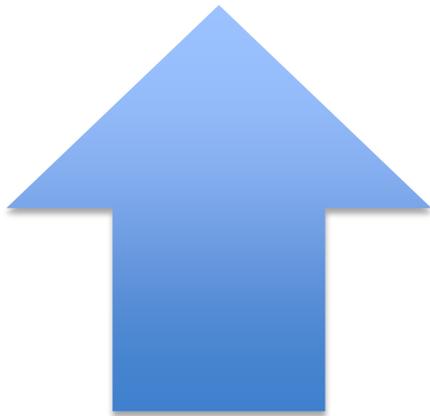


# What Family Supporters Want

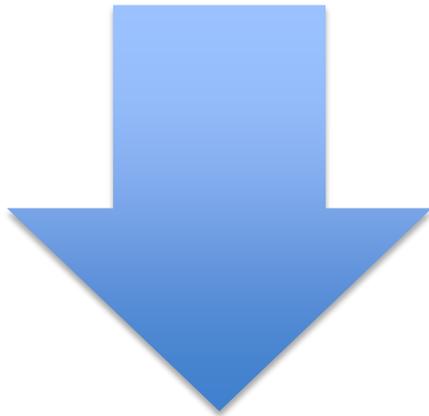
National survey of family supporters:

- Most involved family are willing to assist more with
  - Medications
  - Tracking and responding to home testing and symptoms
  - Tracking medical results and records
  - Communication at appointments
- Involved family members feel limited by
  - Lack of info about patient's health conditions
  - Lack of info about patient's health status
  - Lack of info about health care provider recommendations
  - “Don't know what questions to ask” the patient

# Are Family Better at Supporting Some Self-Care Behaviors More than Others?



Lifestyle (healthy eating, physical activity)



Medical (medication adherence, self-monitoring)

# VA Patient-Family Needs

High-risk diabetes patient and supporter interviews (N 21 pairs):

- Requested patient-specific information
- Clear methods to get patient information and family questions to/from PACT teamlet
- Distinct and personalized after-visit summary with clear way to follow-up with any questions
- Orientation to 'who's who' in primary care and best way to reach them
- Access to information on how to handle diabetes 'medical' issues at home

# VA Patient-Family Insights

- Family who work or live far away find creative ways to stay involved
  - Phone calls
  - Technology
  - Deploy in-town family members
- Family and patients feel more confident in family members when they have received some ‘training’ about diabetes
- Family members feel encouraged to come in or call when they are personally familiar with doctors/nurses and the system
  - Describe VA as especially intimidating
- If have to choose, family prioritize visits related to procedures or specialists
- Concerns about privacy are very rare

# VA Clinical Staff Insights

VA primary care clinical staff survey (N 116) & interviews (N 66)

- Perceive benefits to including supporters and already try to include them
- Interested in:
  - Supporters helping motivate patients to make health behavior change (81%)
  - Including supporters during in-person visits and between-visit calls (74%)
  - Supporters helping patients titrate meds (diabetes meds, diuretics) (71%)
  - Supporters informing team when patient status changes (68%)
- Biggest concerns:
  - Not aware supporter is involved or what their role is (70%)
  - Concern that supporters are not giving 'proper' advice or care (57%)
  - Privacy (46%) and Time (40%)

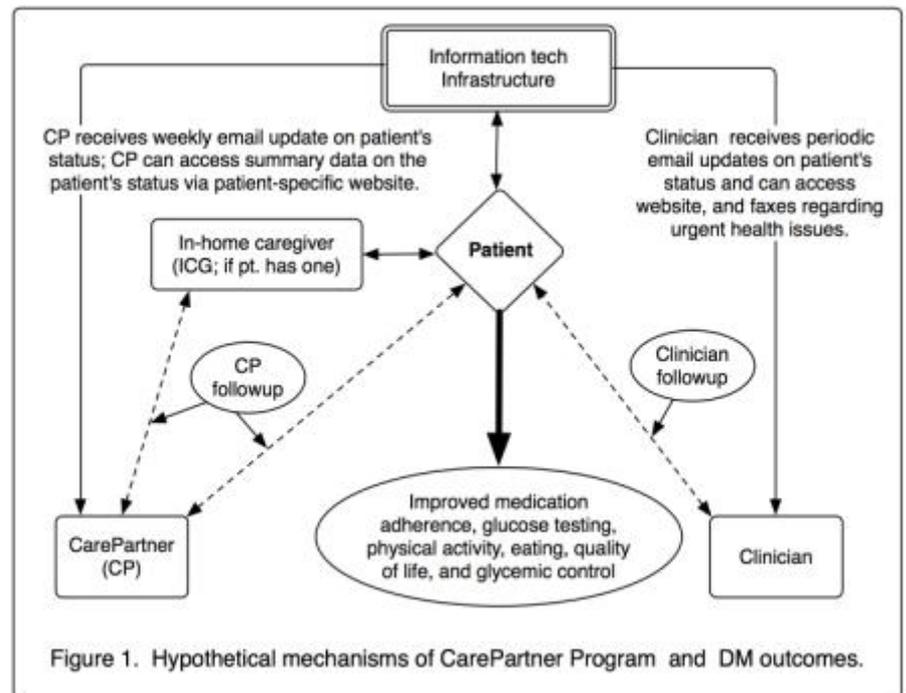


# VA Pilot Programs for Family Supporters in Chronic Disease

- CarePartners
- CarePartners Clinic Connections Pilot
- Couples' Telephone Intervention in Hyperlipidemia Pilot
  - Improved diet and physical activity, C Voils –VA Durham
- Heart Failure Self-Management for Couples
  - R Trivedi, VA Palo Alto Pilot

# CarePartners Program

- Patients answer weekly automated Interactive Voice Response calls about symptoms and self-management
- CarePartners receive automated weekly reports
- Both get (automated) suggested next steps
- Adapted for Diabetes, Heart Failure, Depression, Cancer Symptoms, Transitions



# CarePartners Clinic Connections

- Intervention Goals
  - Improve effective family support for patients' 'medical' diabetes self-management and participation in care
  - By integrating actively involved family members into the PACT care team

# CarePartners Clinic Connections Model

Family Supporter  
Engagement

- Caregiver “In The Loop” – personalized clinical and health system information
- Caregiver helps prepare and debrief PACT visit + Caregiver monitors weekly for clinically relevant changes through IVR

Patient Activation

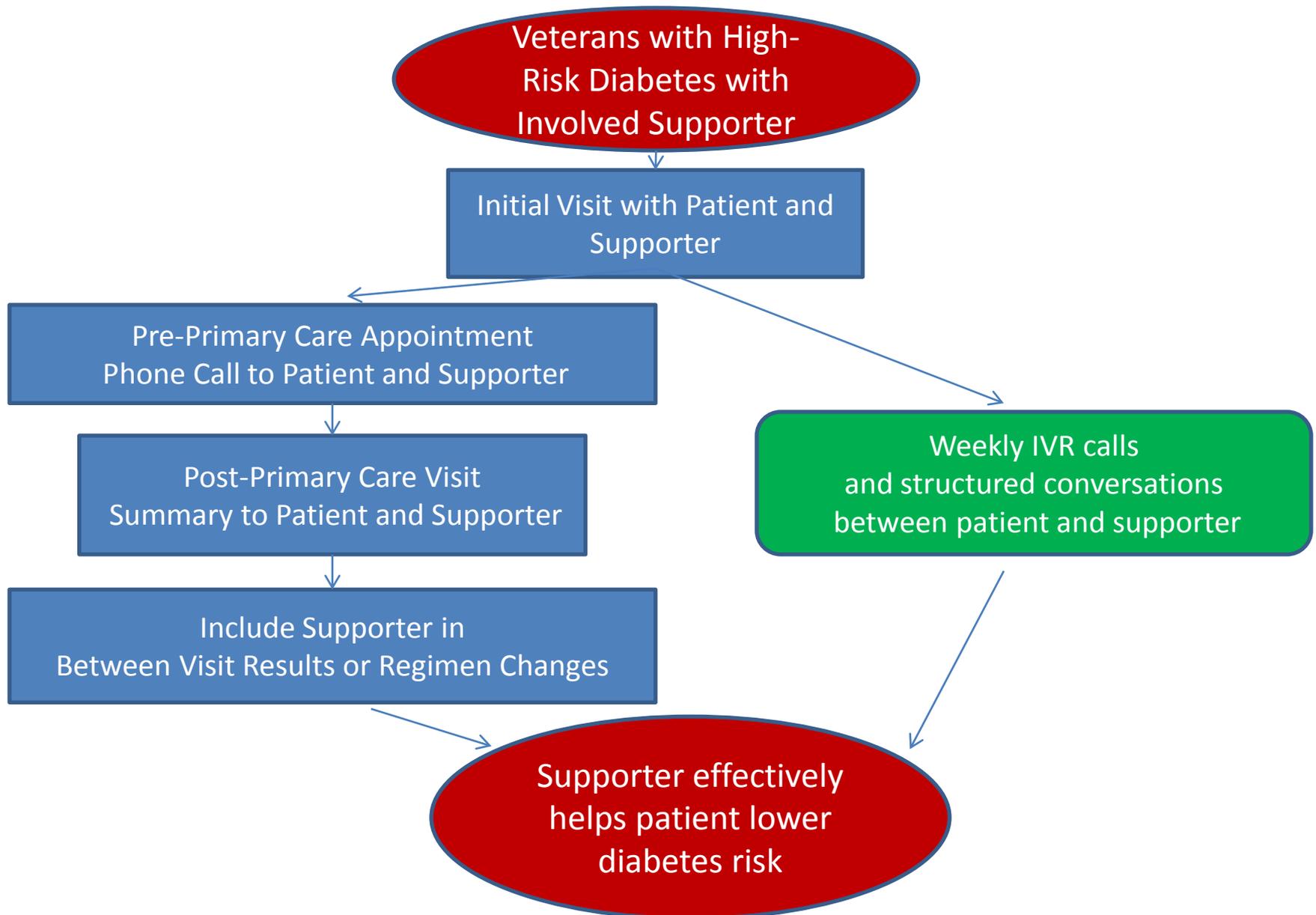
- Patient uses health system resources available
- Patient participates in visit and enacts plan after
- Patient takes timely action when problems arise

Medication Adherence  
Timely changes in regimen  
Better CV risk control  
Better safety (side effects, hypoglycemia, ED visits)

# CarePartners Clinic Connections Population

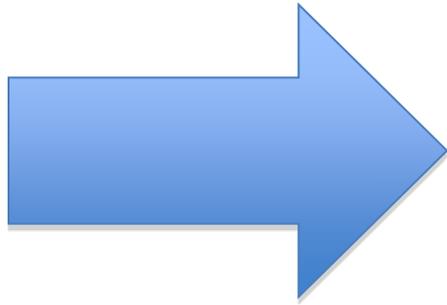
- From VA healthcare system High-Risk Diabetes Registry
  - Active AAVA primary care patient *and*
  - Last HbA1c >9 or HbA1c >8 and <55 yo *or*
  - Last BP>160/100 or mean 6 month BP >150/90
- Supporter who is regularly involved in health care
  - In-home or out-of-home
- Estimated 1100 healthsystem patients are eligible

# CarePartners Clinic Connections Design



# Lessons for PACT Teams

- Ask patients if they have an involved family member
  - What aspects of medical care/navigation are they involved in
  - Document once permission to contact that family member about care
- Introduce PACT team to family member
- Give diabetes-specific information to involved family member
  - And express your confidence that they are 'qualified' to help
- Give patient-specific information to involved family member
  - Particularly if patient is complex and family are involved with medical / navigation tasks
- Encourage family to come to primary care appointments - into the room
- Encourage family to prepare questions/concerns for you
- Encourage productive communication skills among family members
  - Family members can use open-ended listening, autonomy support/motivation, and goal setting too!



# Caregivers of Veterans with Dementia

Dr. Mavandadi

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- Rosland AM et al, *Families, Systems, & Health*, 2013. Current and Potential Support for Chronic Disease Management in the United States: The Perspective of Family and Friends of Chronically Ill Adults
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# Extra Slides

# Modified Poisson Multiple Regression Model-Based Adjusted Relative Risks of Diabetes Self-Management Behavior Adherence with Higher Social Support\*

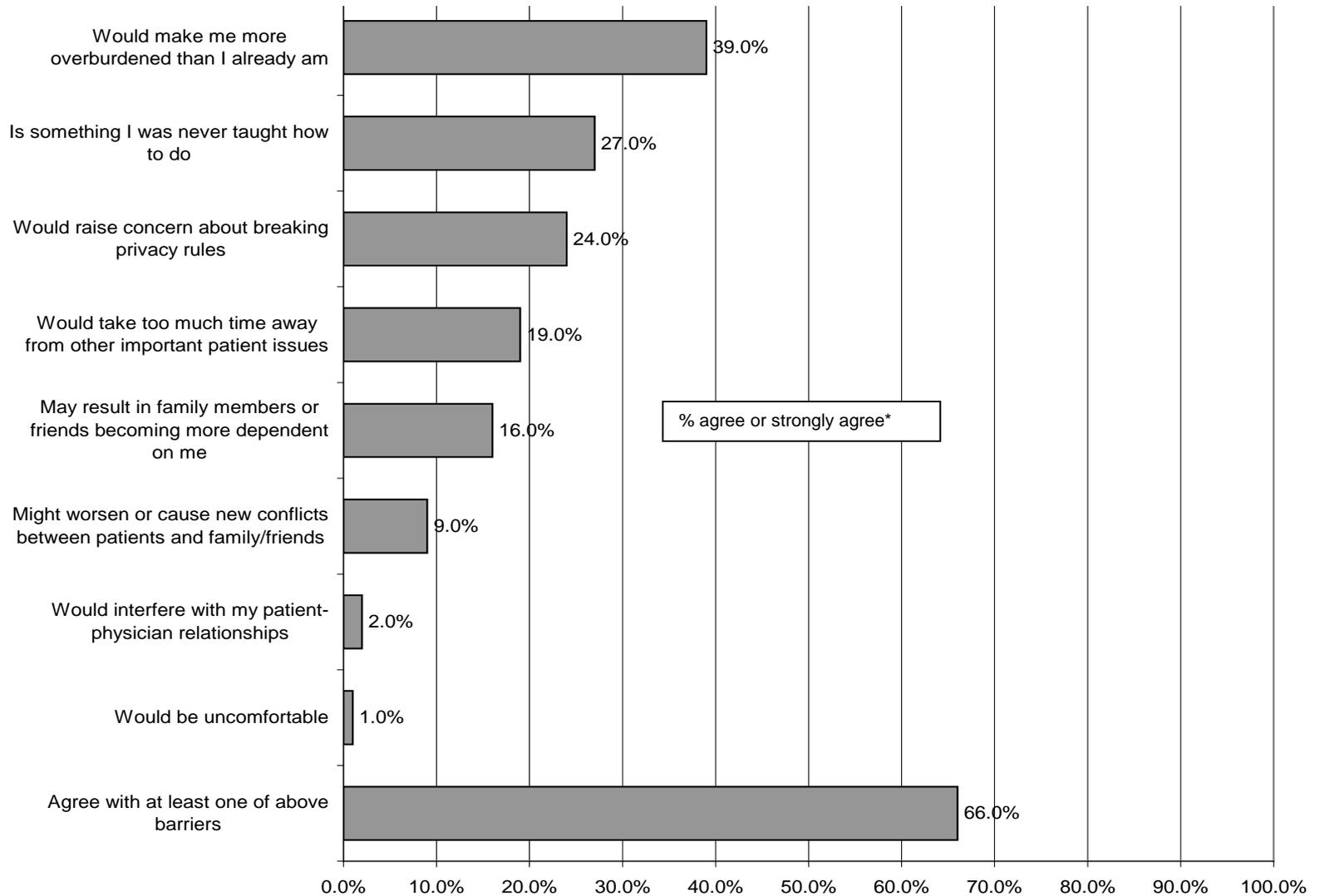
DISTANCE Study, N = 13,366

	Healthy Eating (s)	Adequate Physical Activity (s)	Checking Feet (s)	Diabetes Oral Medication Adherence (s)	Diabetes Oral Medication Adherence (a)	Insulin adherence (s)	Daily SMBG among insulin users (s)	Daily SMBG among insulin users (a)	Primary Care appointment adherence (a)
High Emotional Support ARR (CI)	1.14 (1.08, 1.21) <sup>†</sup>	1.09 (1.01, 1.17) <sup>†</sup>	1.21 (1.12, 1.31) <sup>†</sup>	1.03 (0.99, 1.07)	0.99 (0.93, 1.06)	1.03 (0.96, 1.10)	1.09 (0.95, 1.26)	1.03 (0.91, 1.18)	1.01 (0.99, 1.03)
SN (ref)	---	---	---	---	---	---	---	---	---
1	1.07 (1.02, 1.27) <sup>†</sup>	1.13 (1.05, 1.21) <sup>†</sup>	1.02 (0.95, 1.09)	0.98 (0.95, 1.02)	0.96 (0.91, 1.03)	0.99 (0.93, 1.05)	1.02 (0.89, 1.17)	1.03 (0.92, 1.16)	1.04 (0.99, 1.04)
2	1.10 (1.05, 1.16) <sup>†</sup>	1.20 (1.12, 1.28) <sup>†</sup>	1.10 (1.03, 1.17) <sup>†</sup>	1.00 (0.97, 1.03)	0.98 (0.92, 1.03)	1.02 (0.96, 1.07)	1.08 (0.96, 1.23)	0.98 (0.88, 1.10)	1.03 (0.99, 1.03)

Models adjusted for: age, sex, race/ethnicity, education, income, physical component of SF8, DxcG comorbidity score, duration of diabetes, diabetes treatment, and depression. Medication adherence models also adjusted for: hospitalization in year prior to baseline, number of chronically used medications. Appointment adherence models also adjusted for hospitalization in year prior to baseline and total number of scheduled appointments

# Physician Barriers to More Family Participation

"How do you feel about talking with family and friends of diabetes or heart failure patients more often?"



## Other Team Members

**Clinical Pharmacy Specialist** ± 3 panels

**Social Work:** ± 2 panels

**Trainees**

## Integrated Behavioral Health

Psychologist ± 3 panels

Social Worker ± 5 panels

Care Manager ± 5 panels

Psychiatrist ± 10 panels

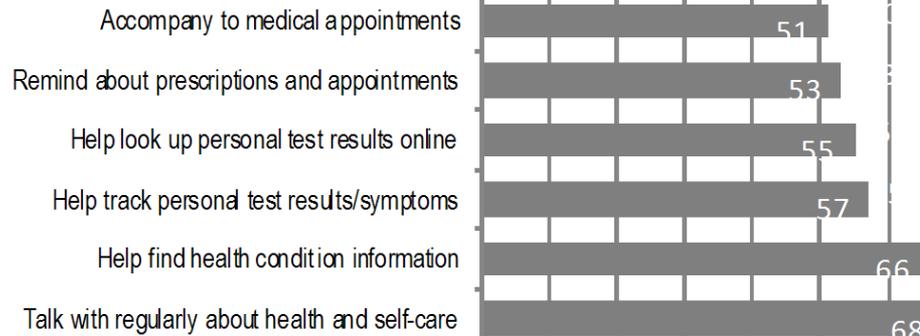
### Teamlet:

Assigned to 1 panel  
(±1200 patients)

- **Provider: 1 FTE**
- **RN Care Manager: 1 FTE**
- **Clinical Associate (LPN, Medical Assistant): 1 FTE**
- **Clerk: 1 FTE**

**Team-Based Care**

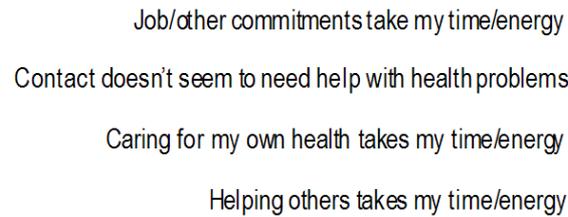
### Willingness to Help With Specific Chronic Illness Management<sup>1</sup>



% somewhat or very likely

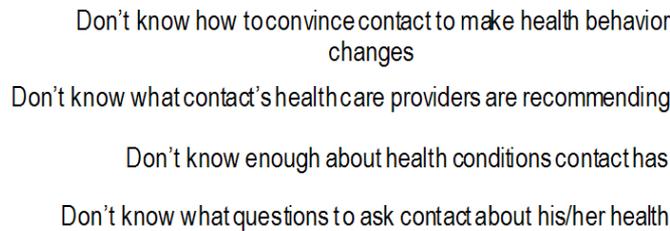
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### Barriers to Helping More - Personal/Interpersonal<sup>2</sup>



% somewhat of a problem or major problem

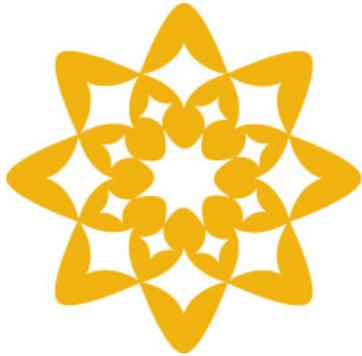
### Barriers to Helping More - Knowledge/Skills<sup>2</sup>



0 10 20 30 40 50 60 70 80 90 100

# Visit Companions and Patient Satisfaction with Primary Care

<b>Association between Companion Participation in Doctor Visit with Patient Satisfaction with PCP Care: Multivariate Logistic Regression Results<sup>#</sup></b>	
	Dependent Variable: Patient Satisfaction with PCP Model N = 411 AOR (95%CI)
<b>Independent Variables</b>	
<b>Visit companion at least sometimes</b>	1.7 (1.1-2.7) *
<b>Age (reference: &lt;50 years)</b>	
51 - 64	0.97 (0.5-1.8)
65 - 74	1.2 (0.6-2.3)
> 75	0.8 (0.4-1.7)
<b>Male</b>	0.9 (0.6-1.3)
<b>Hispanic/Non-Caucasian</b>	2.3 (1.3-4.3) **
<b>Less than college education</b>	0.8 (0.5-1.3)
<b>Self-Rated Health Status (reference: excellent/very good)</b>	
Good	1.2 (0.7-2.1)
Fair/Poor	0.7 (0.4-1.4)
<b>Comorbidities (reference: 0-1)</b>	
2-3	0.7 (0.4-1.3)
4-10	0.8 (0.4-1.5)
<b>Depressive Symptoms</b>	0.9 (0.8-1.1)
<b>Months known PCP</b>	1.0 (1.0-1.0)
<b>Appointments with PCP in last 12 months</b>	1.1 (1.03-1.2) **



VISN4  
CENTER FOR  
EVALUATION OF  
PATIENT ALIGNED  
CARE TEAMS



# Engaging Caregivers in the Care of Veterans with Dementia

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Shahrzad Mavandadi, PhD

Research Health Science Specialist

Mental Illness Research, Education, and Clinical Center (MIRECC)

Philadelphia VA Medical Center

# Poll Question

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- Which best describes your clinical research experience?
  - have not done clinical research
  - have collaborated on clinical research
  - have conducted clinical research myself
  - have applied for clinical research funding
  - have led a funded clinical research grant

# Dementia among Older Adults in the United States: Trends & Implications

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- 1 in 8 older Americans has Alzheimer's Disease (AD)
  - Over ½ million Veterans with dementia in 2013  
(<http://www.va.gov/HEALTHPOLICYPLANNING/reports1.asp>)
- AD is the 6<sup>th</sup> leading cause of death
- Payments for AD care alone estimated at \$200 billion
- The annual incidence of AD and other dementias is expected to double by 2050
- Significant impact will be felt as the population ages



# Provision of Health Care for Older Adults with Dementia

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- Paid Caregivers: Direct-care workers and professionals
    - Fewer than 10% receive all their care from paid caregivers
    - Shortage of workers, insufficient training, and high turnover
  - Unpaid Caregivers: 80% of care provided at home is by family members (Institute of Medicine, 2008)
  - Caregivers are “hidden patients” (Pinquart et al., 2003)
    - Increased risk for social, psychological, and physical health problems
  - Caregiving role associated with adverse outcomes for both caregivers and care recipients (Mittelman et al., 2006)
-

# Caregiver-Based Interventions for Dementia

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- A variety of programs and interventions have been developed and evaluated (<http://www.hsrd.research.va.gov/publications/esp/dementiacare.cfm>)
- Programs focused on caregiver support and psychoeducation have a positive impact on caregiver and care recipient outcomes (Schulz & Martire, 2004)
- Best evidence for individually tailored, multicomponent programs
- Patient-centered, collaborative care programs have yielded especially promising results (PDC, Judge et al., 2011; REACH I & II, Wisniewski et al., 2003, Schulz et al., 2003; Callahan et al., 2006; ACCESS, Vickrey et al., 2006)

# Pilot Project: Purpose

- Examine impact and feasibility of a telephone-based dementia care management program that involves two main components:
  1. Collaborative care management
  2. Manual-driven psychoeducation, support, and skills training
- Supports PACT initiatives:
  - Patient/family centered
  - Care coordinated by care managers in collaboration with PCP and other providers
  - Improved access and engagement via telephone administration
  - Brings specialty dementia care to patient and family

# Pilot Project: Aims

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- To examine whether, relative to UC,
  - The program is associated with improved caregiver and patient outcomes
  - Participants enrolled in the program have greater perceived access to and use of medical and social services
- To evaluate whether the program is feasible and acceptable to caregivers

# Method: Design & Sample

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- Design:
    - Longitudinal (BL, 3, & 6 months), randomized design
    - N=80 (40 intervention, 40 UC)
  - Study Sample:
    - CGs of community dwelling Veterans with a dementia diagnosis and/or on a cholinesterase inhibitor
  - Recruitment Strategies
    - Direct provider referral, Behavioral Health Laboratory, Clinical Patient Record System (Rx)
-

# Method: Program Components

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- All Participants:
    - Baseline/3M/6M Assessments – RA administered
    - Receive printed brochures/materials regarding caregiving
  - Intervention Arm
    - Monitoring Symptoms, Medication and Service Use
      - Contact CG at least 3-4 times over 3 months
      - Evaluate & track: dementia & psychiatric sx, safety issues, CG distress, service use/needs, and medication use
      - Assist in service/resource connection, mail educational materials
      - Consult with PCP as needed
    - Telehealth Education Program
-

# Telehealth Education Program

- CG support group program developed at the VISN2 Center for Integrated Healthcare (CIH) (Wray, Shulan, Toseland, et al., 2010)
- Based on the Stress & Coping model (Lazarus & Folkman, 1984)
- Adapted for use with individual CGs
- Key Components:
  - Psychoeducation, problem solving, action plan development, emotion/problem focused coping, & support
  - Up to 10 modules selected
    - 2 mandatory sessions + individualized menu selections
    - Sample topic areas: behavioral management, communication skills, planning for the future

<https://vaww.visn2.portal.va.gov/sites/natl/cih/Shared%20Documents/Forms/AllItems.aspx>;

Laura.Wray@va.gov



# Methods: Key Assessments

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- **Caregiver-Related:**
    - Sociodemographics, general functioning (SF12), social participation, medical hx checklist
    - Zarit Burden Interview; Lawton Caregiver Appraisal Scales; Pearlin Caregiving and Stress Process Scales
    - Needs Assessment, Desire to Institutionalize Scale
    - PHQ-9 (depression)
  - **Care Recipient-Related:**
    - Sociodemographics, clinical characteristics, ADL/IADLs, medical hx checklist, med/service utilization
    - Revised Memory and Behavior Problems Checklist (RMBPC)
    - Neuropsychiatric Inventory Questionnaire (NPI-Q)
  - **Process Evaluation: care manager tracking sheets**
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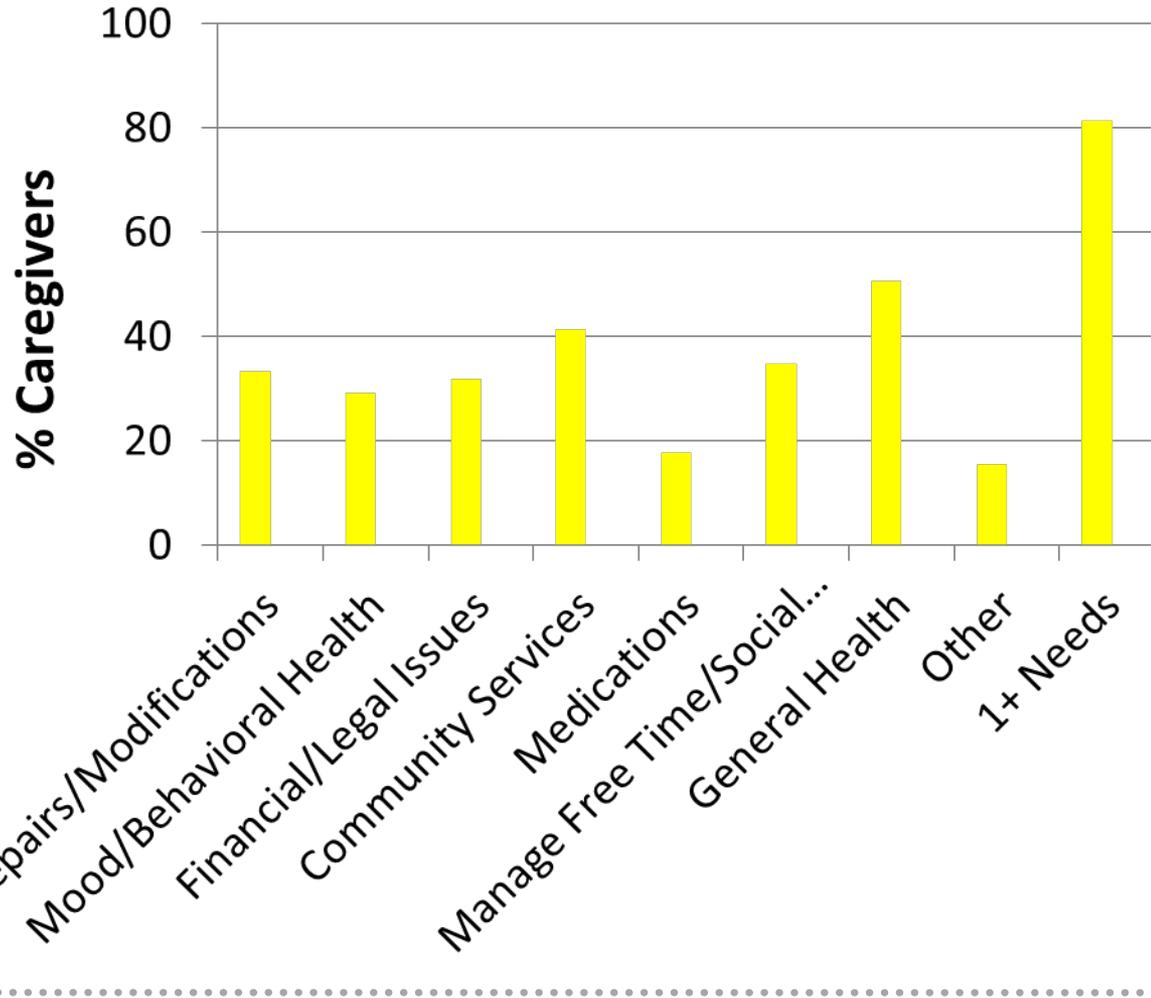
# Caregiver Background Characteristics

Characteristic (n=70)	Mean (SD)/ N (%)	Range
Age	70.00 (11.96)	41-88
Female	68 (97.1%)	
Non-Hispanic White	45 (64.3%)	
Relationship to Veteran – Spouse	59 (84.3%)	
Provide 24 hours of Care/Day	46 (65.7%)	
CG Duration (yrs)		
≤ 2 yrs	32 (46.4%)	
3-5 yrs	21 (30.4%)	
6+ yrs	16 (23.2%)	
Financial Situation – Have at least enough to get by	58 (86.5%)	
General Physical Functioning (SF-12 PCS)	48.29 (10.72)	21.45-69.22
General Mental Functioning (SF-12 MCS)	43.82 (11.87)	11.48-70.62
Total Needs Endorsed	2.5 (2.1)	0-8
Overall Caregiver Burden (Zarit)	14.54 (9.56)	0-40

# Care Recipient Characteristics

Characteristic (n=70)	Mean (SD)/ N (%)	Range
Age	78.80 (8.90)	52-94
Male	69 (98.6%)	
Non-Hispanic White	45 (64.3%)	
Dementia Duration > 3 yrs	39 (55.7%)	
Comorbid Medical Conditions	9.12 (4.76)	
IADL deficits	3.70 (4.12)	0-21
ADL deficits	4.31 (1.95)	0-6
Neuropsychiatric Indices (NPI)		
<i>Symptom Severity</i>	7.43 (5.44)	0-22
<i>CG Distress due to Symptoms</i>	9.91 (8.96)	0-42
Revised Memory Behavior Problem Checklist (RMBPC)		
<i>Frequency Total</i>	9.19 (3.75)	2-21
<i>CG Reaction Total</i>	18.54 (13.26)	0-62

# Preliminary Findings: Caregiver-Reported Needs



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CEPACT



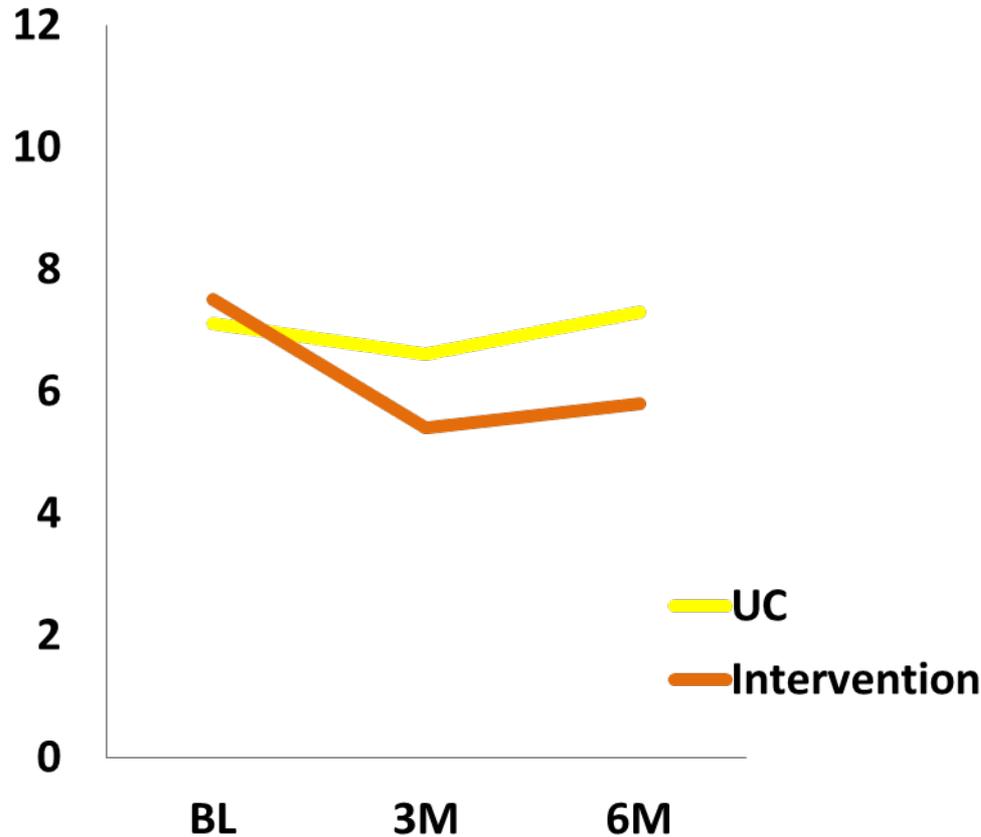
# Participation in Care Management/TEP

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- Engagement
    - Average # Contacts: 5 (range=3-9)
    - Average # of TEP modules selected: 3 (range=2-10)
  - A wide range of needs/concerns addressed
    - Most common: mood/behavioral health, community services, medications, general health, appointments made/facilitated
  - Coaching/practice in various non-pharmacologic strategies to reduce stress and strain
    - Pleasurable event scheduling, cognitive restructuring, problem solving exercises
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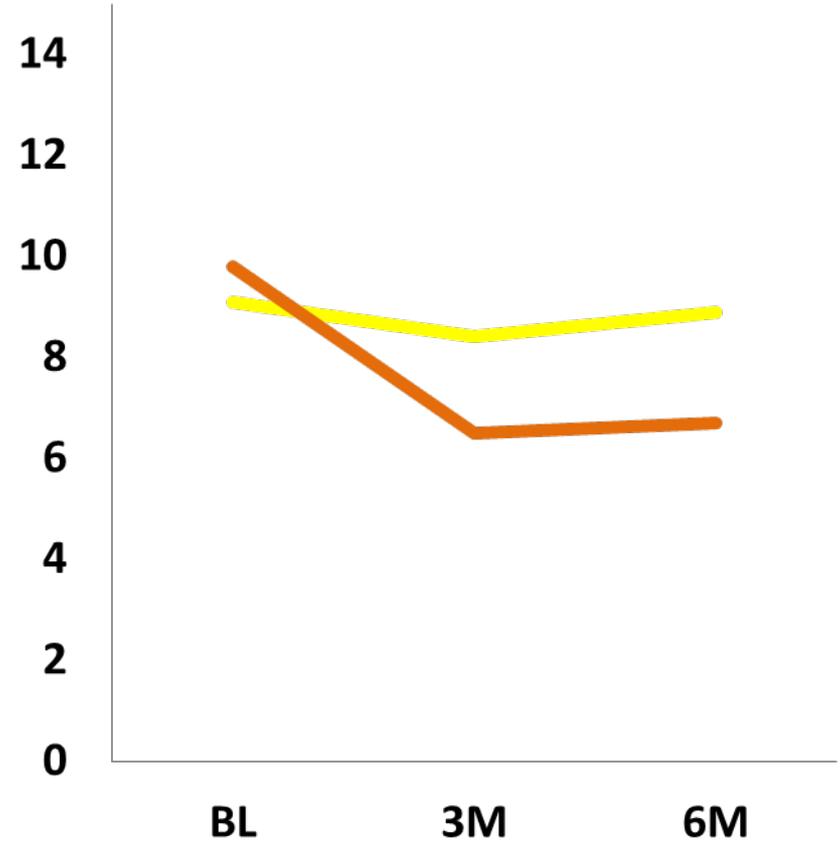
# Preliminary Outcomes: NPI Indices

## NPI Symptom Severity



Visit\*Group :  $F_{(2,92)}=1.55, p=.21$

## Caregiver Distress due to Symptoms

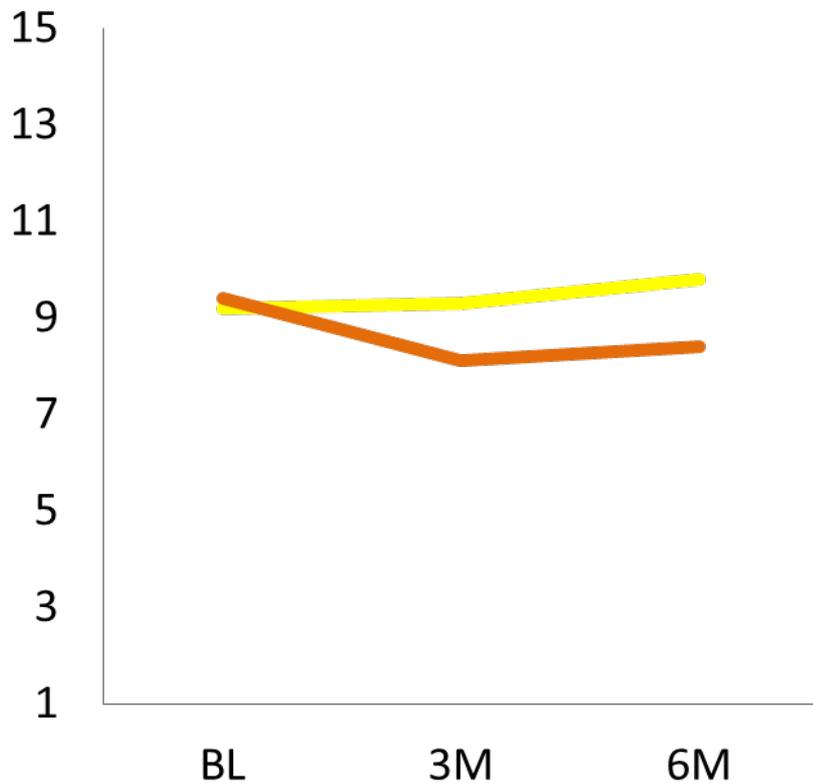


Visit\*Group :  $F_{(2,92)}=2.27, p=.10$

# Preliminary Outcomes – Revised

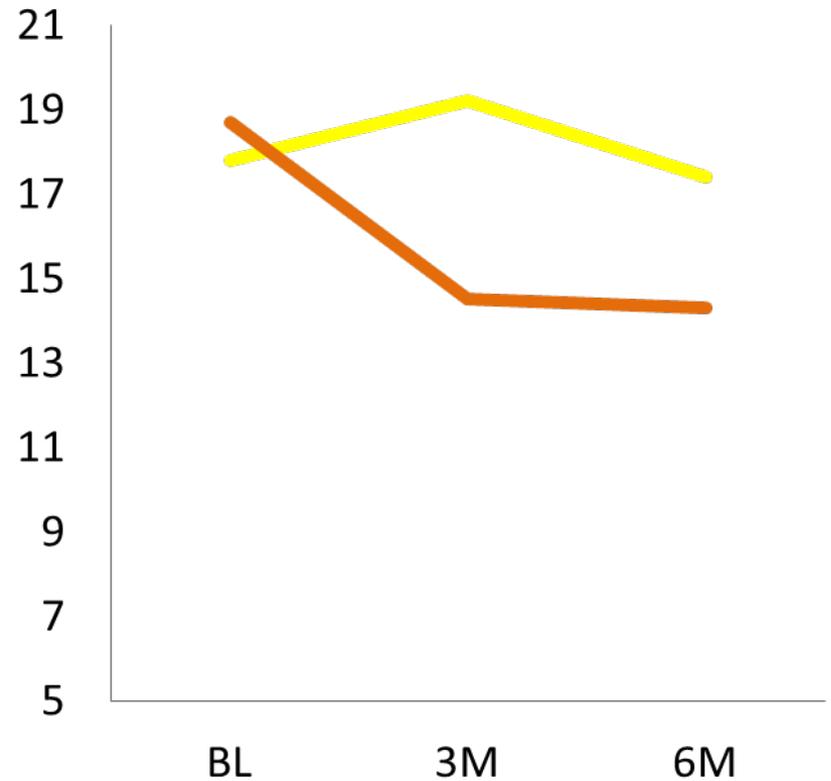
## Memory Behavior Problem Checklist

### Total Symptom Frequency



$F_{(2,92)}=1.36, p=.26$

### Caregiver Distress/Reaction to Symptoms



$F_{(2,91)}=2.81, p=.06$

# Additional Outcomes

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- **Relative to UC, CGs in the intervention arm also reported greater increases in:**
  - **Caregiving mastery (p=.17)**
  - **“Management of meaning” (i.e., cognitive coping) (p=0.02)**
  - **Overall mental functioning (SF12 MCS) (p=0.08)**
  
- **Desire to Institutionalize**
  - **No significant differences between groups**

# Summary & Implications

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- A telephone-based caregiver outreach and support program for community-dwelling older Veterans is feasible and acceptable to caregivers.
- Caregivers of older Veterans with dementia report unmet needs and experience burden and distress.
- Longitudinal trends suggest that caregivers' distress may decrease over time upon receipt of care management services.
- Findings highlight the importance of increasing caregiver access to patient-centered programs and resources that provide support and psychoeducation and can easily be implemented within PACTs.

# Thank You & Acknowledgments

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*VISN 4 Center for Evaluation of  
PACT (CEPACT)*

*Care Managers:*

*Trisha Stump, RN*

*Bree Miller, PsyD*

*Sherry Coccozza, RN*

*Project Coordinators:*

*Erin Clark, BA*

*Meagan Graydon, BA*

*Co-Investigators:*

*Laura Wray, PhD*

*David Oslin, MD*

*Johanna Klaus, PhD*



# Questions?

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Ann-Marie Rosland, MD, MS

[Ann-marie.rosland@va.gov](mailto:Ann-marie.rosland@va.gov)

Shahrzad Mavandadi, PhD

[shahrzad.mavandadi@va.gov](mailto:shahrzad.mavandadi@va.gov)



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