

Family caregivers of patient populations with high mental health burden:

Impacts of VA support for caregivers on patients, caregivers, and the VA system

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Educational Objectives

1. To demonstrate an understanding of the goals of and the services provided by the VA Caregiver Support Program
2. To explain the impacts of the Comprehensive Program of Assistance for Family Caregivers (PCAFC) on Veteran service use and family caregiver perceived value of the program
3. To describe the role that institutional support for family caregivers plays in helping patient populations with high mental health burden engage in VA medical and psychiatric services.

Outline

- Traditional caregiver model  shifts in caregiving
- Family members and patients with mental illness
- VA support for family caregivers
- VA caregiver support evaluation results
- Clinical implications
- New family research initiatives in VA
- Future research/remaining questions

Case

- 38 yo male VA patient
- Diagnoses of PTSD, TBI, shoulder, hip and knee injuries due to service-related events
- Army 70% disability rating due to PTSD
- Used post 9/11 GI Bill to obtain two associates degrees
- Claims has been told that he is “unable to work”
- “Doesn’t mesh well with society”
- Life choices
 - Subsistence farming
 - Homeschools children

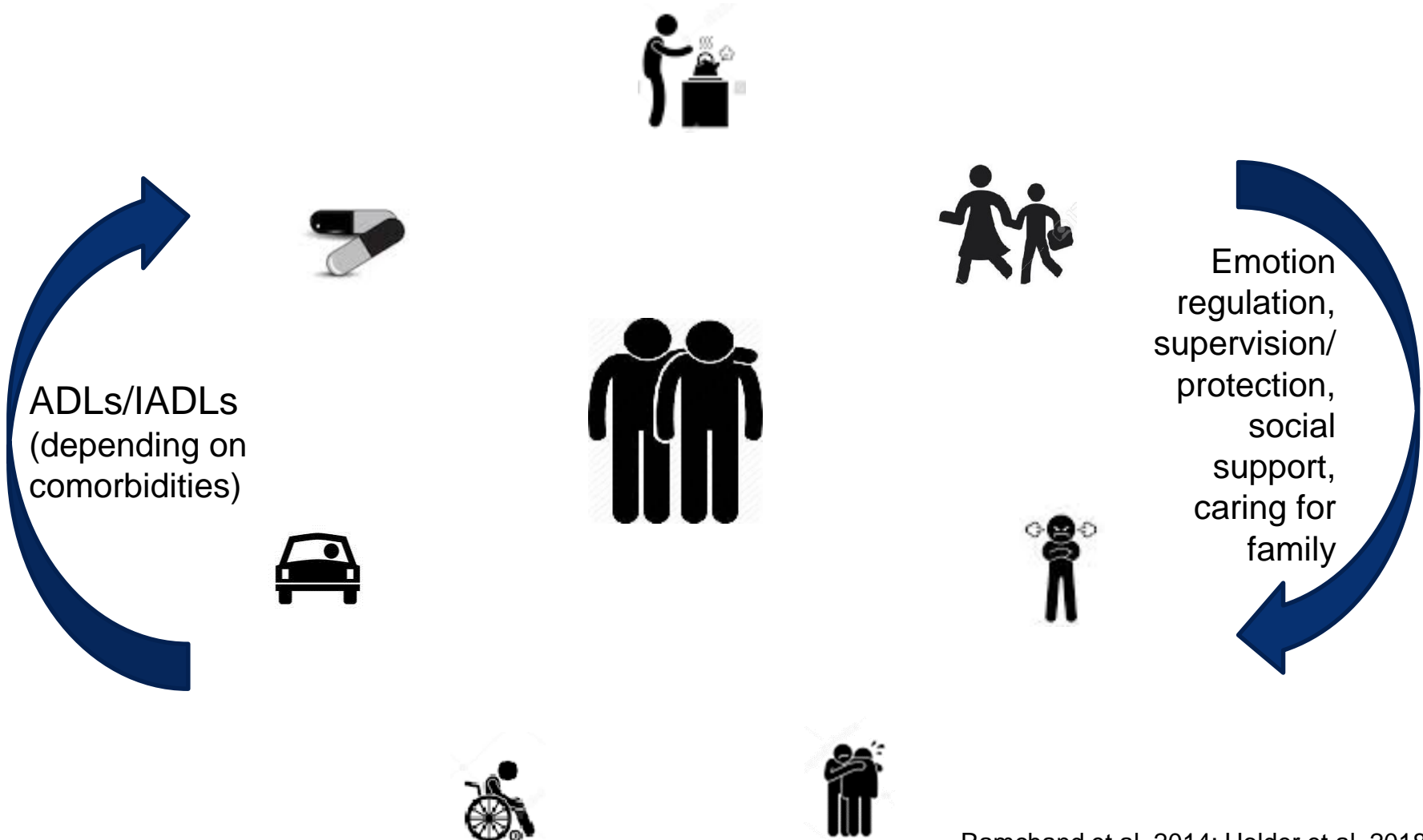


Photo credit Fundamental Health Solutions

Traditional Family Caregiver Model



Realities of post 9/11 Family “Caregivers”



Family caregiver vs. Family member

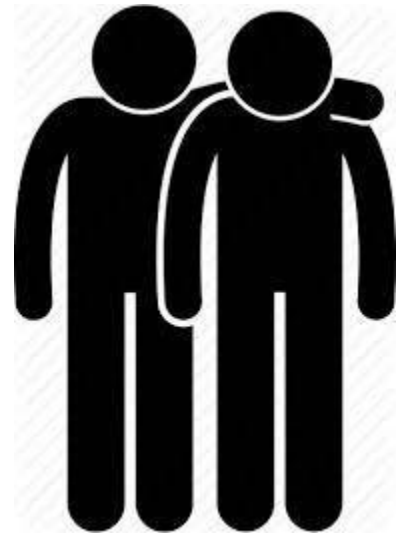
- Self identify
- Normal family tasks versus something more?

CG: "...every time he has appointments, either I take him, or I have to coordinate the travel for him. I mean I feel like that's kind of very common wife stuff."

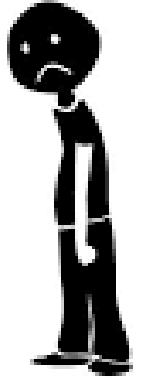
Veteran: "...her workload to take care of me sometimes is a little, heavier than your average couple. As far as able-bodied people or non-military related couples. But I mean there's a fair amount of stuff that she has to do that she probably wouldn't do if she wasn't married to a Veteran, you know?"

Family support is key for patients with mental illness

- Improves mental health symptoms
- Increases patient capacity to sustain broader reintegration outcomes
 - Maintaining employment
 - Improved community reintegration
- Poor family functioning and lack of social support lead to poorer outcomes for psychiatric treatment



Burden among caregivers is high



- Burden higher among caregivers of patients with psychiatric illness versus chronic medical illness
- Leads to less supportive home environment for patient
- May exacerbate patient symptoms, health care costs, and lead to higher levels of undesirable service use



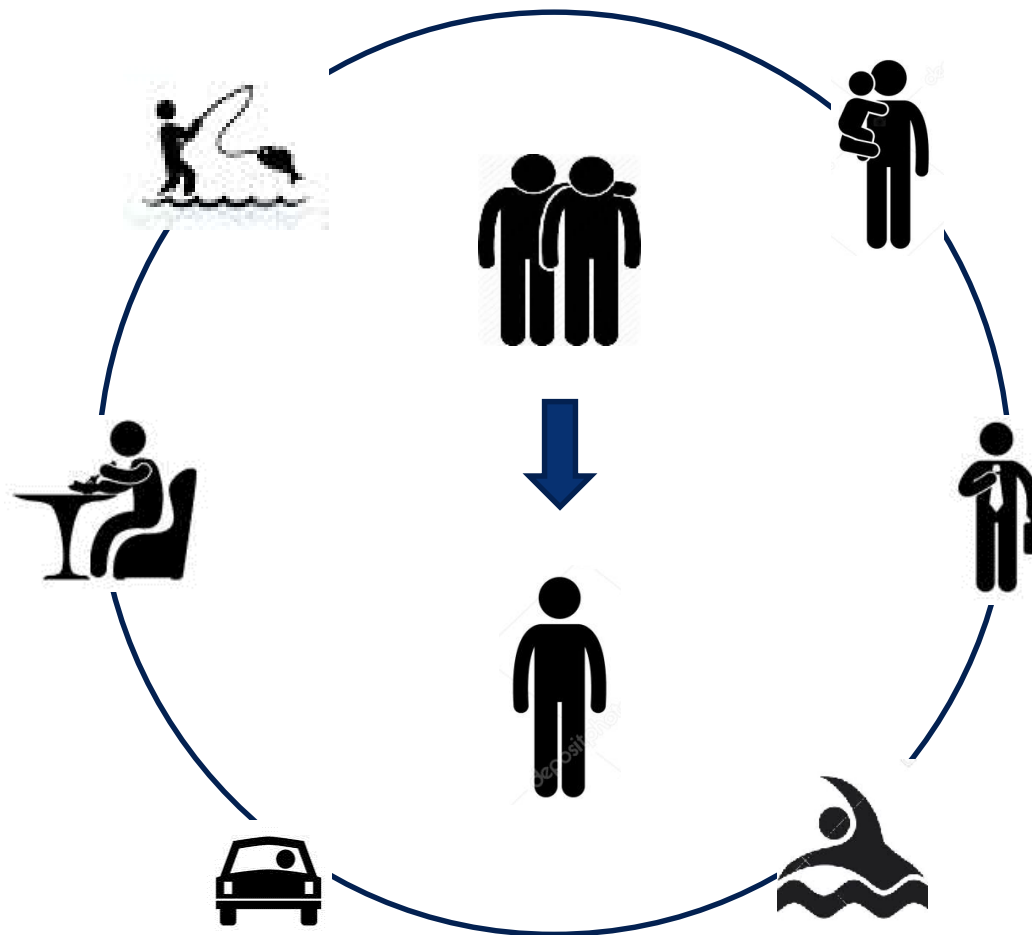
Post 9/11 Caregiver Characteristics

- Younger
- More likely to be a spouse, friend, or parent
- More likely to be employed
- Less likely to have support network
- Less likely to have insurance and regular source of medical care
- More likely to meet criteria for probable depression (~40%)

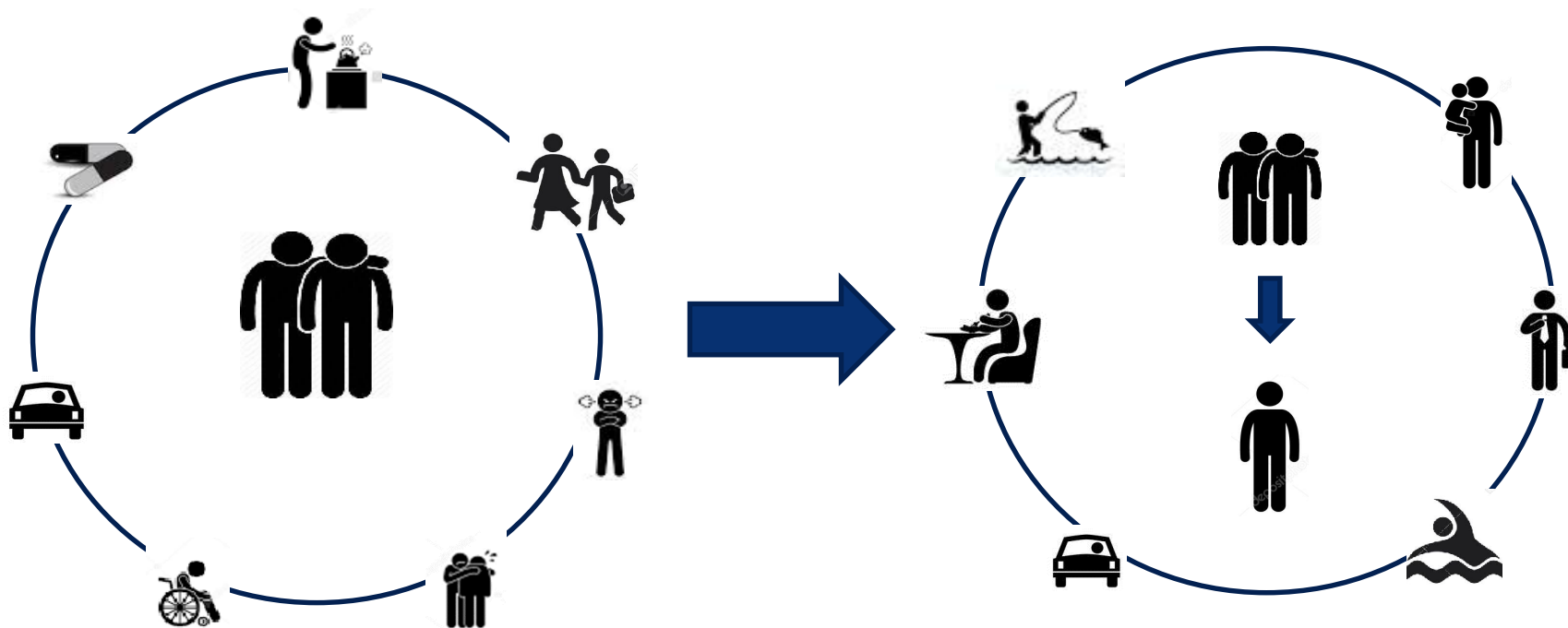


Photo credit RAND Corporation
Ramchand et al, 2014; Miller et al (under review)

Focus on facilitating recovery and success in social, economic, health aspects of life (instead of enabling symptoms)



For caregivers to be successful advocates, they need education and support



Creation of the VA Caregiver Support Program

Caregivers & Veterans Omnibus Health Services Act

(P.L. 111-163; May 5, 2010)

1. Program of Comprehensive Assistance for Family Caregivers (PCAFC) of **eligible Veterans injured in the line of duty on or after 9/11/2001**
2. Program of General Caregiver Support for caregivers of **all Veterans in need of a caregiver**

VA Caregiver Support Program Office housed in Care Management and Social Work Services, Patient Care Services

<https://www.caregiver.va.gov/>

VA Caregiver Support Program (CSP)

Mission Statement: *To promote the health and well-being of family caregivers who care for our nation's Veterans, through education, resources, support, and services.*

Program activities include:

- Mental Health Services (related to caregiving)
- Caregiver Training and Education
 - Building Better Caregivers™
 - Online training (originally through Easter Seals)
- Caregiver Telephone Support Line
- Caregiver Support Coordinators (CSCs)
- Peer Mentoring Support
- Respite Care
- Travel Reimbursement



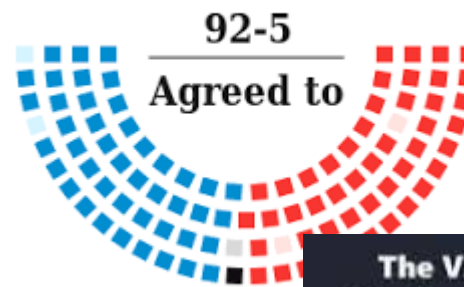
Program of Comprehensive Assistance for Family Caregivers (PCAFC) Overview

- Provides additional services directly to family caregivers of eligible Veterans:
 - Stipend
 - Health insurance through CHAMPVA
 - Beneficiary travel
 - Additional respite care
- Clinical program participation ***must***:
 - Be in the clinical best interest of the Veteran
 - Support the Veteran's progress in treatment
- Served total of 37,400 caregivers; currently serving 20,838

PCAFC Expansion

VA Mission Act 2018 extends PCAFC services to caregivers of Veterans of all eras beginning with caregivers of Veterans who served in Vietnam or earlier (mid-2020)

S. 2372: VA MISSION Act of 2018



Senate Vote #106



Exciting News!

FOR MILITARY AND VETERAN CAREGIVERS

The VA MISSION Act has been signed into law!

★
#VAMMISSIONAct • #MISSIONCompleted

VA MISSION Act of 2018

Learn about the New Veterans Community Care Program

VA CAREGIVER SUPPORT PROGRAM PARTNERED EVALUATION (VA CARES)

June 1, 2014 - May 31, 2019

VA HSR&D Durham

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Caregiver Support Program – VACO

Margaret Kabat
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Quality Enhancement Research Initiative

Amy Kilbourne
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VA HSR&D PEC 14-272

Evaluation Objectives

To **evaluate short-term impacts** of PCAFC on Veterans and caregivers

1. How do caregivers value components of PCAFC?
2. Does PCAFC impact Veteran health care use and total health care costs?

1. How do caregivers value components of PCAFC?

Methods

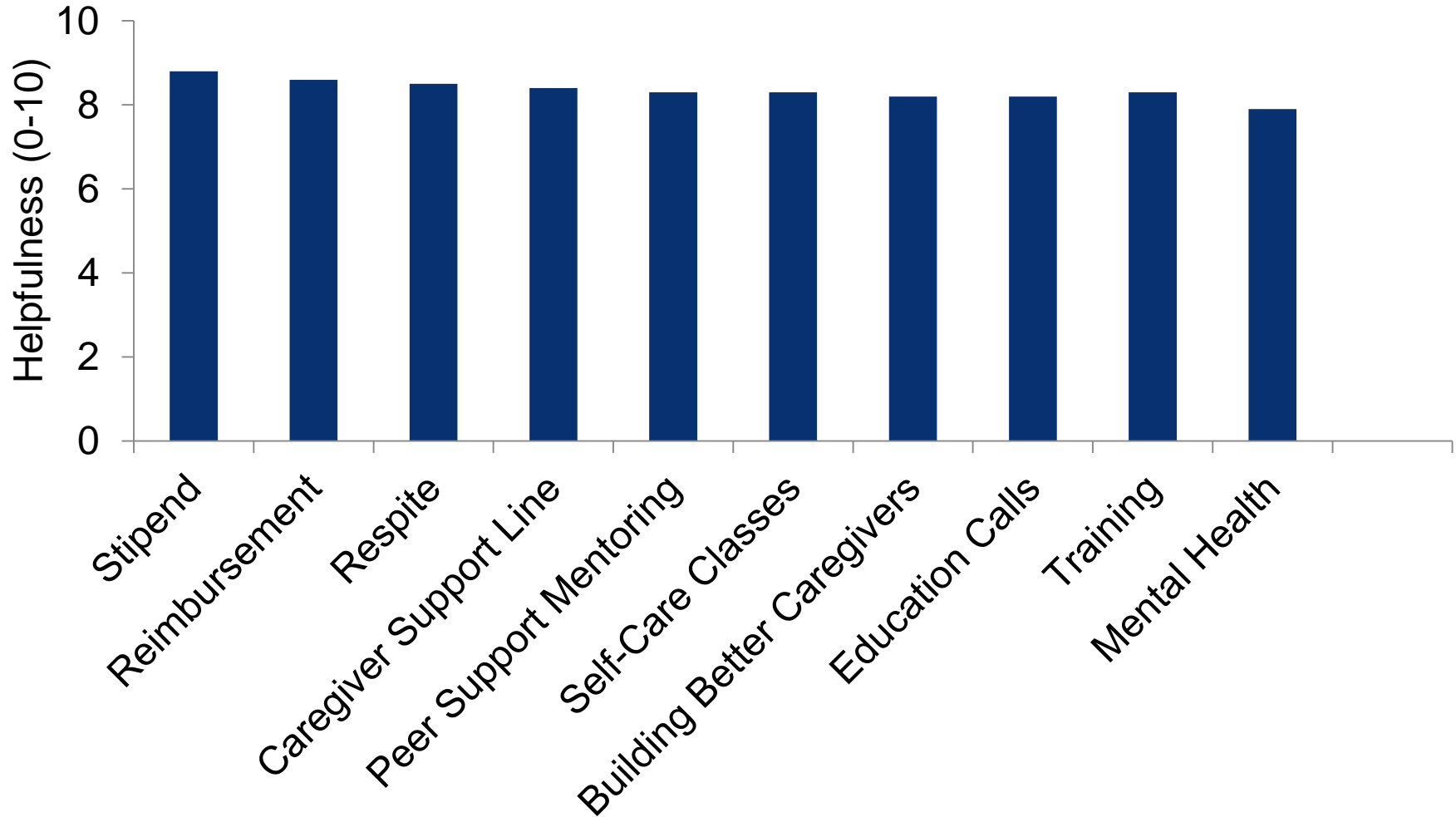
Web survey of caregivers: n=1407

- Stratified sample of caregivers who applied and were eligible for PCAFC from each VA Medical Center (VAMC)
- Low response rate (14%)—not nationally representative

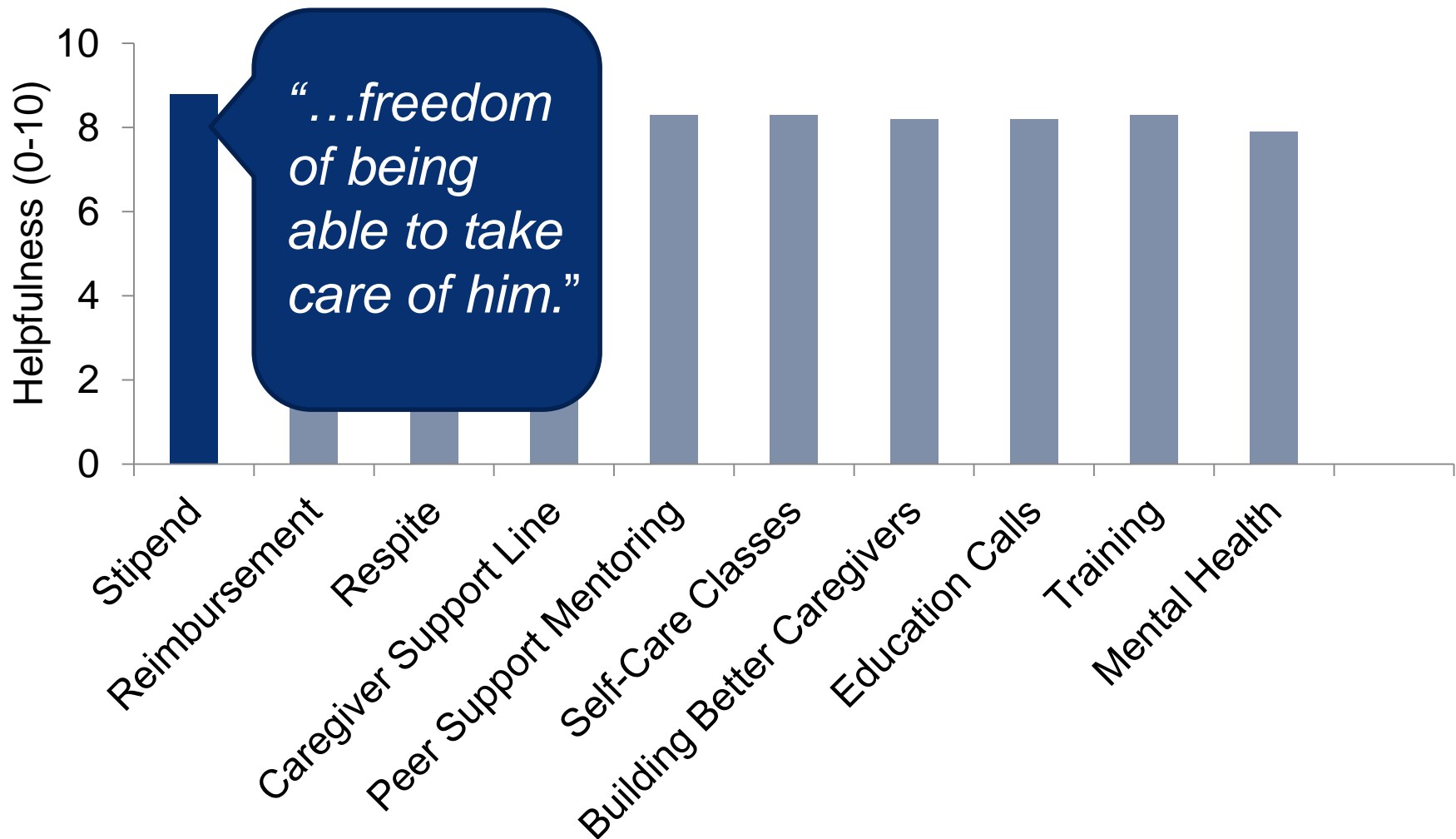
Phone interviews with caregivers: n=50 at 10 sites

- Sites purposefully selected

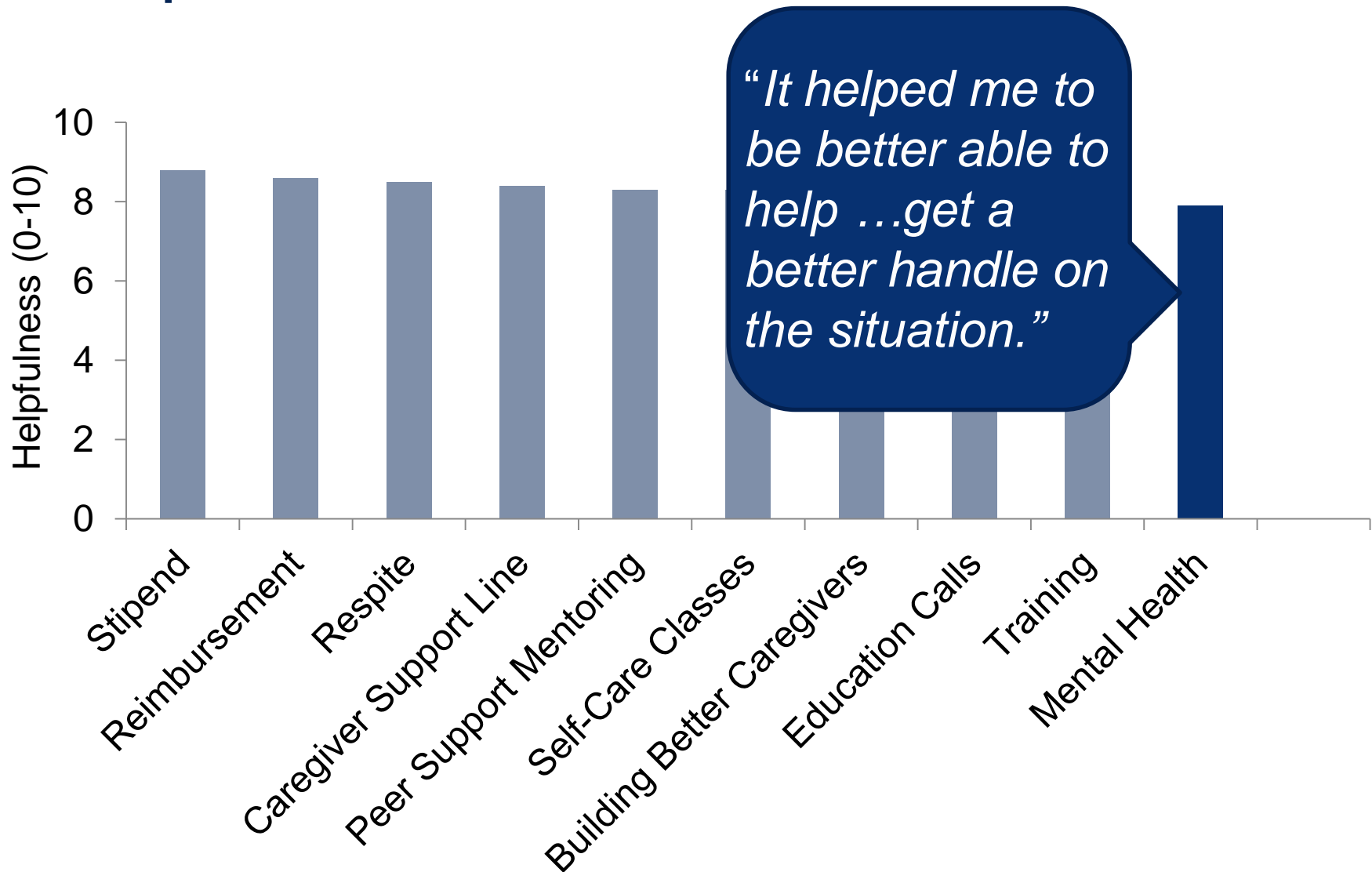
Helpfulness



Helpfulness



Helpfulness



2. Does PCAFC impact short-term Veteran health service use and total health care costs?

Study Design

- Pre-post cohort design with a non-equivalent control group
 - Treatment group: Veterans whose caregivers were enrolled in PCAFC as of March 2014 (n=15,650)
 - Control group: Veterans whose caregivers applied by March 2014 but were **never** approved for PCAFC (n=8,339)
- Merged VHA electronic health records, fee-basis files, and administrative data from the Caregiver Support Program

Service Use Outcomes

Outcome (6 month intervals)	Length of outcome observation period
Primary Care	36 months
Mental Health Outpatient Care	36 months
Specialty Care	36 months
Hospitalization	36 months
Emergency Department Visits	36 months
Long Term Services and Supports (LTSS)	24 months
Total Costs of Health Care	36 months

Baseline Characteristics of Veterans

Baseline Characteristics	Control Group	Treatment Group
Female, %	10.9	7.6
Age, mean (SD)	38.6 (10.3)	36.2 (8.9)
Married, %	66.2	68.8
Race/Ethnicity, %		
White	58.5	69.2
Black	29.1	18.3
Other	5.8	6.8
Unknown	6.6	5.7
Hispanic/Latino(a)	10.0	13.6
Service connected, %		
High ($\geq 70\%$)	64.0	72.3
Medium high (50-69%)	14.8	11.9
Medium low (10-49%)	8.3	5.5
Low (<10%)	12.9	10.3
Enrollment priority group, %		
Group 1	79.8	85.1
Group 2-4	11.4	9.0
Group 5-8 or missing	8.8	5.9
# mental health visits prior 12 mo's, mean (SD)	4.2 (8.4)	5.5 (9.5)
# VA primary care clinic stops prior 12 mo's, mean (SD)	1.3 (1.6)	1.6 (1.7)
Nosos score prior 12 mo's, mean (SD)	1.2 (1.7)	1.5 (2.0)

Most Common Physical Comorbidities

Baseline Characteristics, %	Control Group	Treatment Group
Musculoskeletal disorders/diseases	58.9	64.8
Pain, not including back or joint	39.8	47.7
Joint pain, not including back	35.7	39.9
Hyperlipidemia	28.0	28.1
Hypertension	26.3	24.4
Traumatic brain injury	18.9	32.5

Most Common Mental Health Comorbidities

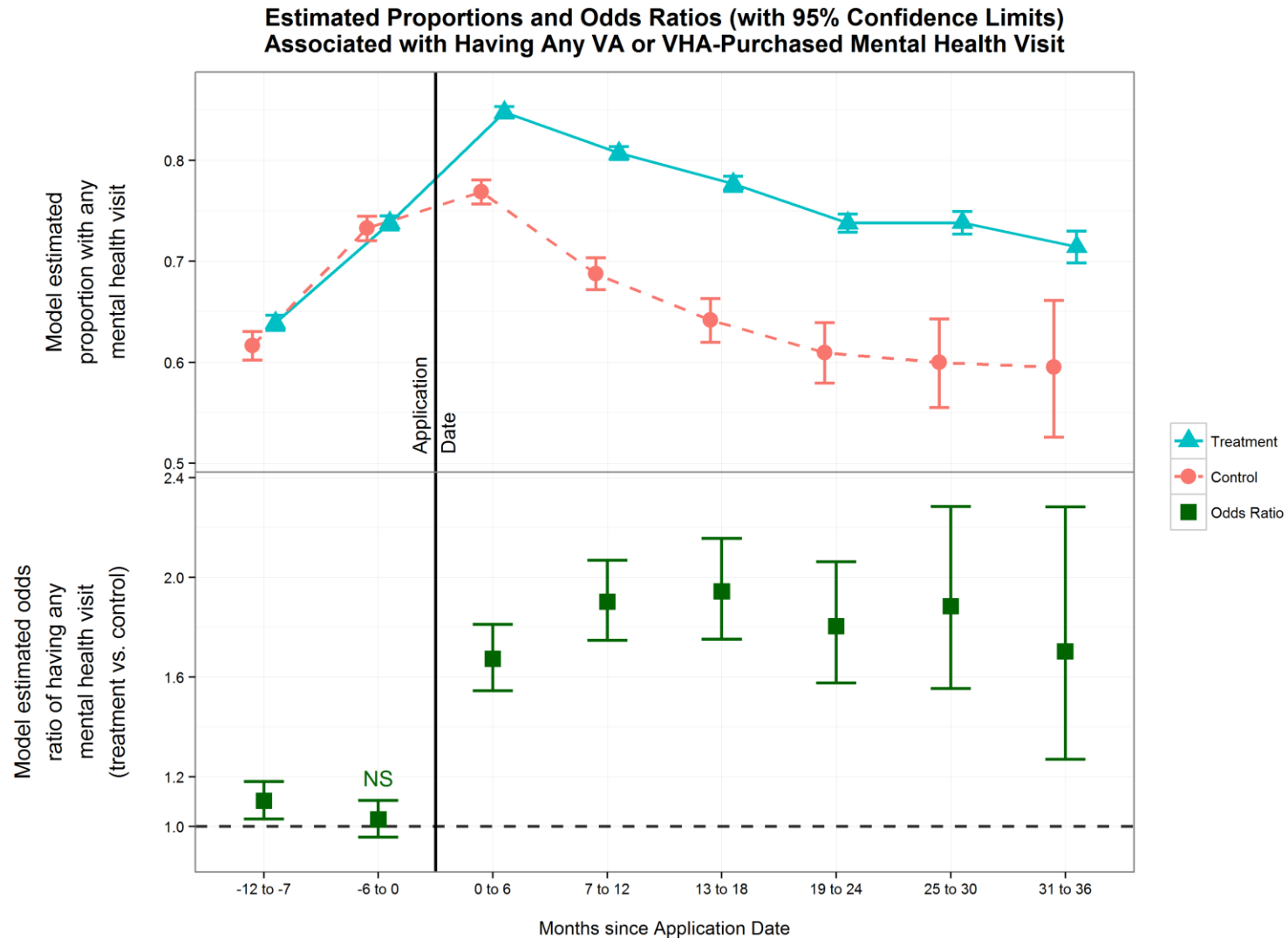
Baseline Characteristics, %	Control Group	Treatment Group
Post-Traumatic Stress Disorder	60.2	73.7
Depression	45.7	52.1
Anxiety	24.1	25.9
Tobacco use	19.7	22.9
Alcohol or substance abuse	19.2	20.9
Other mental health	14.1	17.3
Adjustment reaction	9.8	10.2
Bipolar disorder	9.2	10.9

Methods

- Remember...
 - Treatment group: Veterans whose caregivers were enrolled in PCAFC
 - Control group: Veterans whose caregivers applied for but were **never** approved for PCAFC
- Statistical methods carefully adjusted for differences in observed Veteran health and demographic characteristics



Higher Mental Health Care Utilization



Veterans in PCAFC vs those not in PCAFC experienced...



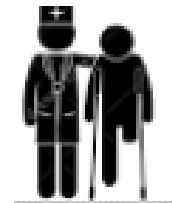
More use of mental health care



No change in hospitalizations



More use of primary health care



More use of long-term services and supports (driven by paid home-based care)



More use of specialty care



Higher health care costs



No change in emergency department visits

PCAFC effects by PTSD diagnosis

Veterans with PTSD
experienced...



More use of primary
care



More use of mental
health care



More use of
specialty care

PTSD moderated the
association between PCAFC
and outpatient service use for
primary care only



Potential mechanisms underlying association between PCAFC and health care use is a black box...

Need empirical information about:

- How PCAFC improves caregivers' abilities to support Veteran engagement in health care

Role of institutional support for caregivers on increasing engagement in health care for patient populations with high mental health burden

Preliminary results from a study funded by the Robert Wood Johnson Foundation Systems for Action Program—"Studying the impact of institutional support for family caregivers on the use of Department of Veteran's Affairs medical and social services for Veterans" (PI: Shepherd-Banigan, Grant # 74941)

Methods

- 26 joint telephone interviews
- Sampling frame: all Veterans who participated in PCAFC and either supported employment, post 9/11 GI Bill, or VBA vocational rehabilitation
- Directed content analysis
- Coding in process (16/26 transcripts, coded 13)
- Results presented are from a rapid analysis and are **preliminary**

Sample Characteristics

Characteristics	
Veteran mean age (out of 26 interviews)	41
	n; %
Caregiver is spouse/significant other of Veteran (out of 26 interviews)	24; 92%
Reported PTSD (out of 16 available transcripts)	8; 50%
Reported TBI (out of 16 available transcripts)	6; 38%
Reported musculoskeletal/joint pain (hip, knee, shoulder) (out of 16 available transcripts)	8; 50%

Features of PCAFC that promote Veteran engagement in medical care

PCAFC features and services	Veteran engagement in medical care
Referrals	Direct referrals for medical/psychiatric services, durable medical equipment, for other services
Coordination	Placing calls to clinic on behalf of family
Stipend	Free up caregiver time to focus on supporting Veteran's recovery, attend medical appointments, coordinate care
Information to family	Disease education, VA navigation and points of contact, training on caregiving tasks/role, acknowledgement of caregiver role
Encouragement (to CG and Veteran)	Acknowledgement of challenges of caregiving, recognition of Veteran's potential (recovery-orientation)

Exemplar Quotes: Role of PCAFC in facilitating Veteran and caregiver health outcomes

Stipend

CG: Without [PCAFC] there's no way I wouldn't be working full-time...I mean the stipend that they give, allows me the freedom to work...a few hours versus every hour. So that way I can make sure to take care of him.

Referral to health services

CG: Yeah, and it's easier for me too because I could call them and be like, I've noticed this with [the Veteran], and they would help me get an appointment.

Encouragement recovery-orientation

CG: ...one of the nurses [with PCAFC]...was saying [to the Veteran] 'well you could do something for yourself, and you can go to school or do something.' You know, to make him feel like he was having some accomplishments...

Conclusions

Observations on role of caregivers

- Caregivers invested in Veterans' recovery (more so than PCAFC benefits)
- Veterans desired caregiver's help
- Family members encouraged Veteran to take independent role in health care, when possible
- Need education/support to know how to engage in recovery oriented process

PCAFC impacts

- Caregivers value PCAFC; report improvements in ability to care for Veteran and for themselves
- Participation in PCAFC increased short-term use of outpatient and LTSS services and health care costs; no reductions in hospital-based or ED visits were observed
- Support for caregivers through PCAFC facilitates engagement in health care

Final Thoughts

Clinical Implications

- PCAFC engagement supports caregivers to facilitate medical and psychiatric care at clinic and at home
 - Appointment management, transportation, medication management, coordination, help improve social functioning/manage avoidance symptoms
- PCAFC challenges
 - Is there a “right” caregiver who will benefit maximally from the program and how to assess this?
 - Does financial support to CG reduce motivation for Veteran to get well? (no evidence of this)
 - Shifting power dynamics (no empirical evidence, anecdotal)
 - Patient privacy (couples worked this out themselves; caregivers attended more medical than mental health appointments)



Current/new family centered initiatives in VA

- QUERI Choose Home Initiative
- Elizabeth Dole Foundation—Campaign for Inclusive Care
- Assessing need for a caregiver for Veterans with mental illness (VA-CARES extension)
- Pre-post effects of PCAFC on caregiver wellbeing (VA-CARES extension)
- Impact of PCAFC expansion through the Mission Act (VA-CARES extension)




Future Research



- How/when to engage families in mental health treatment (e.g. PTSD)
- Measuring outcomes for caregivers of patients with mental illness
- Family support and suicide
- Measuring clinical improvements as a result of PCAFC
- Policy implications of investing in a program of long-term community care (via caregivers) for disorders that may not be chronic (i.e. PTSD)—inhibit recovery? What to do about comorbidities—TBI/PTSD?

**What research questions are
you interested in?**

Thank you



THE CAREGIVERS
WHO GAVE THEIR
TIME, ENERGY,
FRANK INPUT AND
FOR THEIR CARE
OF U.S.
VETERANS



VA
CSP



DURHAM
COIN



QUERI



VA
CARES
TEAM



VA
HSR&D

Key Citations

- Van Houtven CH, Smith VA, Stechuchak KM, Shepherd-Banigan M, Hastings SN, Maciejewski ML, Wieland GD, Olsen MK, Miller KEM, Kabat M, Henius J, Campbell-Kotler M. Comprehensive support for family caregivers of post 9/11 Veterans: impact on Veteran health care utilization and costs. *Medical Research and Review*. March 2017.
- Shepherd-Banigan M, Smith VA, ML, Stechuchak KM, Miller KEM, Hastings NS, Wieland GD, Olsen MK, Kabat M, Henius J, Campbell-Kotler M, Van Houtven, CH. Comprehensive support for family caregivers of post-9/11 Veterans: Impact on Veteran Utilization of Long-Term Services and Supports. *Inquiry*. 2018.
- Sperber, N, Van Houtven, C, Andrews, S, Miller, KEM, Steinhauer, K, Weiland, GD, Smith, VA, Lindquist, J, Shepherd-Banigan, M, Campbell-Kotler, M, Henius, J, Kabat, M. Family caregiver use and value of support services in the VA Program of Comprehensive Assistance for Family Caregivers. *Journal of Long Term Care*. August 2018.
- Shepherd-Banigan M, Smith VA, Maciejewski ML, Stechuchak KM, Hastings NS, Wieland GD, Miller KEM, Kabat M, Henius J, Campbell-Kotler M, Van Houtven, CH. Training and support for family members on outpatient service use among Veterans with PTSD. *Administration and Policy in Mental Health*. 2018.
- Ramchand R, Tanielian T, Fisher MP, et al. *Hidden Heroes: America's Military Caregivers*. Santa Monica, CA: Rand Corporation; 2014.