

The Hero Care Survey



Elizabeth Dole Center of Excellence
for Veteran and Caregiver Research

Stuti Dang, MD, MPH
Miami GRECC
GRECC Connect Seminar Series
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Presentation



BACK
GROUND



SURVEY
OVERVIEW



VETERAN
SURVEY RESULTS



CAREGIVER
SURVEY RESULTS



CLINICAL
IMPLICATIONS

Learning Objectives:

At the conclusion of this learning activity, participants will be able to:

1. Describe the needs of High Need High Risk Veterans
2. Identify some ongoing efforts in to understand these needs
3. List some steps to address these needs

Background

- Empowering Veterans to age in place is a VA priority.
- Informal caregivers play a crucial role in supporting Veterans with functional and cognitive impairments by direct care provision and/or home and community-based services (HCBS).
- Veterans and their caregivers often do not receive the help they need with daily living activities.
- Allowing people to age in place requires that we identify and support each Veteran's needs.
- Identifying the needs and unmet needs is important to be able to provide adequate timely support to prevent or delay long term institutionalization (LTI).

Survey 1

- We developed a survey selecting validated questions and components from screening tools, regarding chronic conditions, physical and mental function, frailty status, mobility, access to healthcare, healthcare utilization, social support, and technology use.
- Target population: 1300 HNHR Veterans in Miami VA
- We combined these survey data with the GECDAC generated Jen frailty index (JFI), care assessments needs (CAN) score, Selection score and NOSOS score to predict frailty, ADL dependency, likelihood of hospitalization or death, and healthcare cost and utilization.

*Needs of the
HNHR
veterans
often extend
beyond
medical needs
to social and
behavioral
services*

- 3/4 have mobility challenges
- 2/3 had fallen in the previous year
- >1/3 (40%) are frail
- >1/3 likely to be socially isolated
- 1/3 have ≥ 3 ADL deficits
- 1/3 screen positive for depression
- The sicker ones less likely to enroll for outpatient programs
- Lack of caregivers in a significant majority

Elizabeth Dole Center of Excellence funded by VA HSR&D



Expand VA capacity to deliver integrated, Veteran and caregiver-partnered, data-driven approaches to care

Multi-site collaboration of a virtual group of interdisciplinary researchers

Interconnected set of national research projects



Center Lead: Dr. Luci Leykum

- Miami VA: Dr. Stuti Dang
- Salt Lake City VA: Dr. Mary Jo Pugh
- Palo Alto VA: Dr. Ranak Trivedi
- South Texas VA: Dr. Lauren Penney
- Canandaigua VA: Dr. Orna Intrator

VA



U.S. Department of Veterans Affairs

Veterans Health Administration
Elizabeth Dole Center of Excellence
for Veteran and Caregiver Research



Hero Care Survey

Understanding Unmet Needs of
Veterans and their Caregivers
Using a Prospective Survey

Rationale for survey

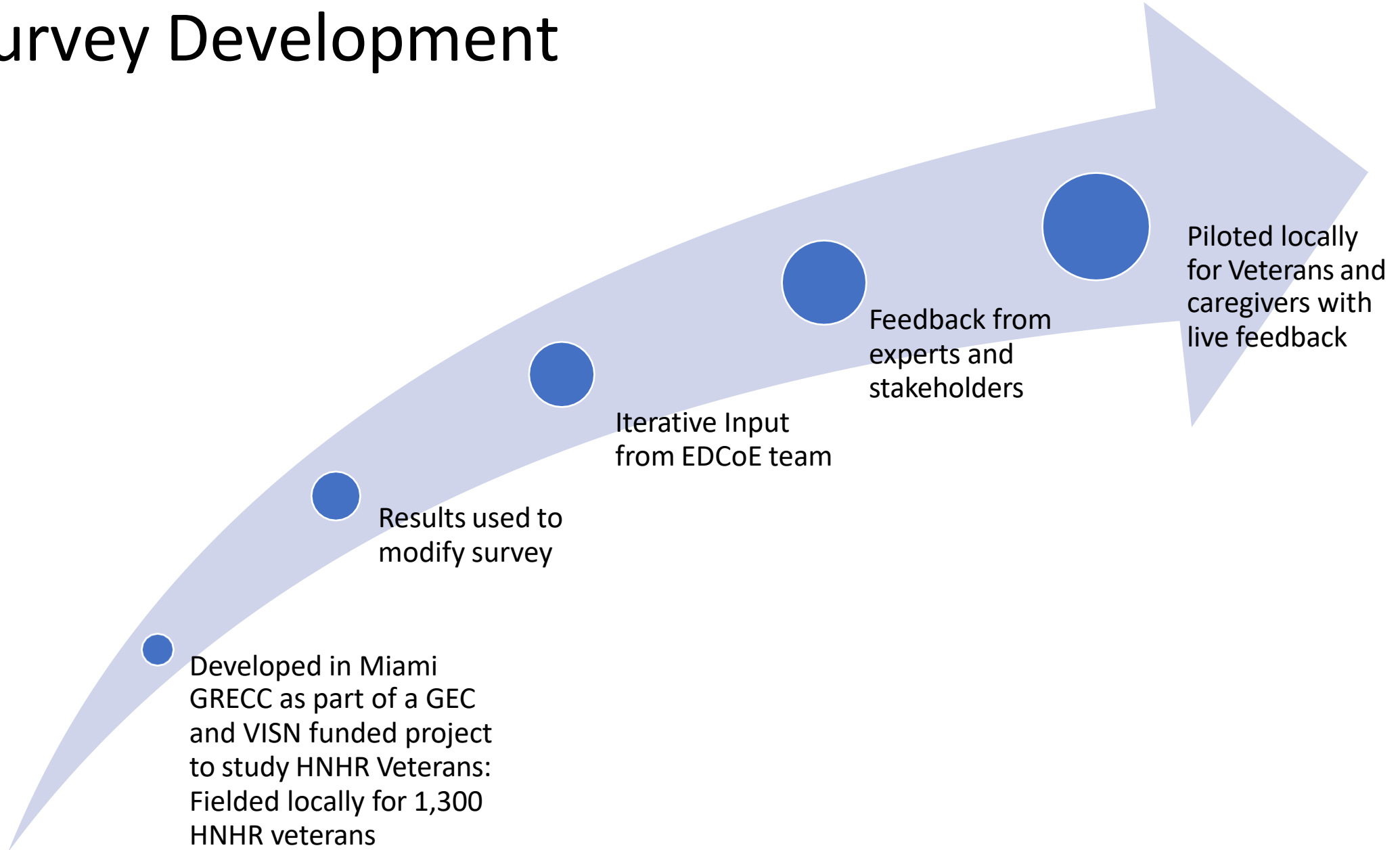
- Prospective longitudinal survey augmented with historical/retrospective data
- Explore the nature of unmet needs
- Measure the prevalence of unmet need
- Identify factors which predict development of unmet need
- Explore the links between unmet need and well-being of both Veterans and caregivers
- Approved by Office of Management and Budget

Dole Survey Aims

Cross-sectional Aims for Round 1

- **Aim 1.1:** Describe the needs and unmet needs of Veterans and caregivers
- **Aim 1.2:** Identify determinants of unmet need stratified by predicted risk of institutionalization.
- **Aim 1.3:** Are the needs and unmet needs reported by Veterans in congruence with those reported by caregivers?
 - Is caregiver burden and other caregiver characteristics (i.e., frailty, disease burden) associated with Veteran unmet needs?

Survey Development



Veteran Survey Domains

VETERAN DESCRIPTION

- Marital status
- Education
- Health literacy
- Gender
- Sexual orientation
- Employment

PHYSICAL

- General health and wellbeing
- Symptom burden
- Mobility, falls, assistive device, homebound status
- Frailty
- ADL/IADL unmet needs
- Healthcare utilization
- Health care needs

PSYCHOLOGICAL

- Quality of life
- Depression
- Anxiety
- Resilience
- Substance use

SOCIAL

- Social integration, socialization and social support needs
- Financial stability, medication and food insecurity
- Housing /density/neighborhood safety
- Legal concerns
- Transportation

CAREGIVER DESCRIPTION

- Caregiver age and relationship
- Caregiving hours, formal/informal care
- Other caregivers

OTHER

- Covid-19 impact
- Technology access and use
- Advance directives

Caregiver Survey Domains

CAREGIVER DESCRIPTION

- Age
- Gender
- Race/ethnicity
- Language
- Marital status
- Sexual orientation
- Health Literacy
- Caregiver relationship
- Caregiver Frailty
- Employment status
- Chronic disease burden
- Financial security

CARE PROVISION

- Caregiver Status (primary, secondary)
- Length of time caring for Veteran
- Caregiving hours, formal/ informal care
- Veteran ADL/IADL/other unmet needs
- Provides help to Veteran for chronic conditions

IMPACT OF CAREGIVING

- Quality of life
- Caregiver burden
- Caregiver stress
- Caregiver leisure
- Employment change due to caregiving
- Caregiver burden from Veteran disease
- Caregiver health decline
- Caregiver vigilance
- Additional care recipients

CAREGIVER SUPPORT & RESOURCE USE

- Use of resources and satisfaction
- Caregiver satisfaction with VA
- Caregiver preparedness
- VA caregiver assistance improvements

OTHER

- COVID-19 impact
- Desire to institutionalize

Survey Sites

Miami

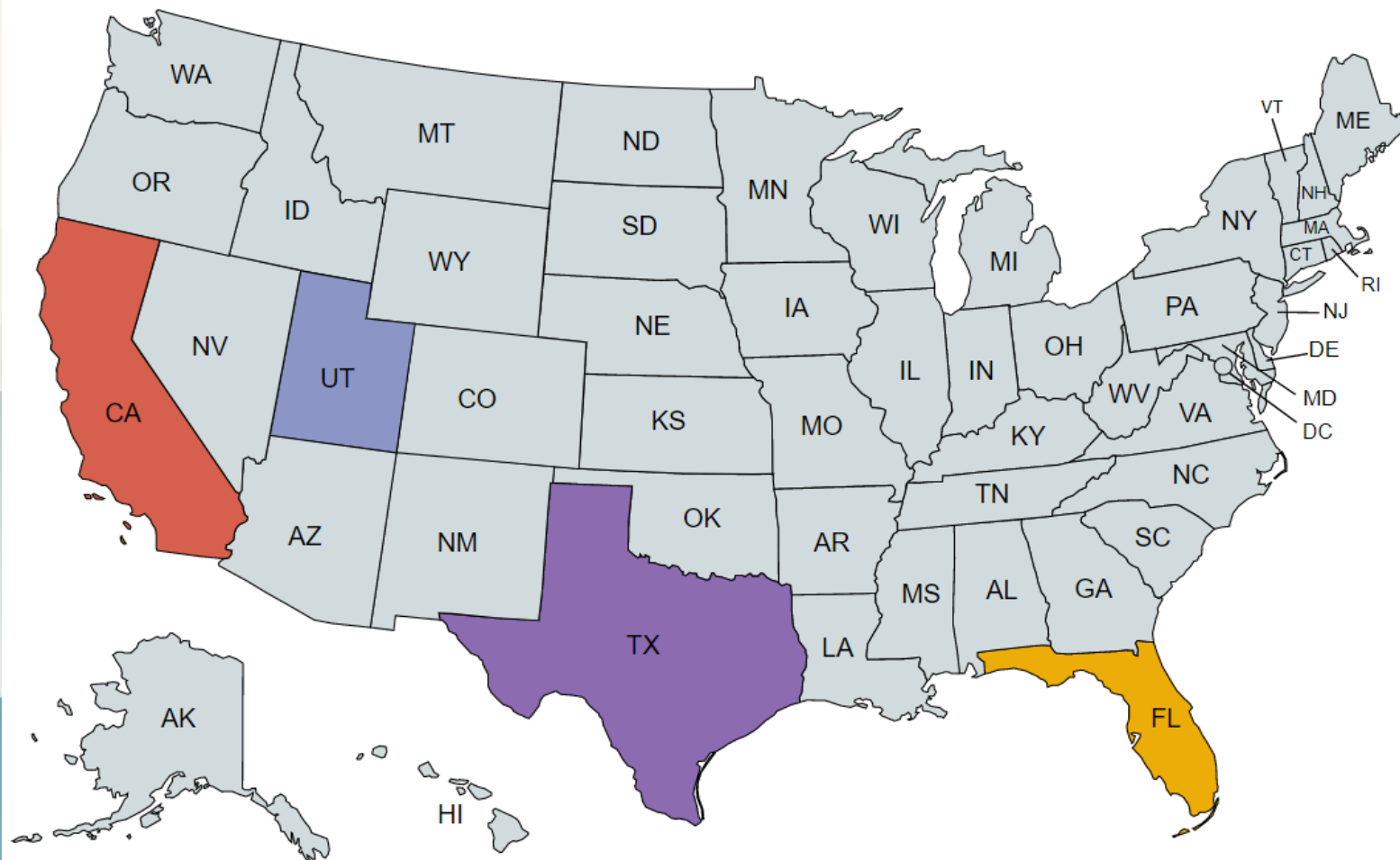
Palo Alto

Salt Lake City

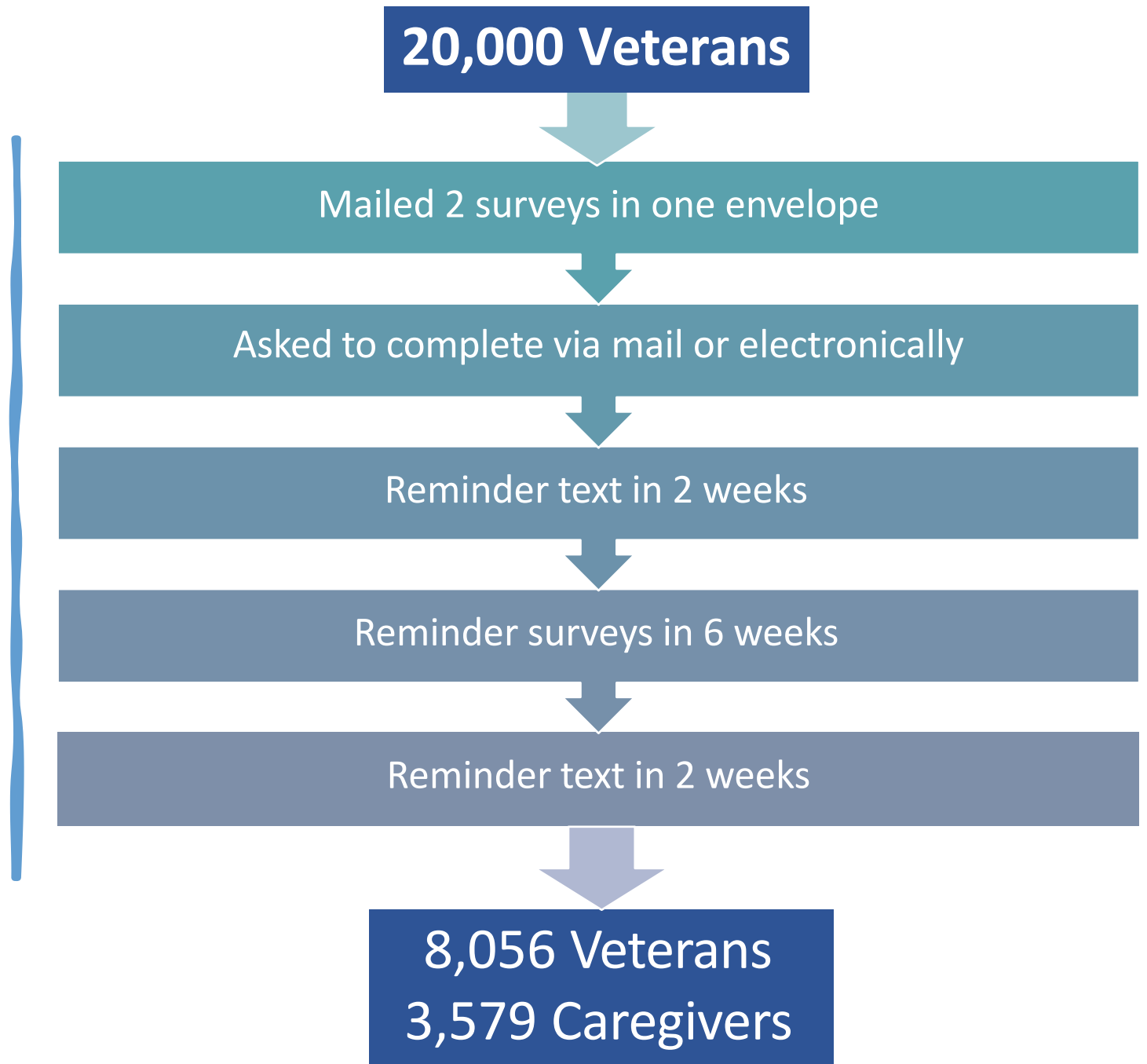
San Antonio

VISN 8

Four EDCoE sites \approx 2,000 Veterans each + VISN 8 \approx 12,000 Veterans based on 2-year risk of institutionalization

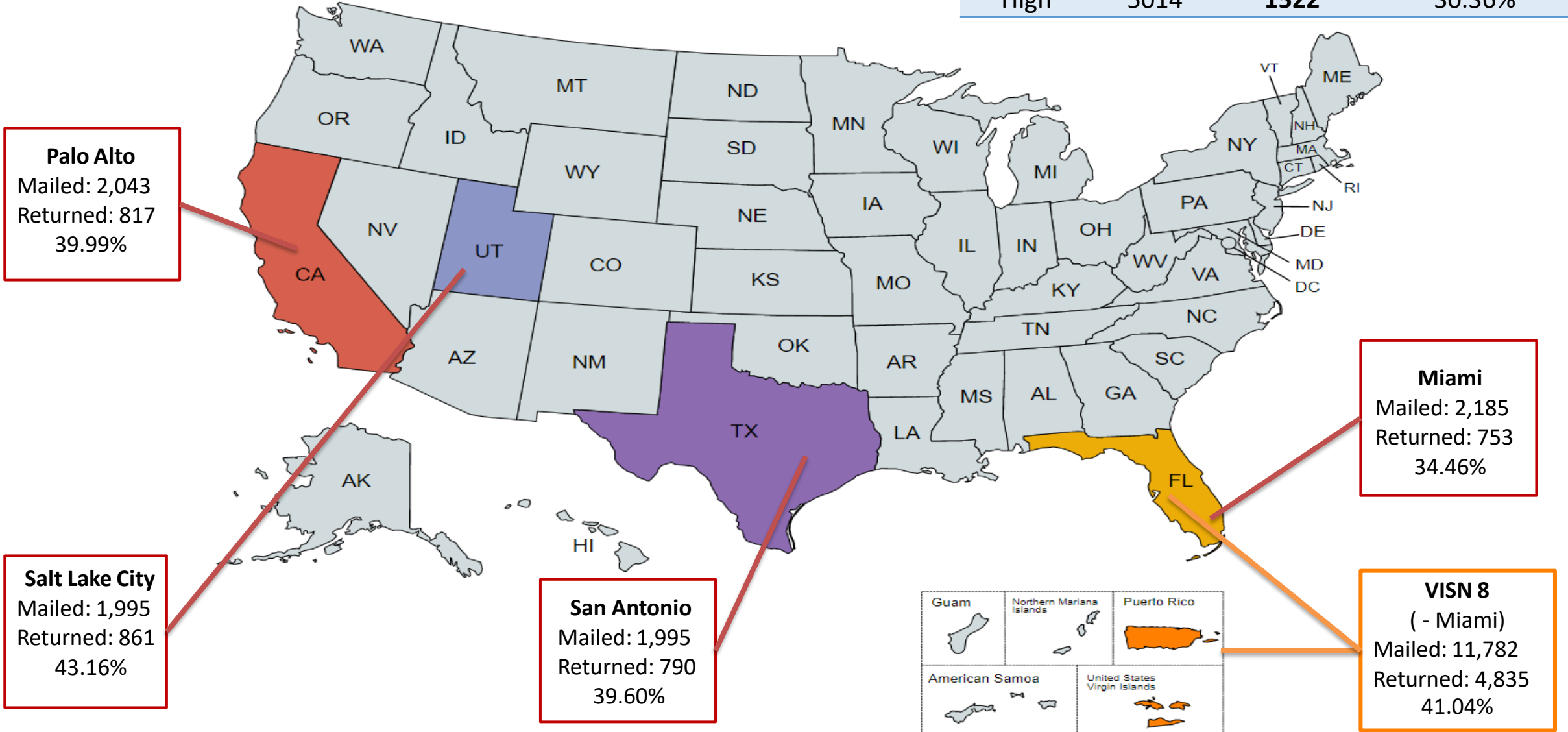


Survey Methods



Response Rate by VA site and PLI Status

PLI Status	Mailed	Returned	Response rate
Low	8582	3765	43.87%
Moderate	6404	2769	43.24%
High	5014	1522	30.36%





Respondents by Age

	Survey Returned	% Survey Response
Age group:		
20-24	0	0.00%
25-34	10	0.12%
35-44	25	0.31%
45-54	61	0.76%
55-64	322	4.00%
65-74	1670	20.73%
75-84	2864	35.55%
85-94	2403	29.83%
95+	446	5.54%
Blanks	255	3.17%
Totals	8056	100.00%

Veteran Survey Results

VA



U.S. Department of Veterans Affairs
Veterans Health Administration
Elizabeth Dale Center of Excellence
for Veteran and Caregiver Research

Veteran Survey supporting HERO CARE

Survey Instructions

Please select the responses that best describe you, your healthcare needs, and your experience with the U.S. Department of Veterans Health Affairs.

All questions are about the Veteran.

If someone other than the Veteran is completing the survey, please answer each question as it applies to the Veteran.

Who is filling out this survey:

- Self (Veteran)
- Someone else with help from Veteran
- Someone else without help from Veteran

1. Is English your preferred language?

- Yes
- No, I prefer to communicate in another language (Specify which language):

2. What is your preferred way to be contacted from the VA? *Mark all that apply.*

- By home phone
- By cell phone
- By internet (My HealthVet secure message)
- By mail

3. Has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living? *Mark all that apply.*

- No
- Yes, it has kept me from medical appointments or from getting my medications
- Yes, it has kept me from non-medical meetings, appointments, work, or from getting things that I need

4. How many times within the last 12 months have you missed an appointment or have been unable to obtain needed health care because of problems with your transportation to the VA?

- None
- _____ Times *Fill in the blank*

Questions # 5-8 are about leaving your home or building to go outside.

5. In the last month, how often did you leave your home to go outside?

- Every day (7 days a week)
- Most days (5-6 days a week)
- Some days (2-4 days a week)
- Rarely (once a week or less)
- Never

6. In the last month, did anyone ever help you leave your home to go outside?

- Yes
- No

7. In the last month, when you left your home to go outside, how often did you do this by yourself?

- Most times
- Sometimes
- Rarely
- Never

SOME FACTS ABOUT THE VETERAN RESPONDENTS

**TOTAL RESPONDENTS
= 8,056**



**Age: 80.2+/-9.7y
Range: 25-107**



**Gender: 97% Men
Race: 80.1% NH White**



**35% ≤high school
Health Literacy Score ≥3: 45%**



55% Married



**81% Urban, 20% Rural,
22% Highly disadvantaged**



**15% Homebound
33% Semi Homebound**



**57% reported
having a caregiver**



**16% Food Insecure
5% Medication Insecure**



**PHQ ≥3: 22%
GAD ≥3: 15%**

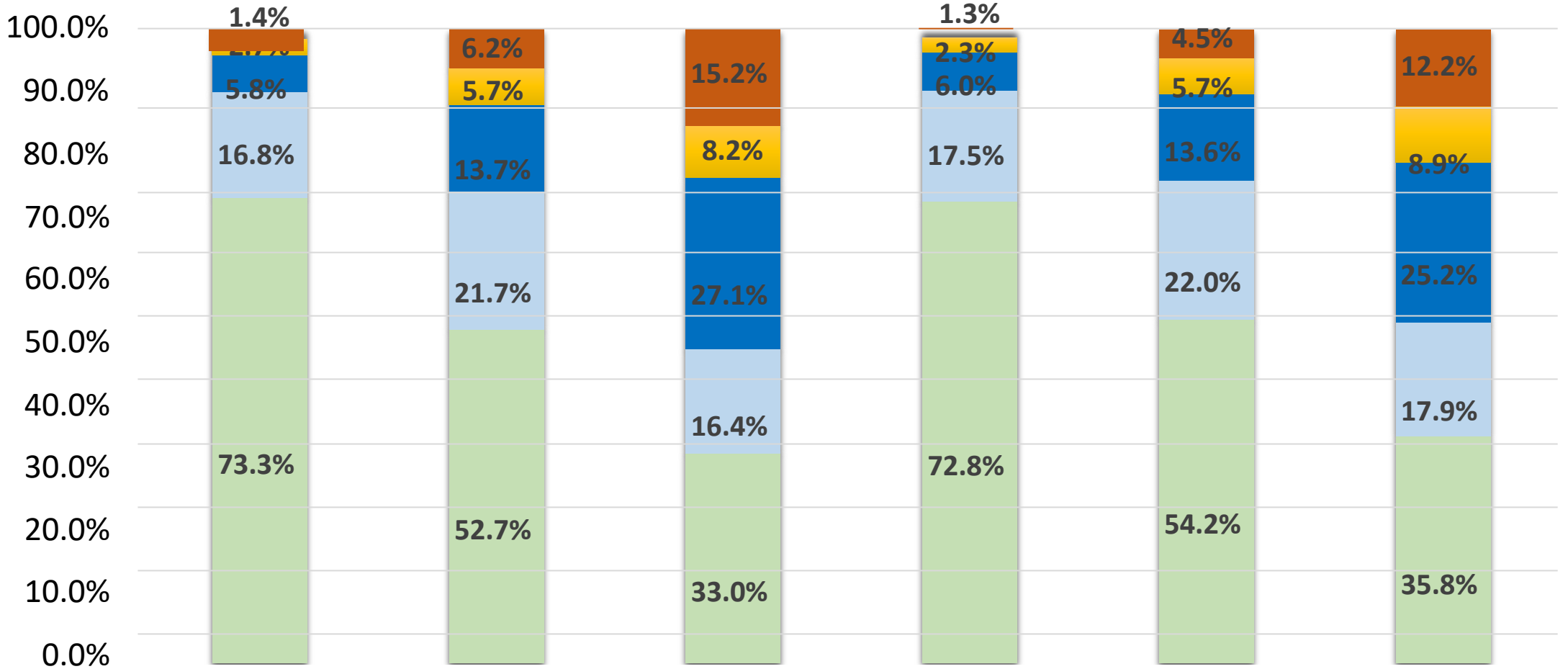


**48% had fallen
in the past 12 months**

Unmet Needs for ADLs

		This is a problem for me but...					
		N	This is <u>NOT</u> a problem for me	I can manage on my own	I get all the help I need	I need a little more help	I could use a lot more help
Bathing or showering	High Risk	1423	33.0%	16.4%	27.1%	8.2%	15.2%
				MET NEED		UNMET NEED	

ADL Needs by PLI Tier



Low Risk

Medium Risk

High Risk

Low Risk

Medium Risk

High Risk

Bathing or showering

Getting dressed or changing clothes

■ This is not a problem for me
 ■ I can manage on my own
 ■ I get all the help I need
 ■ I need a little more help
 ■ I need a lot more help

↑ ↑
UNMET NEED

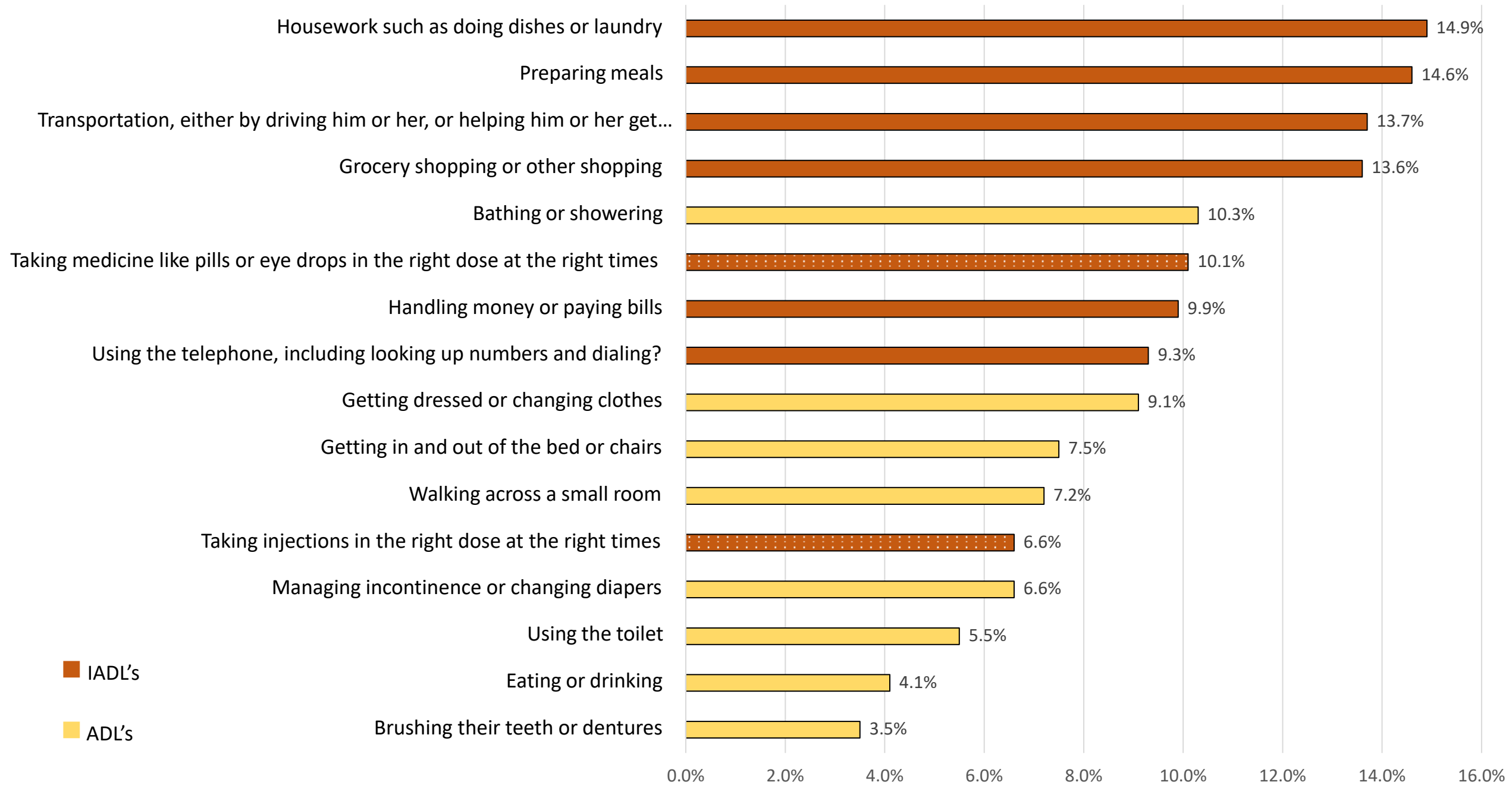
Veteran ADL and IADL Needs

		No Need	Have Needs
ADL Needs	N= 7863	3646 (46.4%)	4217 (53.6%)
Mean ADL Count (SD)	Range 1-8	0	5.2 (2.6)
IADL Needs	N= 7869	2835 (36.0%)	5034 (64.0%)
Mean IADL Count (SD)	Range 1-8	0	5.0 (2.5)



Among those with reported needs	Unmet Need
ADL Unmet Needs	1238 (29.4%) <i>16% of total</i>
Mean Unmet ADL Count (SD)	3.3 (2.4)
IADL Unmet Needs	2044 (40.6%) <i>26% of total</i>
Mean Unmet IADL Count (SD)	3.4 (2.4)

Unmet Needs for ADL's and IADL's (avg. N = 7618)



Description of Veteran-reported Needs and Unmet Needs by Domain

	n=	No Need	Met Need		Unmet Need		Mean number of needs (SD)
		This is <u>not</u> a problem for me	I can manage on my own	I get all the help I need	I need a little more help	I could use a lot more help	
ADL Needs	7863	3646 (46.4%)	2979 (37.89%)		1238 (15.7%)		2.76 (3.2)
IADL Need	7869	2835 (36.0%)	2990 (38.0%)		2044 (26.0%)		2.86 (2.8)
Managing pain	7543	3569 (47.3%)	2834 (37.7%)		1140 (15.1%)		
Nursing or medical tasks in the home	7288	5068 (69.5%)	1644 (22.6%)		576 (7.9%)		
Healthcare Communication and information Needs	7801	3510 (45.0%)	2874 (36.8%)		1417 (18.2%)		
Social Needs	7747	4997 (64.5%)	1810 (23.4%)		940 (12.1%)		

Veteran-reported characteristics of helpers

	1st helper	2nd helper	3rd helper	4th helper
Overall N = 8,056	n = 4575 (56.8%)	n = 2039 (25.3%)	n = 913 (11.3%)	n = 587 (7.3%)
Age Categories (n (%))				
Adult (35-49)	372 (8.1)	405 (19.9)	155 (17.0)	67 (11.4)
Adult (50-64)	1050 (23.0)	632 (31.0)	216 (23.7)	98 (16.7)
Adult (65 or older)	2409 (52.7)	435 (21.3)	173 (19.0)	112 (19.1)
Relationship (n (%))				
Spouse	2636 (57.6)	282 (13.8)	169 (18.5)	164 (27.9)
Ex-spouse	43 (0.9)	16 (0.8)	4 (0.4)	5 (0.9)
Son/daughter	871 (19.0)	830 (40.7)	261 (28.6)	102 (17.4)
Healthcare worker	417 (9.1)	483 (23.7)	227 (24.9)	116 (19.8)
Hours per day (mean (SD))				
	10.3 ± 9.4	6.2 ± 7.3	5.6 ± 7.4	5.9 ± 8.2
Days per week (mean (SD))				
	5.4 ± 2.6	3.8 ± 2.6	3.1 ± 2.7	2.9 ± 2.9
Paid Care (n (%))				
No	3392 (74.1)	1215 (59.6)	579 (63.4)	414 (70.5)
Yes, by Veteran or family	360 (7.9)	244 (12.0)	104 (11.4)	60 (10.2)
Yes, by VA	377 (8.2)	289 (14.2)	136 (14.9)	71 (12.1)
Yes, by other	179 (3.9)	138 (6.8)	70 (7.8)	42 (7.2)
Total Paid	916 (21.3)	671 (35.6)	310 (34.9)	173 (29.5)

Caregiver Survey Results (N=3579)

VA



U.S. Department of Veterans Affairs
Veterans Health Administration
Elizabeth Dole Center of Excellence
for Veteran and Caregiver Research

Caregiver Survey supporting HERO CARE

Thank you for agreeing to participate in this survey.

First, we would like to confirm that you are a caregiver (18 years or older) for a Veteran. A caregiver is someone who may provide regular care or assistance to a friend or family member who has a long-term health problem, illness, or disability.

During the past month, did you provide regular care or assistance to a Veteran because of a long-term health problem, illness, or disability?

NO → Please hand this survey to the person who helps provide regular care or assistance to the Veteran.

YES → Please continue with the survey.

Who is filling out this survey? Self (Caregiver) Caregiver with help from someone else

The first set of questions ask about you.

1. How old are you? ____ years
2. Are you a Veteran?
 Yes No
3. Are you of Hispanic, Latino, or Spanish origin?
 Yes No
4. What is your race? *Please select all that apply.*
 White
 Black or African American
 Asian or Asian American
 Native Hawaiian or Other Pacific Islander
 American Indian or Alaska Native
 Some other race or origin
 Don't know
 Prefer not to answer
5. Is English your preferred language?
 Yes, I prefer to communicate in English
 No, I prefer to communicate in another language (specify language below):

6. What is your current marital status?
Mark one box.
 Married, in a civil union or domestic partnership, or living with a partner
 Separated
 Divorced
 Widowed
 Single, never married
 Prefer not to answer
7. What is the highest level of education that you completed?
 Less than high school
 Some high school
 High school graduate or GED
 Some college credit, no degree
 Associate degree
 Bachelor's degree
 Master's degree
 Professional/Doctorate degree
 Prefer not to answer
8. How confident are you filling medical forms by yourself?
 Extremely
 Quite a bit
 Somewhat
 A little
 Not at all

CAREGIVER RESPONDENT FACTS

TOTAL RESPONDENTS
= 3,579



71.1+/-12.9 y
Range: 18-104



77% Women
71% NH White



58% Spouses



33% ≤High school
Health Literacy >3: 17%



53% are Retired



CGS by Veteran's PLI Risk Tier
28% High
39% Medium Risk
33% Low Risk



81% Urban
19% Rural
>1 Highly Rural



23% help Veterans in
highly disadvantaged areas



CGs by Veteran ADI
76-100: 23%



CAREGIVING FACTS AMONG RESPONDENTS

TOTAL RESPONDENTS
= 3,579



82% are primary CG



50% helped >5 years



11.2 ± 9.2 hours/day



34% have a 2nd helper
13% a 3rd helper
6% a 4th helper



57% help with IADLs



43% help with ADLs



47% help with medications

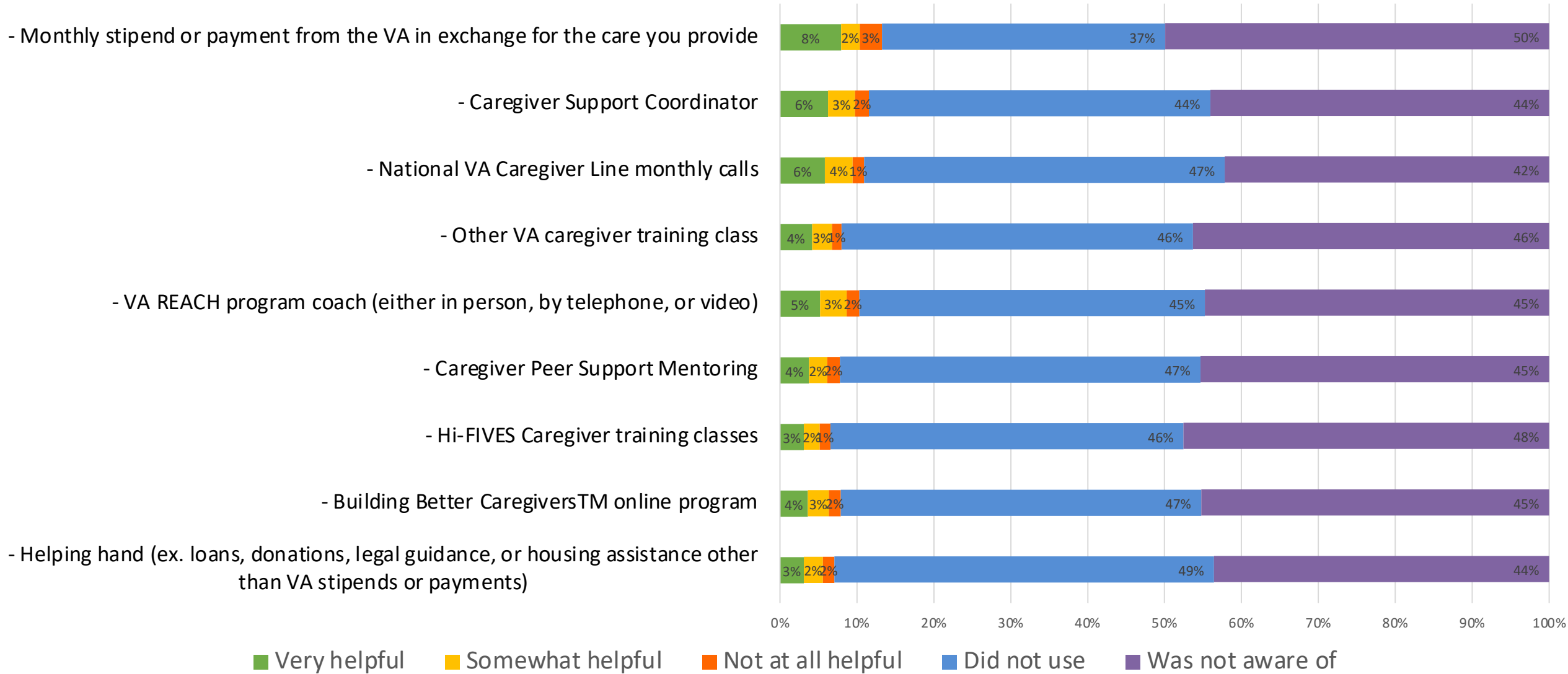


52% help in communicating
with care team

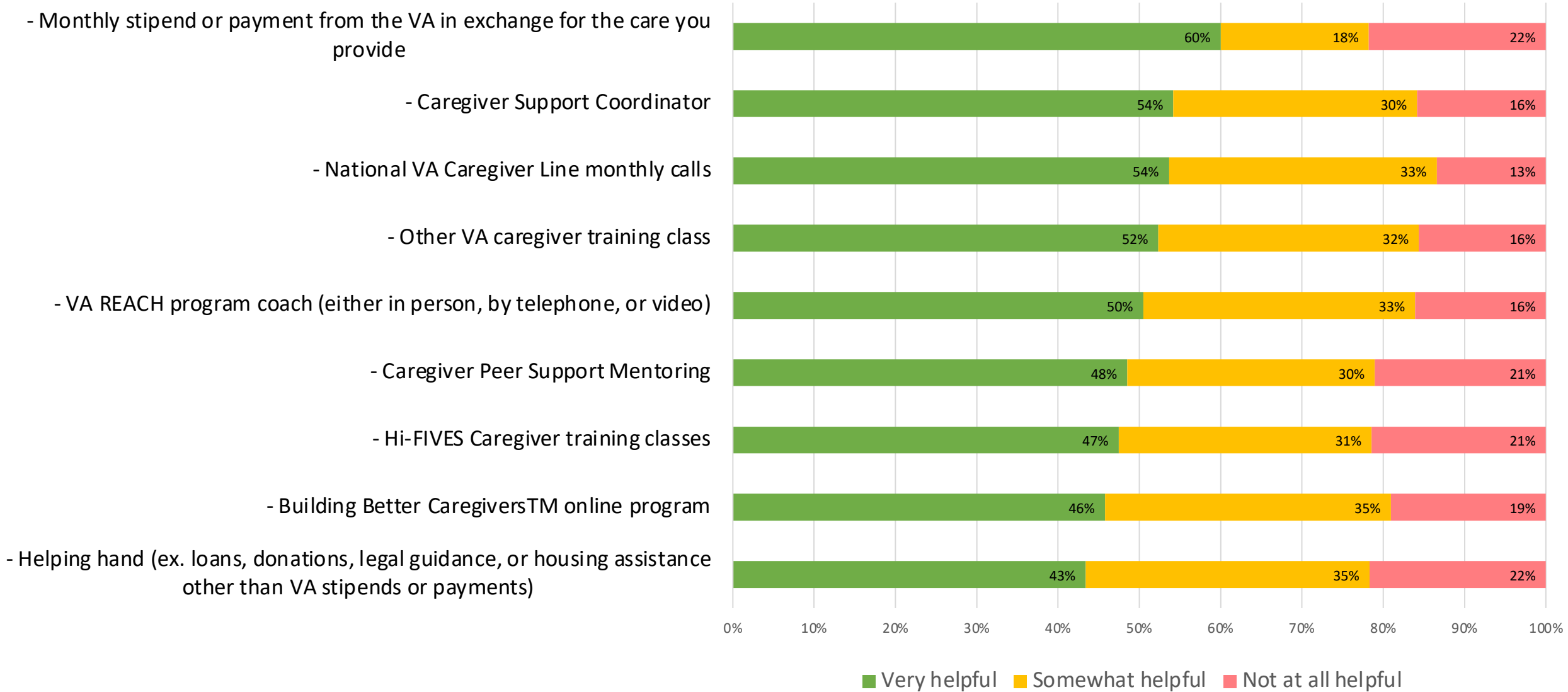


36% help with social needs

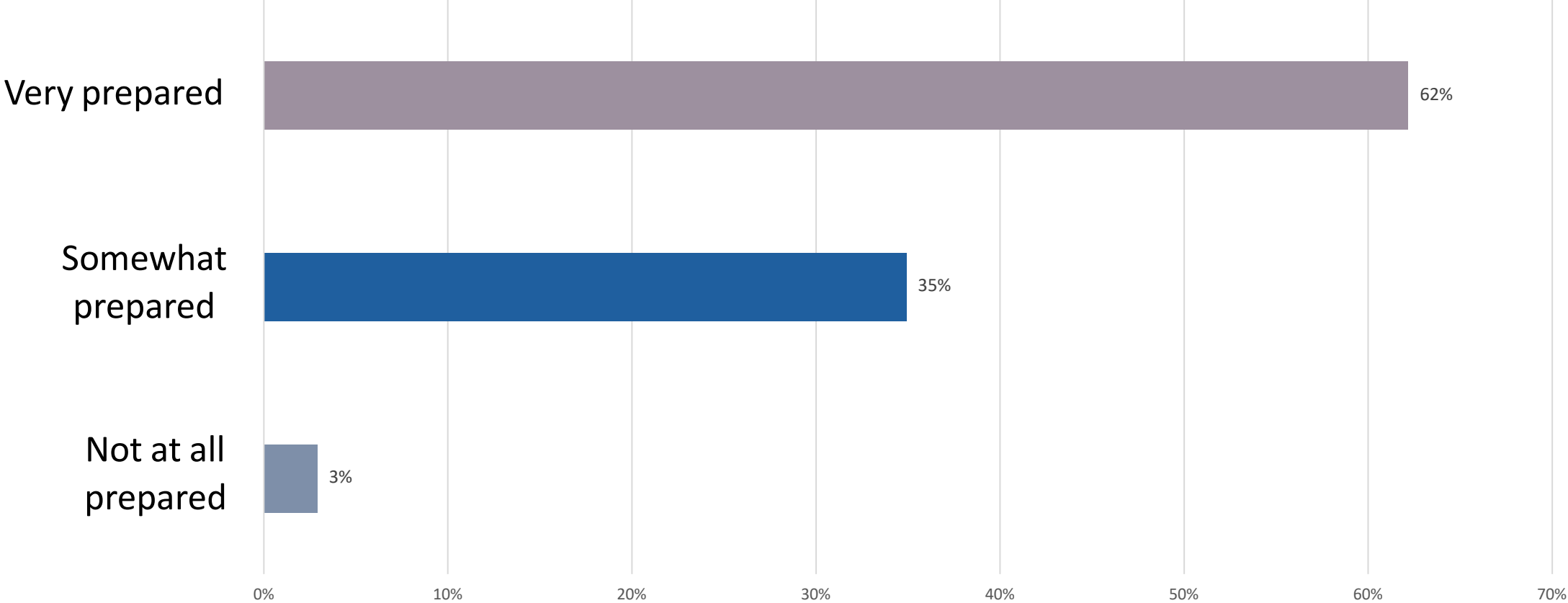
VA Caregiver Program Use



VA Caregiver Program Use and Satisfaction



Of all the tasks that YOU help the Veteran with, how prepared do you feel to do these tasks?



Consideration for HNHR Veteran management

Urgent need to devise viable strategies offering integrated interventions that incorporate mental health needs and reduce social isolation, with focus on mobility and function

Important to screen for social determinants of health

IADL needs

Screen caregivers as well for needs and burden

Link to resources and services

- Mobility challenges/falls → Gerofit, exercise, PT/OT, home safety, assistive devices, home modifications
- Frail → address modifiable risks (nutrition, exercise, isolation)
- Social isolation → ADHC, community agencies, transportation
- ADL deficits – home maker home health aid
- Depression → mental health
- Sicker ones less likely to enroll for outpatient programs → HBPC, MFH

Conclusions

- Both Veterans and caregivers describe complex Veteran unmet needs that include medical, psychological, and social domains.
- More Veterans reported unmet IADL needs compared to ADL, communicating with the healthcare team, or social needs.
- Providers should intentionally screen for not just health needs, but also social determinants of health and caregiver needs.
- Barriers to accessing caregiver support programs may include lack of awareness of VA and non-VA programs.
- Link to VA programs and community resources to bridge gaps for HNHR Veterans and their caregivers, to allow aging Veterans' to age in place.

Thank you!!

Miami GRECC

Stuti Dang, MD, MPH

Willy Valencia, MD, MS

Diana Ruiz, RN

Hermes Florez, MD, PhD, MPH

GECDAC:

Orna Intrator, PhD

Bruce Kinosian, MD

VISN 8

Sam Nasr, MD

GRECC Connect Team

VACO

- Tom Edes, MD, MS
- Darlene Davis, LCSW

Dole Center of Excellence

- Luci K. Leykum, MD, MBA, MSc
- Erin Finley, PhD, MPH
- Mary Jo Pugh, PhD, RN
- Ranak Trivedi, PhD
- Rand Rupper, MD, MPH
- OTHERS

Miami support staff





Thank You!!
