

Inclusion of Family Caregivers in Patient Health Care Teams: Innovations from Veterans Affairs

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Veteran Caregivers and Importance

- There are more than **5.5 million** caregivers of Veterans (RAND, 2014)
 - Veteran caregivers are **case managers**, undertaking a variety of the responsibilities a formal healthcare provider will deliver (RAND, 2014)
 - In addition to knowing patient status, provide **critical information to providers** about their own capacity to provide care safely in the home (Van Houtven, 2017)
- RAND (2014) recommended that health care environments serving Veterans should **acknowledge caregivers** as part of the health care team
 - And yet, NASEM report “Families Caring for an Aging America” (2016) found that practical approaches for inclusion/engagement of caregivers remain **poorly defined**

Timeline of Advancing Caregiver Inclusion in VA

Partnered
Evaluation of
VA Caregiver
Support
Program
2014

VA and
Elizabeth
Dole Launch
Campaign for
Inclusive Care
2018

Next Steps:
Spreading
Culture
Change

How do we
quantitatively measure
caregiver perceived
inclusion?
2016

VA and EDF
Develop and Launch
Academy for
Inclusive Care
2020

Partnered Evaluation VA CSP

How Does VA Caregiver Support Affect Outcomes?

Increases Veteran primary care engagement

Appreciation for Caregiver Support Coordinators
AND frustration with 'system'

I do not have a sense that there is a team, somebody coordinating his condition, saying, "Okay, that's your primary care doctor, that's the neurologist .. I'm the person coordinating all this and you're the caregiver and we're all part of this team." I don't have that sense at all.

CAPACITY MEASURE

How well do caregivers feel the team communicates with them?

How well do caregivers feel the team considers their preferences, needs, and capacity to care?

Caregiver Experiences on the Veteran Care Team

2017 survey of post-9/11 caregivers of Veterans

56%

For their ideas about managing their Veteran's health

69%

Whether they have the skills or training they need to help their Veteran

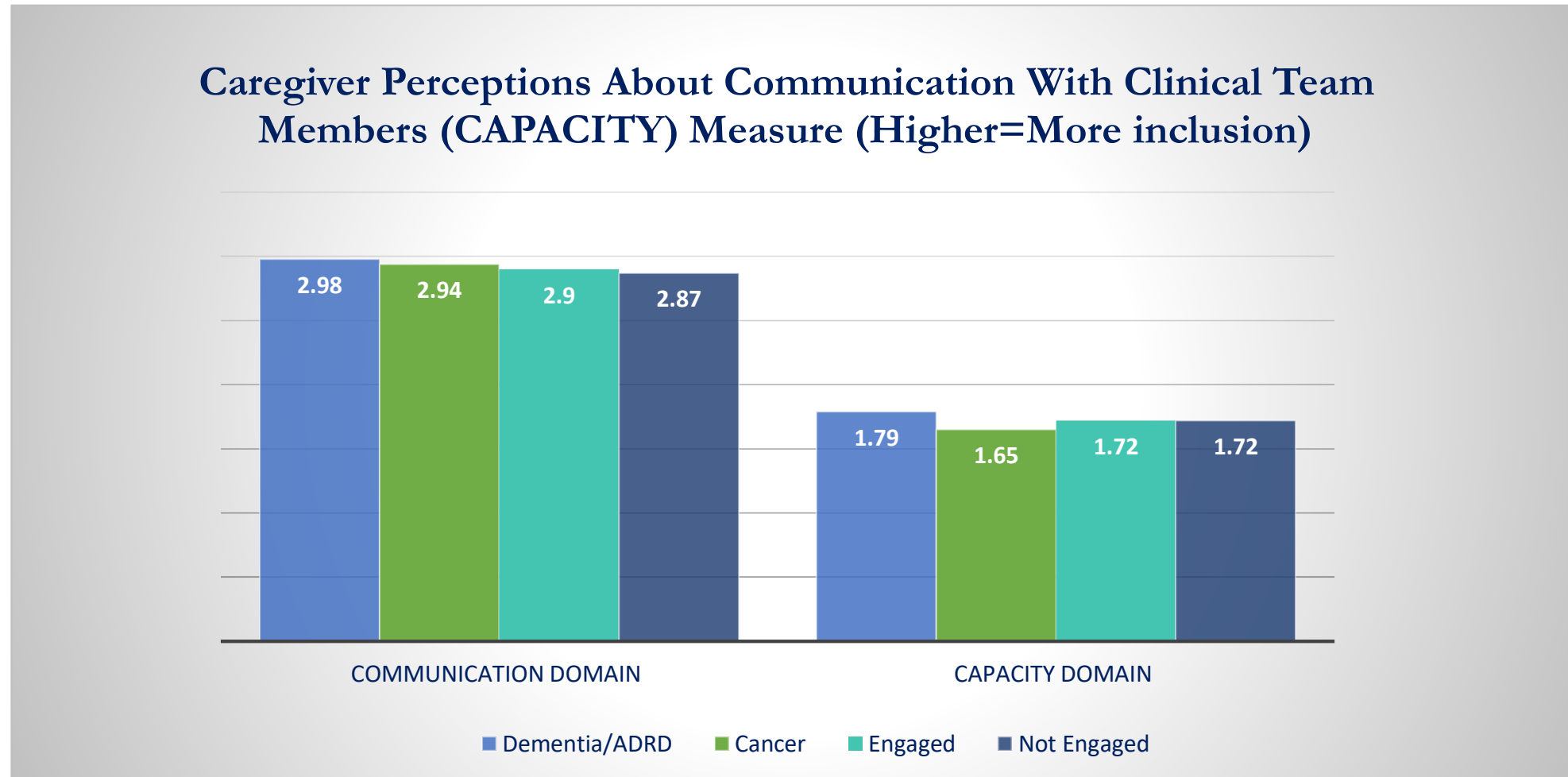
72%

If they needed help at home in managing their Veteran's health condition(s)

said the
patient's
health care
team never
asked

n=929, Van Houtven, Miller et al. MCRR, 2017

Caregiver Experiences on the Veteran Care Team



n=1509, CHASE Survey Shepherd-Banigan et al, JAGS 2021

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Mission Statement: Campaign for Inclusive Care

To empower healthcare providers and professionals to engage Veteran caregivers as part of the Veteran care team through policy, practice and culture change.

Inclusive Care Definition Derived w/ Multiple Perspectives

5 KEY COMPONENTS OF INCLUSIVE CARE:



Sperber et al, Health Affairs, 2017

Inviting the caregiver to participate in shared decision making and treatment planning (Shepherd-Banigan et al, Medical Care, 2022).

According to Caregivers, Top Barriers to Inclusion:

- 1 Lack of time by the medical staff to “deal” with the caregiver (50%)
- 2 Because I am not a provider, they don’t think I need to know any details (40%)
- 3 Legal or privacy concerns (38%)
- 4 Health care team changes frequently (38%)



Academy for Inclusive Care

1. [Introduction to the Practice of Inclusive Care](#)
2. [Who are Military and Veteran Caregivers](#)
3. [Communicating with the Caregiver](#)
4. [Understanding the Caregiver Journey and Caregiver Journey Map](#)

REMEMBER, CARE

CONSIDER

Consider who else needs to be present. Ask the Veteran “Is there someone you would like in the room during your visit?” “Is there someone who you rely on for support that you would like to have here as part of this conversation about planning your care?” or “Is there someone who helps you with your everyday medical needs?” Do not assume the Veteran can handle their medical care by themselves. Ask them directly to ensure clarity.

ACKNOWLEDGE

Recognize that the Veteran’s caregiver has taken on extra work, and that it will impact their wellness. Empathetic remarks such as “I imagine it’s a big responsibility to care for your loved one” and “I appreciate your dedication to their health” can go a long way to establish rapport.

REVIEW ROLE

Determine the responsibilities that the caregiver is comfortable with. Questions for the caregiver can include “what tasks are easy for you to perform?” and “are there any duties that cause you to feel uneasy while you are performing them?” Early identification of what the caregiver can and can’t do will help ensure that the Veteran achieves their highest possible level of health and well-being.

ENCOURAGE

Find out any barriers that exist and how you can help overcome them to make the caregiver’s responsibilities easier. Simple questions such as “how can I help with your at-home responsibilities for the Veteran?” and “what would make taking care of your Veteran simpler?” If you believe the caregiver could benefit from additional supports, refer to the Caregiver Support Program at your facility and encourage the caregiver to use the free Caregiver Support Line: 1-855-260-3274.

Campaign for Inclusive Care Achievements

- Implemented VA-wide expansion 2020+, 5000 VA Providers trained
- Champions of Inclusive Care spreading awareness, recruiting providers

Practicing inclusive care during the pandemic more important than ever for veterans, caregivers

Anne Adkinson Guest Opinion

Published 5:13 p.m. PT Oct. 2, 2020



Veteran's wife thankful for inclusive care

By Sharon Urbina Nov 19, 2020 0

My husband made the ultimate sacrifice, putting his life on the line for our country during his 16 years in the U.S. Marine Corps.

Now, as his caregiver, I help him in ensuring that he can live his most authentic life as independently as possible while he copes with the illnesses and injuries he endured during his two tours to Iraq. Though a challenging job, it is the most rewarding role I have ever held. I quickly learned that my new role would be

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What's Next for Caregivers at VA?



Enrolled caregivers now have own record in VA EHR



Environmental scan to assess change from Campaign



Caregiver toolkit to provide skills needed to partner effectively



Engaging leadership to make Inclusive Care VA standard of care

What's Next for Caregivers Nationally?

1. Test and evaluate models of caregiver inclusion in private health systems
 - Outpatient and inpatient settings
 - How does inclusion affect ED visits? Hospitalizations? Costs? Discharge to home?
 - Establish return on investment
2. Policy change
 - Create reimbursement for health care team visits with caregivers (Riffin et al, 2022)
 - Performance rewards for teams that include caregivers (VH, Hastings, CCE 2017)
 - Pay caregivers. (Werner and Van Houtven, 2020, HA)
 - Increase caregiver supports (e.g. RAISE Act)

What's next for Caregivers Nationally? (continued)

3. Education

- Incorporate topics of “**caregiving**” and “**inclusive care**” into health professions’ educational curricula. (Leykum et al JGIM 2021)

4. Health Systems

- Support system-level changes to formally recognize and identify caregivers and document this information in health records in a standardized way (Leykum et al 2021; Van Houtven et al, 2022)
- Increasing provider-identification and referrals will be an equitable health system solution if it expands supports to groups that face inequities by race, ethnicity, and economic status, groups that face more care responsibility, costs, and worse outcomes. (Choi et al, 2021)

**Thank You
to VA & EDF
(& Duke
& Beyond)
Collaborators
&
All Caregivers**

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