

AWARD NUMBER: W81XWH-20-1-0756

TITLE: Supporting Caregivers of Veterans with TBI and Mixed Dementia: The REACH Hope Behavioral Intervention

PRINCIPAL INVESTIGATOR: Linda Nichols, PhD

CONTRACTING ORGANIZATION: Research Inc/VA Medical Center, Memphis, TN

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14. ABSTRACT Family members who care for Veterans with post traumatic brain injury (TBI) dementia often have heavy burden. Currently, there is no caregiving intervention that combines one-on-one coaching with digital flexibility for caregivers of Veterans with both TBI and dementia. The Department of Veterans Affairs (VA) national Caregiver Center and Virginia Commonwealth University have developed and are evaluating a one-on-one plus smartphone-based intervention, REACH Hope. REACH Hope combines two award-winning interventions: the VA's REACH VA (Resources for Enhancing All Caregivers Health) one-on-one behavioral caregiving intervention and the Department of Defense's Virtual Hope Box mobile app. The REACH VA component involves training in problem-solving and stress management skills one-on-one from a coach. The customizable Hope Box app provides anytime access to personalized coping and stress reduction content. This randomized clinical trial is testing the ability of REACH Hope to improve caregivers' burden, depression and anxiety, and confidence in themselves as caregivers, as well as Veteran safety. In a wait-list control design, half of 110 caregivers of Veterans with TBI and dementia receive REACH Hope at the beginning of the study and half after three months. Outcomes are measured at the start of the study, 3 months, 6-months for all participants, and 9-months later for wait list control participants.					
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1. INTRODUCTION:

Family members who care for Veterans with both traumatic brain injury (TBI) and dementia often have heavy burden. Currently, there is no caregiving intervention that combines the strengths of one-on-one coaching with digital flexibility. In addition, there are no interventions for caregivers of Veterans with both TBI and dementia. The Department of Veterans Affairs (VA) national Caregiver Center and Virginia Commonwealth University have developed and are evaluating a one-on-one plus smartphone-based intervention, REACH Hope. REACH Hope combines two award-winning interventions: the VA's REACH VA (Resources for Enhancing All Caregivers Health) one-on-one behavioral caregiving intervention and the Department of Defense's Virtual Hope Box mobile app. The REACH VA component involves training in problem-solving and stress management skills one-on-one from a coach. The customizable Hope Box app provides anytime access to personalized coping and stress reduction content. This randomized clinical trial is testing the ability of REACH Hope to improve caregivers' burden, depression and anxiety, and confidence in themselves as caregivers, as well as Veteran safety. In a wait-list control design, half of 110 caregivers of Veterans with TBI and dementia receive REACH Hope at the beginning of the study and half after three months. Outcomes are measured at the start of the study, 3 months, 6-months for all participants, and 9-months later for wait list control participants.

2. KEYWORDS:

Brain injuries, Traumatic
Dementia
Caregivers
Veterans
Military Family
Mobile applications

3. ACCOMPLISHMENTS:

What were the major goals of the project?

Goals	Timeline	Dates	Dates and Year 1 % Completed
Major Task 1: Prepare Regulatory Documents	Months		
<i>Milestone Achieved: Local IRB Approval, Memphis, VCU</i>	4	Nov-2021	100%, Memphis 26-Mar-2020 VCU 17-Jul-2020
<i>Milestone Achieved: HRPO Approval</i>	6	Jan-2021	100%, 30-Nov-2020
<i>Milestone Achieved: Local IRB and HRPO Approval as needed and yearly</i>	4-36	Nov-2021 - Aug-2023	Memphis continuing review 07 -Jan-2021 VCU continuing review - as an expedited proposal, there is no continuing review. Original approval date still applies. HRPO continuing review 12-Mar-2021
Major Task 2: Train Study Staff	Months		
<i>Milestone(s) Achieved: Staff hired</i>	1-6	Aug-2020-Jan-2021	100%, (final staff hired 10-Jun-2021)
<i>Milestone(s) Achieved: Staff trained, certified</i>	2-9	Sep-2020-Apr-2021	100%, 28-Jun-2021 (final staff)
<i>Milestone Achieved: Maintained trained and certified Staff throughout study</i>	2-36	Sep-2020-- Aug-2023	Ongoing
Major Task 3: Finalize Research Protocol/Manual of Operations (MOP)	Months		
<i>Milestone(s) Achieved: REACH Hope Program Coach Manual with format, topics and scripts</i>	8-9	Mar-2021-Apr-2021	100%, 02-Feb-2021
<i>Milestone(s) Achieved: Caregiver Notebooks</i>	8-9	Mar-2021-Apr-2021	100%, 09-Feb-2021
<i>Milestone(s) Achieved: Data collection forms, scripts, and documentation</i>	8-9	Mar-2021-Apr-2021	100%, 31-Jan-2021
Major Task 4: Screening and Recruitment	Months		
<i>Milestone(s) Achieved: Screening forms and scripts</i>	6	Jan-2021	100%, 01-Jul-2020
<i>Milestone(s) Achieved: Brochures, web site,</i>	6	Jan-2021	100%, Website live 16-Jan-2021; Brochures mailed

Goals	Timeline	Dates	Dates and Year 1 % Completed
<i>social media blurbs</i>			15-Feb-2021; no social media yet
<i>Milestone(s) Achieved: Approximately 250 participants screened</i>	27	Nov-2022	17.2% screened (n=43), first person screened 18-Feb-2021
<i>Milestone(s) Achieved: 111 participants recruited</i>	27	Nov-2022	27.3% (n=30)
Major Task 5: Randomization and Intervention Delivery	Months		
<i>Milestone(s) Achieved: 111 participants randomized</i>	27	Nov-2022	27.3% (n=30) enrolled and randomized, first person enrolled 25-Mar-2021
<i>Milestone(s) Achieved: Completed interventions</i>	9-30	Apr-2021-Feb-2023	2.7% (n=3) completed
Major Task 6: Data Collection/Data Entry	Months		
<i>Milestone Achieved: Data collection (385 total interviews)</i>	9-33	Apr-2021-May-2023	35.4% (n=39), first data collected 25-Mar-2021
<i>Milestone Achieved: Data entry, quality</i>	35	Jul-2023	35.4% (n=39)
Major Task 7: Data Analysis	Months		
<i>Milestone(s) Achieved: Data analysis</i>	36	Aug-2023	Not yet begun
Major Task 8: Preparation and Dissemination of Results	Months		
<i>Milestone(s) Achieved: Papers and Presentations</i>	28-36	Dec-2022-Aug-2023	CDMRP IPR presentation upcoming 20-Aug-2021
<i>Milestone(s) Achieved: Manuals and materials and plan for dissemination</i>	36	Aug-2023	Not yet begun

What was accomplished under these goals?

1) Major activities

- Obtained regulatory approval
- Hired and trained staff
- Developed study protocol and Manual of Operations
- Developed REACH Hope Coaches Manual and Caregiver Notebook
- Developed detailed Hope Box installation and use guide
- Developed videos for inclusion in Hope Box app
- Began recruitment, which is on target (n = 30, with four more consented and awaiting data collection)
- Developed access data bases for recruitment, data collection, and intervention
- Began baseline and three-month data collection
- Began intervention delivery

2) Specific objectives

- Aim 1 completed: Modify/refine the REACH Hope intervention and caregiver materials for caregivers of Veterans with TBI and AD/MD, in conjunction with subject matter experts (SMEs).

3) Significant results

- Nothing to report

4) Other achievements

- See Products below

What opportunities for training and professional development has the project provided?

- Nothing to report.

How were the results disseminated to communities of interest?

- Nothing to report.

What do you plan to do during the next reporting period to accomplish the goals?

- Continue recruitment
- Continue to provide intervention
- Continue to collect data
- Continue treatment fidelity checks, interventionist coaching, and data quality control

4. IMPACT::

What was the impact on the development of the principal discipline(s) of the project?

- No outcomes yet. However, planned submission of grant to Department of Defense Traumatic Brain Injury and Psychological Health Research Program (TBIPHRP) – all 5 VA Polytrauma TBI Model Systems – Richmond, Minneapolis, Palo Alto, Tampa, and San Antonio, as well as Caregiver Support Program's Caregiver Center at Memphis. Project will explore implementation of REACH for caregivers of Veterans with TB.

What was the impact on other disciplines?

- Expanded Hope Box Users Guide has been shared with DoD developers of app

What was the impact on technology transfer?

- Nothing to report

What was the impact on society beyond science and technology?

- Nothing to report

5. CHANGES/PROBLEMS:

:

Changes in approach and reasons for change

- Nothing to report

Actual or anticipated problems or delays and actions or plans to resolve them

- Problem: Delay in hiring data analyst at Virginia Commonwealth University
Solution
Hired data consultant at Memphis who developed data bases
Data analyst hired 06-Jun-2021 and joined study 22-Jun-2021
- Problem: Caregiver difficulty downloading Hope Box app (19%)
Solutions:
Developed detailed screen-shot instructions and four short YouTube videos to walk caregiver through process
Discuss downloading app and assist during introduction and randomization call
If caregiver continues having difficulty, ask caregiver if they have someone to help them with downloading app

Changes that had a significant impact on expenditures

- Delay in hiring data analyst, was not hired until June 2021 (month 11 and third interventionist program coach also hired in June 2021)

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

- Nothing to report

Significant changes in use or care of human subjects

- Nothing to report
- Memphis VAMC IRB approval - 26-Mar-2020, Memphis continuing review – 07-Jan-2021

- VCU IRB approval - 17-Jul-2020, VCU continuing review - as an expedited proposal, there is no continuing review. Original approval date still applies.

6. PRODUCTS:

Publications, conference papers, and presentations

- CDMRP IPR presentation presented August 20, 2021

Journal publications.

- Nothing to report

Books or other non-periodical, one-time publications.

- Nothing to report

Other publications, conference papers, and presentations

- Nothing to report

Website(s) or other Internet site(s)

- REACH Hope site - https://www.memphis.va.gov/MEMPHIS/features/Memphis_researchers.asp

YouTube Hope Box videos - <https://www.youtube.com/channel/UCT01GHq08qma66gZKYdOuCQ/videos>

Technologies or techniques

- Expanded Hope Box User's Guide has been developed and shared with Department of Defense developers of Hope Box app

Inventions, patent applications, and/or licenses

- Nothing to report

Other Products

- **REACH Hope Caregiver Notebook** – an easy-to-use resource with 28 short chapters on managing behaviors and 16 chapters on reducing stress and burden

Behavioral Chapters

An Overview of TBI and Dementia
Activities
Bathing
Combateness
Communicating with a Person with TBI and Dementia
Confusion
Dressing
Driving
Early-Stage Dementia
Eating
Environment
Hallucinations and Delusions
Hospitalization
Incontinence
Lifting and Moving
Medications
PTSD, TBI, and Dementia
Repeated Questions
Safety Concerns
Sexuality

Caregiving Chapters

Addressing Problems
Adult Day Care
Asking for Help
Challenging Emotions
Communicating with Health Care Providers
Communicating with Others
Depression
Feelings
Financial and Legal Concerns
Grief
Healthy Lifestyle
Holidays
Mood Management
Navigating the System
Organizing Your Caregiving Life
Sexuality
Stress Management
Taking Care of You

Shadowing
Sleeping
Sundowning
Telling Your Loved One and Others
Traveling
Understanding and Managing Anger
Visiting
Wandering

- **Hope Box Users Guide** – screen shots and detailed descriptions for installation and use for Android and iPhone
- **Twelve REACH Hope YouTube videos** – that caregivers can download into their personalized Hope Box app)
link to all videos: <https://www.youtube.com/channel/UCT01GHg08qma66gZKYdOuCQ/videos>
 - Content videos
 - REACH Stretching Video – https://youtu.be/pti5Ty1_kUU
 - REACH Conflict Resolution Video – <https://youtu.be/AU9JHdAVHtc>
 - REACH Self-Esteem Video - <https://youtu.be/-1Yw-uaV82M>
 - REACH Goal Setting Video – https://youtu.be/_7gyyh3Kd-4
 - REACH Stress Management Video – <https://youtu.be/jk7OGrYuXqw>
 - REACH Mood Management Video – <https://youtu.be/IR5LIUYnPIU>
 - REACH Problem Solving Video – <https://youtu.be/4PtI0Hs6-8U>
 - REACH Guided Imagery Video – <https://youtu.be/IB5UaCXH-HQ>
 - Process videos – need links
 - How to Download the Virtual Hope Box app
<https://www.youtube.com/watch?v=NQVcRR2L7bg&pp=sAQA>
 - How to Add REACH Signal Breath Video and Coping Card
<https://www.youtube.com/watch?v=ZhUdIYnFin4&pp=sAQA>
 - Adding REACH YouTube Videos to Virtual Hope Box
<https://www.youtube.com/watch?v=RTRxeoXZwgo&pp=sAQA>
 - How to Create Coping Cards in your Virtual Hope Box
https://www.youtube.com/watch?v=zYiz4pD_p6I&pp=sAQA
- **Databases** to track study activities – recruitment, data collection, and intervention
- **Recruitment brochure**

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Memphis VAMC

Name: Linda Nichols
Project Role: PI
Researcher Identifier: LNichols1
Person month: 3.0
Contribution: Overall direction and approval, writing and editing of materials

Name: Jennifer Martindale-Adams
Project Role: Co-I
Researcher Identifier: Jmartindale
Person month: 0.6
Contribution: Writing and editing of materials

Name: Carolyn Clark
Project Role: Research specialist
Person month: 6
Contribution: Development of materials for recruitment and intervention and data collection

Name: Jessica Roxy Martin
Project Role: Research specialist
Person month: 3.0

Contribution: Development of materials for recruitment and intervention

VCU

Name: Paul Perrin
Project Role: Co-PI
Researcher Identifier: PPERRIN
Person month: 3.0
Contribution: Overall direction and approval, writing and editing of materials

Name: Ronald Seel
Researcher Identifier: RON_SEEL
Project Role: Co-I
Person month: 1.2
Contribution: Research design

Robert Perera
Project Role: Statistician
Research Identifier: ORCID: 0000-0002-0375-0427
Person month: .36
Contribution: Statistical support

Carmen Tyler
Project Role: Program Coach (interventionist)
Research Identifier: ORCID: 0000-0001-5265-184X
Person month: 6.0
Contribution: Delivery of intervention

Chimdindu Ohayagha
Project Role: Program Coach (interventionist)
Research Identifier: <https://orcid.org/0000-0003-3325-5424>
Person month: 6.0
Contribution: Delivery of intervention

Ashley MacPherson
Project Role: Program Coach (interventionist)
Research Identifier: <https://orcid.org/0000-0001-9654-4640>
Person month: 6.0
Contribution: Delivery of intervention

Alexandra Ulbing
Project Role: Data analyst
Research Identifier: ORCID: 0000-0002-4578-0026
Person month: 4.8
Contribution: Management of data and data bases, statistical support

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Paul Perrin, PhD.

Active support ended for grant: Identifying cognitive barriers to effective pressure ulcer self-care
Time Commitments: 5% (.6 Calendar Months)
Supporting Agency: Department of Defense
Performance Period: 03/01/2019 – 08/31/2020
Level of Funding: .

Ronald Seel, PhD

Active Support: Virginia Traumatic Brain Injury Model System
Time Commitments: 25%
Supporting Agency: National Institute on Disability Independent Living and Rehabilitation Research

Performance Period: 9/29/17-9/30/22

Level of Funding:

Active Support: Long-Term Impact of Military-Relevant Brain Injury Consortium (LIMBIC) Award

Time Commitments: 20%

Supporting Agency: Department of Defense, CDMRP W81XWH-18-PH/TBIRP-LIMBIC

Performance Period: 09/30/2019 – 09/29/2024

Active Support: Advanced Rehabilitation Research Training Project

Time Commitment: 5%

Supporting Agency: National Institute on Disability Independent Living and Rehabilitation Research

Performance Period: 9/30/15-9/29/21

Level of Funding:

Active Support: BeHEALTHY: Chronic Disease Management for Traumatic Brain Injury

Time Commitments: 3%

Supporting Agency: National Institute on Disability Independent Living and Rehabilitation Research

Performance Period: 9/1/20-8/31/2021

Level of Funding:

Active Support: Epidural Stimulation and Resistance Training for Overground Locomotion after Spinal Cord Injury

Time Commitments: 3%

Supporting Agency: Department of Defense, CDMRP

Performance Period: 09/01/2020 – 08/31/2024

Level of Funding:

Active support ended for grant: Evaluating Brain Injury Clubhouses and their effects on Neurobehavioral Functioning and Participation

Time Commitments: (percent effort) 4%

Supporting Agency: Community Brain Injury Services (VA Department for Aging and Rehabilitative Services)

Performance Period: 7/1/2018 – 3/31/2020

Active support ended for grant: LiveWell RERC: The RERC for Community Living, Health and Function

Time Commitments: (percent effort) 12%

Supporting Agency: Shepherd Center (NIDILRR prime)

Performance Period: 2/15/2019 – 9/29/2020 Level of Funding:

What other organizations were involved as partners?

Organization Name: Virginia Commonwealth University (VCU)

Location of Organization: Richmond, VA

Partner's contribution to the project: VCU conducts intervention for caregivers, manages data, and will analyze all data

Financial support: Contract from Memphis to VCU

In-kind support: VCU provides all resources (space, computers, telephones) to their project staff

Facilities: VCU Departments of Psychology and Physical Medicine & Rehabilitation

Collaboration): VCU and Memphis staff share data and meet together weekly

Personnel exchanges: N/A

Other: N/A

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS: N/A.

QUAD CHART: Quad Chart with Recruitment and Consort Diagram attached.

9. APPENDICES:

- a. Recruitment Brochure
- b. Caregiver Notebook sample
- c. IPR Presentation
- c. Baseline Data Collection Battery



PI: Linda Nichols

Org: Research Inc/VA Medical Center

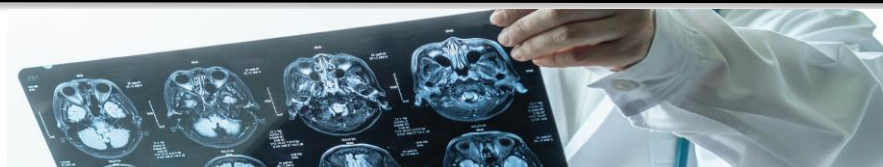
Award Amount: \$1,299,885.00

Study/Product Aim(s)

- **Aim 1.** Modify/refine REACH Hope intervention and caregiver materials for caregivers of Veterans with TBI and dementia.
- **Aim 2.** Compare efficacy of REACH Hope in improving burden, depression, anxiety and caregiving self-efficacy for caregivers of Veterans with TBI and dementia to a waitlist control.
- **Aim 3.** Compare efficacy of REACH Hope in improving safety for Veterans with TBI and dementia whose caregivers have participated in REACH Hope to a waitlist control.

Approach

Randomized clinical trial of 110 caregivers of Veterans with TBI and dementia, half in each arm. Compare 6 one-hour individual sessions and use of Hope Box app, focusing on education, skills building and support over three months to wait list control. Data collected at baseline, 3, and 6 months for all, and 9 months for wait list control.



Study Highlights During First Project Year

- Obtained regulatory approval
- Hired and trained staff
- Developed study protocol and Manual of Operations
- Developed REACH Hope Coaches Manual and Caregiver Notebook
- Developed detailed Hope Box installation and use guide
- Developed videos for inclusion in Hope Box app
- Began recruitment, which is on target
- Developed access data bases for recruitment, data collection, and intervention
- Began baseline and three-month data collection
- Began intervention delivery

Timeline and Cost

Activities	CY	20	21	22	23
Finalize materials, obtain approval, print materials					
Recruit subjects					
Administer interventions					
Collect, analyze, and process data					
Disseminate findings					
Estimated Budget (\$K)		\$143	\$447	\$483	\$227

Goals/Milestones

CY20 Goals

- ☒ Prepare regulatory documents
- ☒ Train study staff
- ☒ Finalize research protocol/manual of operations (MOP)

CY21 and CY22 Goals

- ☐ Screening and recruitment
- ☐ Randomization and intervention delivery
- ☐ Data collection

CY23 Goal

- ☐ Data analysis
- ☐ Preparation and dissemination of results

Comments/Challenges/Issues/Concerns

- Nothing to report

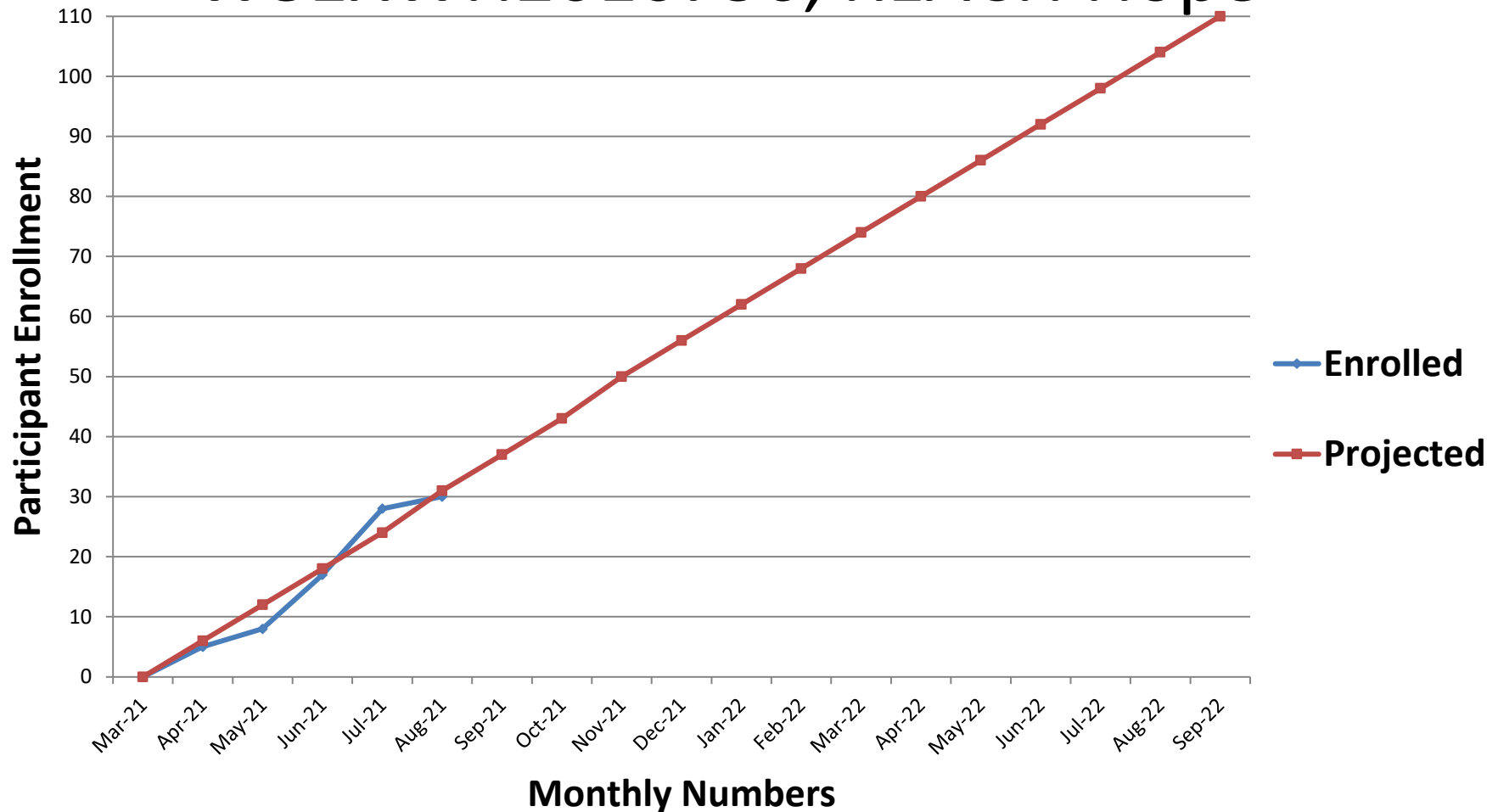
Budget Expenditure to Date

Projected Expenditure:\$382,382.85

Actual Expenditure: \$\$245,295.50

Recruitment and Retention

W81XWH2010756, REACH Hope

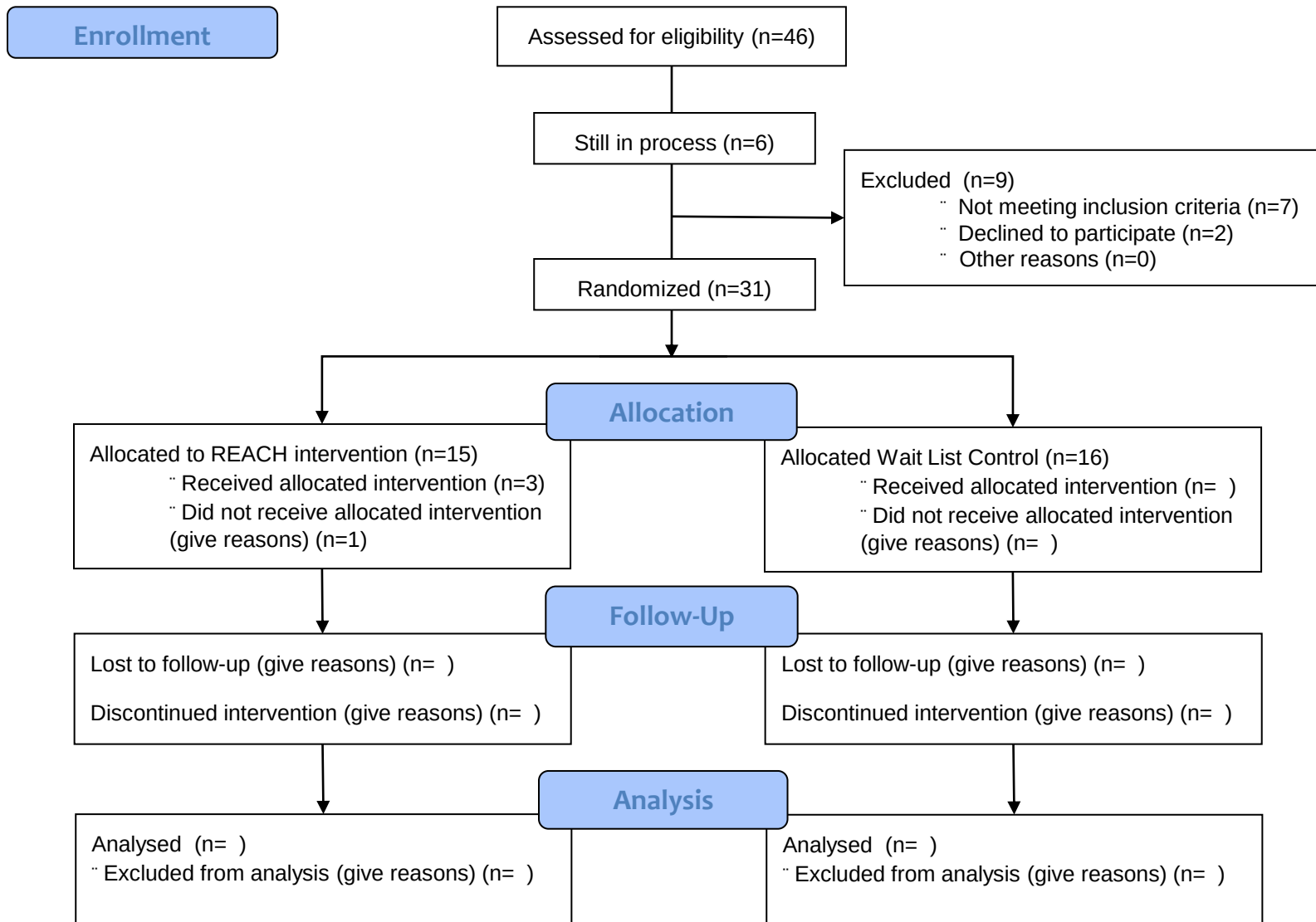


Percent of participants that complete study

%

W81XWH2010756 CONSORT Diagram

15-Aug-2020 through 14-Aug-2021





Help for Caregivers of Veterans with Traumatic Brain Injury and Dementia

Are you caring for a Veteran with Traumatic Brain Injury (TBI) and Dementia?

If so, we would like to talk with you about a six month research project. The research program will be completed over the phone and provides information on:

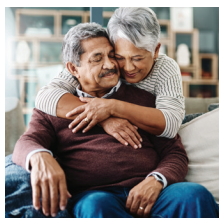
- Caregiving
- Safety concerns
- Emotional well-being
- Health concerns
- Social support
- Patient problem behaviors

Sponsored by Department of Defense (DoD) & Veteran Affairs Medical Center, Memphis, TN

VA



U.S. Department
of Veterans Affairs



What Will I Do?

During this six month project you will be assigned by chance to one of two groups. One group will participate in six individual REACH (**R**esources for **E**nhancing **A**ll **C**aregivers **H**ealth) sessions for three months, receiving stress reduction and coping skills (mood management, communication, problem solving). A mobile app will also be used. One group will participate right after starting the study. The second group will participate after three months.

You will receive payment for answering questions during three or four interviews and a program evaluation, for a total of \$100–\$125. There is no cost to participate.

How Do I Enroll?

PHONE:

(901) 577-7485 or
(800) 636-8262 Ext. 7485

EMAIL:

vhamemreach@va.gov

WEB:

www.memphis.va.gov/reachhope

LET US CALL YOU.

**ALL INFORMATION WILL BE KEPT
CONFIDENTIAL.**



USING YOUR CAREGIVER NOTEBOOK

As you go through this Notebook you will find brief worksheets at the end of each chapter. The worksheets are designed to help you address concerns you may have and relate the material in each chapter to your situation. There are Commitment pages at the back of the Notebook. The Commitment page provides space to document the strategies you develop with your Program Coach so that you can track your progress.

If you are unable to attend a session, please notify your REACH VA Program Coach for your individual sessions. If you are participating in Telephone Support Groups, contact your Group Leader. You can contact them by telephone or through e-mail.

Program Coach name: _____

Program Coach telephone number: _____

Program Coach e-mail: _____

Group Leader name: _____

Group Leader telephone number: _____

Group Leader e-mail: _____

TBI AND DEMENTIA

SUPPORT *for* CAREGIVERS OF VETERANS

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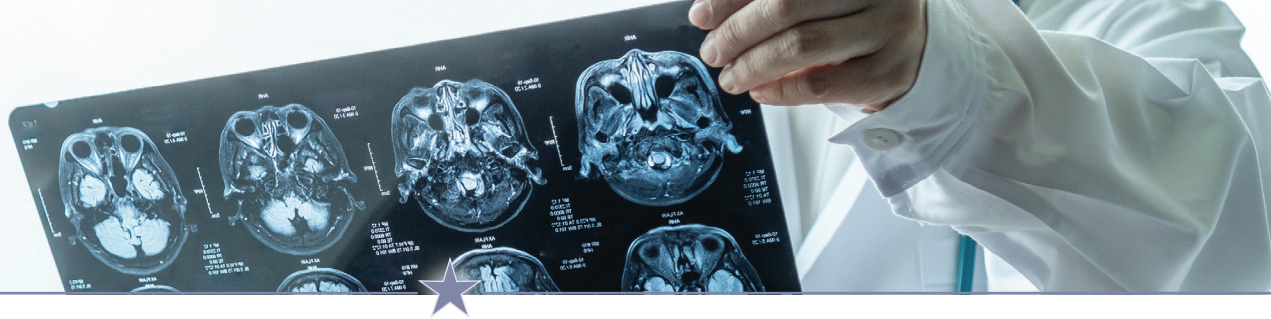
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BEHAVIORAL ISSUES



AN OVERVIEW OF TBI AND DEMENTIA

Understanding the diagnoses of Traumatic Brain Injury (TBI) and dementia is important to help you as a caregiver. In this Notebook, we discuss these two diagnoses and what it means in terms of daily life as a caregiver for someone who lives with these two conditions. The challenges of having these two diagnoses are not just the increased number of symptoms; they also have to do with the way TBI and dementia relate to each other. Mostly, and perhaps most importantly, we will discuss numerous daily living topics and offer tips for coping as a caregiver for your loved one.

In this chapter, you will learn about:

- The brain
- TBI causes, symptoms, and treatment
- Dementia causes, symptoms, and treatment
- Resources for understanding TBI and dementia
- Comparison between TBI and dementia
- In this book, we will use the term comorbidity to refer to the existence of two medical conditions at the same time in terms of how these two conditions relate to each other. The two conditions, dementia and TBI, are complex in how they relate to each other. Dementia may be more likely to occur before the age of 65 in a person who has TBI compared to people without TBI.
- Many symptoms will overlap, and there may be times when it will be unclear which diagnosis is responsible for a symptom (for example, diminished ability to smell). Other times, it may be clearer which diagnosis is likely responsible for a symptom (for example, seizures occurring with a penetrating TBI).

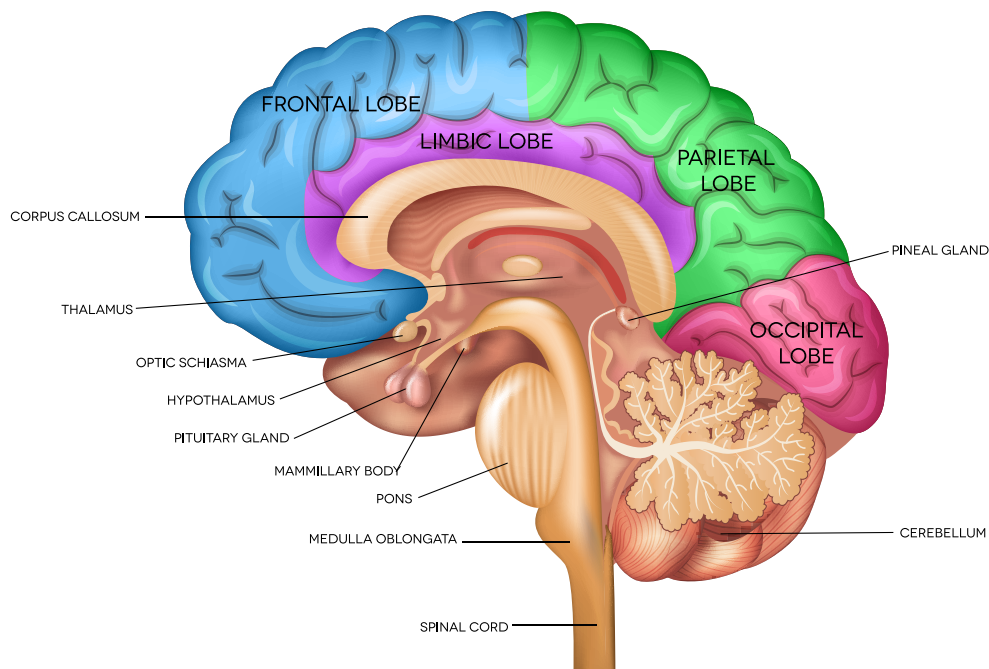
The brain...

The healthy brain

Understanding the basic structures, functions, and process of the brain may help you to understand your loved one's TBI and dementia. The healthy brain controls all the body's functions. These functions include breathing, sensing, and moving. The brain is the center of thinking, judgment, and emotional reactions to people and events. The brain includes these parts:

- ☐ The brain stem connects the brain to the spinal cord. It controls consciousness, arousal, swallowing, sense of balance, and basic vital functions such as breathing, respiration, and heart rate.
- ☐ The cerebellum coordinates movement and remembers movement patterns.
- ☐ The cerebrum is responsible for language, thinking, remembering, learning, mathematical reasoning, initiation of activity, emotional control, creativity, and expression of personality.
- ☐ The cerebrum is divided into two sides (hemispheres). Each hemisphere has four lobes with specific functions:
 - Frontal lobes – emotions and higher intellectual functioning
 - Parietal lobes – sensation, reading, listening, spatial sense, and memory
 - Temporal lobes – memory, language, hearing, sequencing, and music
 - Occipital lobes – visual perception

Diagram of the basic parts of the brain



Traumatic Brain Injury (TBI)...

A traumatic brain injury (TBI) happens when something outside the body impacts the head with force, either directly or indirectly, such as with whiplash.

TBI is the leading injury among military personnel in war zones. Motor vehicle crashes and falls are the leading causes for civilians. There are three main types of TBI:

- ☐ Closed-head injuries account for most brain injuries and occur when the brain is traumatized inside the skull.
- ☐ Penetrating head injuries or open-head injuries occur when there is a forceful blow to the head that pierces the skull. This type of injury is often life-threatening.

- ☐ Crushing injuries happen when the brain is compressed between two objects. This type of injury is rare but is the most destructive and life-threatening of the TBIs.

Other conditions that result in an injury to the brain

- ☐ Anoxic brain injury occurs when there is a death of brain cells from lack of oxygen to the brain, such as occurs with a stroke or suffocation.

Symptoms of TBI

TBI can range in seriousness from mild to severe, and a person with TBI might physically look the same as before the head injury.

- ☐ Physical symptoms can include headache, feeling dizzy, being bothered by noise or light, being tired, trouble sleeping, or vision problems. More severe injuries can cause paralysis, speech difficulties, changes in sexual functioning, and decreased muscle coordination.
- ☐ Mental functioning changes may include lack of focus, poor memory, and trouble putting thoughts into words. A severe or moderate TBI may cause poor judgment or acting without thinking (e.g., impulsivity or disinhibition).
- ☐ Emotional changes can involve decreased ability to engage in social situations, changes in personality or mood, depression, anxiety, anger outbursts, and being quick to anger.

Treatment of TBI

Treatment of TBI depends on the severity, type, area of injury, and amount of time since the injury. Initial treatment may include strategies that decrease pressure inside the brain or surgery. Mild TBI treatment may focus on rest and a slow return to activity.

- ☐ Medications can sometimes be used to treat symptoms such as anxiety, depression, muscle spasms, and decreased alertness and attention.

Medications may also help prevent risks associated with TBI such as blood clots, seizures, excess fluid, and pressure in the brain.

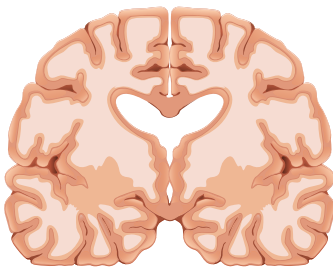
- ☐ Physical, occupational, speech, and cognitive therapy can help persons with TBI relearn, improve, or strengthen skills. Vocational counseling can help with return to work.

Dementia...

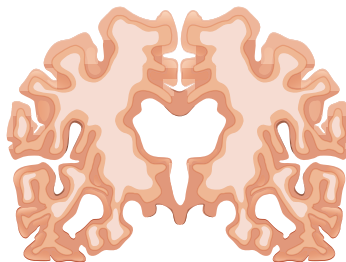
Dementia is a term used to describe loss of cognitive functioning (thinking, remembering, and reasoning) and behavioral abilities to such an extent that it interferes with a person's daily life and activities. The causes of dementia vary, and many people have mixed dementia, a combination of two or more disorders.

Common types of dementia

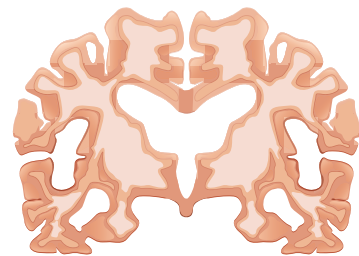
- ☐ Alzheimer's disease is the most common form of dementia in the U.S., accounting for 60-80% of dementia. Because of how common it is, much of the information in this Caregiver Notebook is targeted to Alzheimer's disease. It is caused by the deposit of two proteins in the brain, which cause brain cells to die, as shown in the picture below.



Healthy Brain



Mild
Alzheimer's Disease



Severe
Alzheimer's Disease

- ☐ Vascular dementia is the result of strokes, or decreased blood flow to the brain or bleeding in the brain, which causes brain cells to die. Vascular dementia alone accounts for around 10% of those with dementia, but approximately 40-60% of those with Alzheimer's disease also have vascular dementia.
- ☐ Lewy Body dementias (dementia with Lewy bodies and Parkinson's disease dementia), affecting around 10% of those with dementia, are caused when abnormal proteins are deposited in the brain. This causes both memory loss and Parkinson's disease symptoms.
- ☐ Frontotemporal disorders (such as Pick's Disease) involve damage to nerve cells in the frontal and temporal parts of the brain. Symptoms include personality and behavior changes, difficulty with language, and movement and muscle difficulties.

Other conditions that may cause memory loss

- ☐ Emotional problems such as depression can make it difficult for someone to concentrate, increase memory loss, make a person more forgetful, and can be mistaken for dementia. Emotional problems can worsen cognitive symptoms for someone who has dementia.
- ☐ Acute (short-term) changes in memory, over hours, days, occasionally weeks, are emergencies. These can be caused by medicines, infections, falls, or injuries to the brain. Strokes can cause acute memory issues or chronic memory loss. Alcohol use and acute intoxication can also cause memory problems. Chronic alcohol use can cause dementia. Chronic liver and kidney disease can cause memory loss.

Symptoms of dementia

Symptoms of dementia vary between types of dementia and individuals. Each person will have different symptoms at different times. There are some

common behaviors, however. These behaviors may lead to a loss of ability to perform familiar tasks.

- ☐ Problems with memory may include not remembering recent events or people and losing or misplacing things.
- ☐ Problems with abstract thinking, concentration, language, and confusion about time and place can lead to getting lost or problems with paying bills.
- ☐ People with dementia may experience changes in behavior and mood, becoming irritable, suspicious, afraid, or less interested in activities.

Treatment for dementia

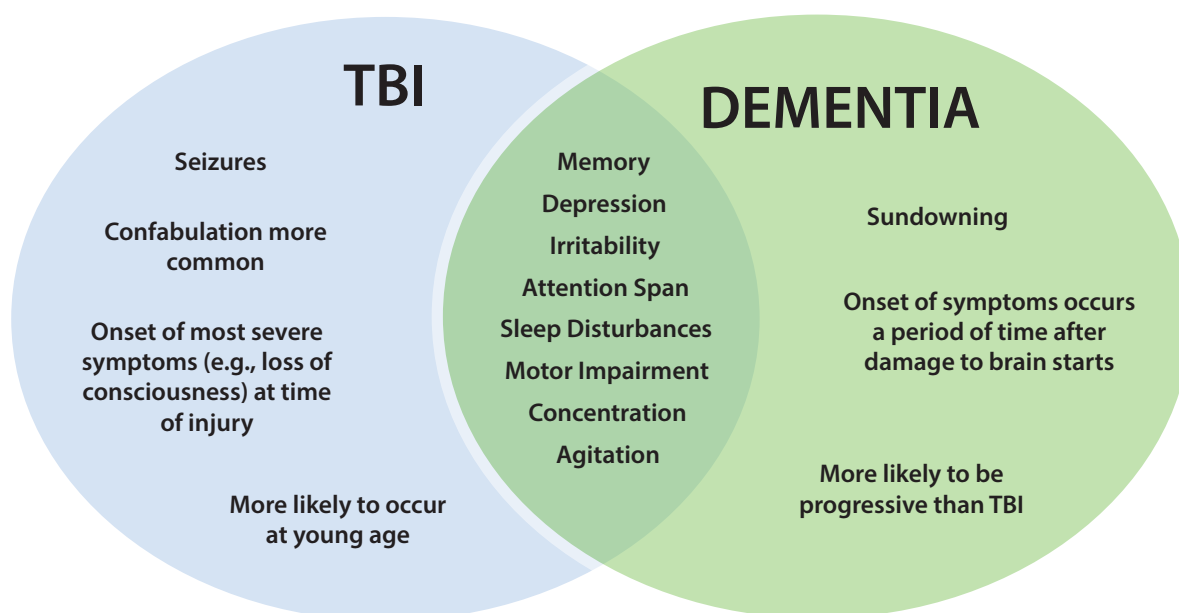
Treatment for dementia focuses on maintaining mental ability, managing behavioral symptoms, and slowing or delaying symptoms.

- ☐ Drugs approved to treat Alzheimer's disease do not slow the disease or return memory and function to normal. Medications can help manage symptoms of Lewy body dementia and Parkinson's disease dementia and manage vascular dementia risk factors, such as hypertension, diabetes and high cholesterol. Medications may reduce behavioral symptoms of frontotemporal dementia.
- ☐ Behavioral management to decrease and manage symptoms and behavioral problems is an important part of treatment for dementia. The REACH program focuses on behavioral management.

TBI and dementia comparison...

As a caregiver of someone who has been diagnosed with TBI and dementia, you may already be familiar with how much these two diagnoses overlap. Concentration, memory, and motor functioning are just a few of the areas where these two conditions overlap. There are other symptoms that are more closely associated with one diagnosis than the other. The diagram below shows some of these symptoms and their overlap.

- ☐ Seizures, although known to occur with dementia (10-22%), are significantly more likely to occur with an open-head TBI (65%).
- ☐ It is likely that you will not know if a specific symptom of your loved one is a product of the disease or the injury. However, the care techniques that you put in place will most often be the same, regardless of the source.



Resources for TBI and dementia...

As a family caregiver, you play an important role in caring for the Veteran at home and in the community. Each VA Medical Center has a Caregiver Support Coordinator available to assist you. Contact your local Caregiver Support Coordinator, check the website at www.caregiver.va.gov, or call the toll free VA Caregiver Support Line at 1-855-260-3274. Other resources are below.

(VA does not control content for non-VA resources.)

- ☐ VA's Polytrauma/TBI System of Care at www.polytrauma.va.gov.
- ☐ Traumatic Brain Injury Center of Excellence (formerly Defense and Veterans Brain Injury Center) <https://health.mil/About-MHS/OASDHA/Defense-Health-Agency/Research-and-Development/Traumatic-Brain-Injury-Center-of-Excellence>
- ☐ Alzheimer's Disease Education and Referral Center (ADEAR), National Institute on Aging. <https://www.nia.nih.gov/alzheimers>; toll-free number is 1-800-438-4380; and e-mail is adear@nia.nih.gov.
- ☐ Alzheimer's Association. The website is <http://www.alz.org>; and the toll-free 24/7 Helpline is 1-800-272-3900 with translation into more than 200 languages.
- ☐ The National Institute on Aging A-Z Health Topics website has publications and facts on all the different types of dementia. <https://www.nia.nih.gov/health/topics/dementia>



ACTIVITIES

The activities a person living with TBI and dementia can do will change as the disease goes on. As memory and the ability to pay attention change, basic activities can become hard. Your loved one will lose the ability to plan and start activities. Persons with TBI and dementia may sit in one place, pace, or search for objects. They may show little interest in activities that brought joy and meaning in the past. You can help your loved one enjoy life. The following ideas can help you plan exercises and activities your loved one can enjoy.

Here are some reasons a person living with TBI and dementia may not want to be active:

- Depression
- Trouble with eyesight and hearing
- Physical discomfort
- Change in routine
- Physical illness

How to get your loved one to stay active...

Plan activities

- ☐ Think about what your loved one has always enjoyed. Use the Pleasant Events planning materials in the Stress Management chapter to plan activities you can do together.
- ☐ Simplify your loved one's past activities (work and hobbies) to match current abilities.

Make activities routine and structured

- ☐ Do the same activities on the same day each week or at the same time each day. A daily routine may help your loved one feel more comfortable about an activity.

Keep favorite activities even if they aren't the same as before

- ☐ A person who liked to read magazines may still enjoy looking at them. Your loved one may look through the paper without being able to understand it. The important thing is that your loved one enjoys the activity.
- ☐ Your loved one can do activities that are similar to past hobbies. A person who was a gardener may still be able to rake leaves. Someone who played the piano may like listening to piano music.
- ☐ For some, activities that are similar to work are enjoyable. A former bank employee might enjoy counting coins and putting them in holders.
- ☐ A person who liked to cook may enjoy sorting cutlery in a kitchen drawer or baking something, using simple recipes or enjoy decorating cookies.
- ☐ Jot down a list of activities your loved one can do. Keep it handy. Adapt the list as abilities change over time.

Activities take planning and flexibility

- ☐ Adapt to your loved one's ability level. The level will change over time. Your loved one may refuse or not want to do an activity. This may mean the activity is too difficult, or your loved one can't do it or is afraid.
- ☐ Your loved one may have trouble with some part of an activity or task but may be able to do another part of the activity. Sorting and folding socks may be too hard. You can sort them. Your loved one can then fold them.
- ☐ Be aware of times of day that are better for your loved one; plan activities accordingly.
- ☐ Accept compromise. Let your loved one do what is possible, even if it isn't up to your standards.

Keep your loved one involved in household activities and family life

- ☐ Choose activities that make your loved one feel like an important member of the household. Your loved one can still contribute.
- ☐ Dependent on the severity of the TBI and the stage of dementia, your loved one can do simple chores. Your loved one can sweep, vacuum, or help empty the trash. Persons with TBI and dementia often enjoy simple yard work.

Plan activities that include your loved one with the whole family

- ☐ Continue to plan for the family to get together. Keep the needs of your loved one in mind. Plan rest periods.
- ☐ Make sure the extra movement and noise in the house do not upset your loved one.

Don't make activities a test of skill or achievement

- ☐ Choose activities that fit your loved one's skills now. Dependent on the severity of the TBI and the stage of dementia, your loved one may become upset at not being able to do a task.

- ☐ Set your loved one up for success, not failure.
- ☐ Give your loved one plenty of support when working on tasks.

Plan for a realistic amount of activity

- ☐ You do not need to fill the whole day with activity. Balance activity with rest. Take breaks. As the disease gets worse, your loved one will have a shorter attention span. You may need to stop an activity or change activities.

Some suggestions for activities...

Self-expression

A person with TBI and dementia may like to do things that express feelings and personality. Your loved one may enjoy reliving old memories. You may want to try these activities:

- ☐ **Music.** Music has been used across the ages to calm distressed individuals. Musical activities often work well with persons with TBI and dementia. Music may lower levels of agitation. Many musical activities do not need a long attention span or good coordination. Music is especially good for a person who has enjoyed or played music in the past.

Use music that is familiar and brings back pleasant memories or feelings. Soothing, slow pieces are very calming.

Activities such as singing, dancing, clapping along or keeping a beat are fun. Music that was popular when your loved one was growing up is also a good choice for singing along.

- ☐ **Crafts.** Some individuals enjoy crafts. Keep activities simple. Plan them so they can be completed in a short time. It is best to use a few large pieces of material. Your loved one may like collages or scrapbooks. Try

simple activities, such as drawing, winding a ball of yarn, molding clay, or finger painting.

- ☐ **Animals.** Activities with animals can help your loved one express emotion. Your loved one can visit with a loving, good mannered dog or cat or watch birds in outdoor bird feeders. A live animal may not be available or practical. Your loved one may enjoy a stuffed animal.
- ☐ **Toys.** Some persons with TBI and dementia enjoy playing with children's toys or looking at children's books. Toys could include dolls, puzzles, or simple board games. Don't worry about what others think. Feel free to take your loved one with you to local stores to look at toys.

Exercise

There are simple exercise activities you might try. They depend on your loved one's ability.

- ☐ Play catch with a ball. Use a ball that is soft, such as a Nerf ball, to avoid injury or damage. A beach ball is large and easy to catch. Sitting down may make it easier for your loved one to catch the ball.
- ☐ Household tasks, like sweeping or dusting furniture, provide exercise.
- ☐ Take walks with your loved one on a regular basis. Walk daily if your loved one is able. You can walk to the corner, to the grocery store, or around the mall.
- ☐ Your loved one can get hand and arm exercise by rolling clay or tying simple knots. Both activities should be supervised. For example, show the person how to shape clay into a long roll. Then roll it back and forth from palm to fingertips. Tie simple knots in a soft cord and have your loved one copy you.
- ☐ Chair exercises can be done from a sitting position. For all chair exercises, begin slowly. Ask your loved one to imitate you.

- Chair exercises for the upper body. Sit upright with knees spread apart. Slowly bend forward from the waist, reaching the hands toward the floor. Hold for a count of two. Slowly return to a straight position.
- Place your hands behind your head. Twist to the right and then back to the center. Twist to the left and then back to the center. Do not move your hips. Repeat five times.
- Chair exercises for the legs. Start with feet placed flat on the floor. Raise one bent leg in front as far as you can. Hold for a count of two. Return foot to the floor and relax. Repeat with other leg. Hold onto chair arms if needed for balance.
- Stretching after the exercises. Chair exercise sessions should be ended with a slow stretch to cool down. Sit straight with arms on the lap. Slowly raise arms above the head. Take a deep breath. Slowly lower arms and exhale. Then relax.

Household tasks

Taking part in routines around the house may help your loved one feel useful. Stick with simple activities that can be repeated:

- ☐ Setting the table.
- ☐ Folding napkins, towels, or laundry.
- ☐ Raking leaves or picking up sticks.
- ☐ Sweeping or dusting.

Old memories

Recalling past events can provide your loved one with a mental activity.

- ☐ Help your loved one think about old times by looking together at pictures of family and friends.
- ☐ Old music or movies may be another way to recall the past.
- ☐ Create a memory board to display photos of people, places, and things that bring up good memories.

Self-care

Certain self-care activities may be enjoyable. Your loved one may need help from you, a hairdresser, or barber. Consider:

- ☐ A beauty hour (working on hair, nails, or the face).
- ☐ Hand massage.

General ideas

These are things that have worked for other caregivers. They may work for you, too. They are not the only activities that can be done. They may not be right for everyone. Always plan activities with your loved one in mind. What activities best fit your loved one's likes and dislikes, past activities, and current ability? Using activities that fit will make your loved one's day, and your own day, more positive and enjoyable. Here are some suggestions:

- ☐ Sort things: beans; cards (by color, suit, etc.); silverware.
- ☐ Make cookies out of pre-formed dough.
- ☐ Play memory games: matching pictures and oversized numbers on cards; rolling dice.
- ☐ Wash dishes with sponge and liquid soap, one dish at a time.

- ☐ Complete familiar phrases, such as, “A stitch in time saves _____.”
- ☐ Keep a list of activities and an activity box with things you might need handy.
- ☐ Use simple math or word puzzles.
- ☐ Use simple hand-held games such as solitaire or tic-tac-toe. These can be brought along to appointments.

Activities Worksheet

1. What activities did your loved one formerly enjoy? Can you modify any activities to make them simpler?

2. What does your loved one like to do now?

3. What activities will let your loved one continue to contribute to the household?



Supporting Caregivers of Veterans with TBI and Mixed Dementia: The REACH Hope Behavioral Intervention

**Linda O. Nichols, PhD Department of
Veterans Affairs Paul Perrin, PhD
Virginia Commonwealth University**

15-Aug-2020 through 14-Aug-2023

AZ190094, W81XWH2010756

NCT04969796





Militarily relevant issue to be solved



- » Between 2000 and 2016, over 350,000 service members diagnosed with TBI (Defense and Veterans Brain Injury Center)
- » Moderate-to severe-TBI is associated with increased risk of dementia among those 55 years and older
- » Growing evidence suggests that sustaining 3+ mild TBIs increases dementia risk
- » People with post-TBI dementia often have more issues than those with dementia alone including:
 - » depressive, agitated, and irritable symptoms
 - » gait dysfunction, motor slowness, and falls
 - » Disinhibition and dysregulation
- » Caregivers often lack the practical skills to manage post-TBI dementia and experience significant distress and burden
- » There are no evidence-based interventions that utilize both personalized strategies and digital resources to meet the complex needs of post-TBI dementia caregivers



Solution



- » REACH Hope combines and delivers two award-winning behavioral interventions, incorporating one-on-one personalized coaching sessions and mobile supports
 - » Department of Veterans Affairs' REACH VA (Resources for Enhancing All Caregivers' Health)
 - » Personalized, one-on-one coaching to address caregiver's specific situations that create burden
 - » Department of Defense's Virtual Hope Box mobile app
 - » Anytime access to tools to meet caregiver needs during and beyond the one-on-one sessions
- » Randomized, controlled clinical trial compares caregivers of Veterans receiving the REACH Hope intervention to those in a waitlist control group



Solution



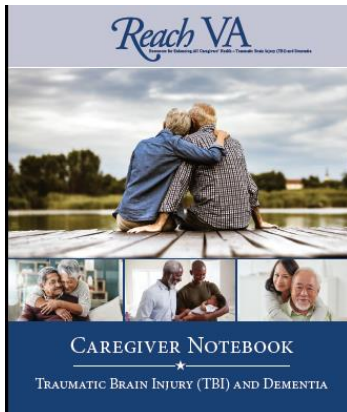
REACH VA

- » Evidence-based; protocol-driven
- » Targeted to dyad's risks
 - » safety, emotional and physical well being, social support, problem behaviors
- » Caregiver Notebook
- » Six individual one-hour sessions
- » Information, support, skills building
 - » problem solving, cognitive reframing, stress management

REACH Hope

Hope Box App

- » Remind Me – photos, videos, messages, music
- » Distract Me – games, puzzles
- » Inspire Me – quotes
- » Relax Me – breathing, relaxation, guided meditation
- » Coping Tools – coping cards, positive activity planner
- » Support Contacts – user-selected contacts





Project Description



Aim

Modify/refine the REACH Hope intervention and caregiver materials for caregivers of Veterans with TBI and AD/MD, in conjunction with subject matter experts (SMEs).

Aim

Compare efficacy of REACH Hope in improving burden, depression, anxiety and caregiving self-efficacy for caregivers of Veterans with TBI and AD/MD to a waitlist control.

Aim

Compare efficacy of REACH Hope in improving safety for Veterans with TBI and AD/MD whose caregivers have participated in REACH Hope to a waitlist control.

Primary Hypothesis

Caregivers of Veterans with TBI and dementia who participate in REACH Hope, compared to a waitlist control, will show reduced burden.

Secondary Hypothesis

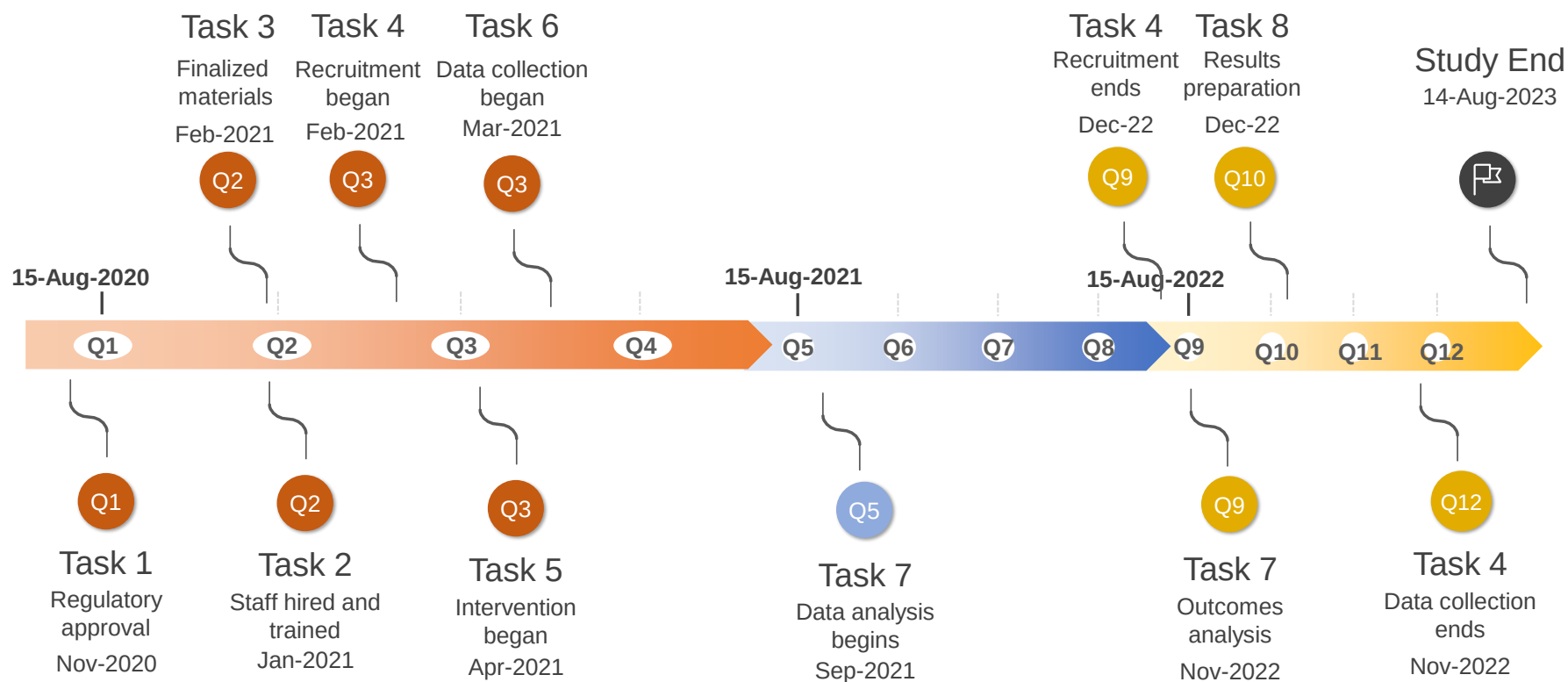
Veterans with TBI and dementia whose caregivers participate in REACH Hope, compared to a waitlist control, will show an improvement in reported safety risks.

Secondary Hypothesis

Caregivers of Veterans with TBI and dementia who participate in REACH Hope, compared to a waitlist control, will show an improvement in depression, anxiety, and caregiving self-efficacy.



Study Timeline/Milestones

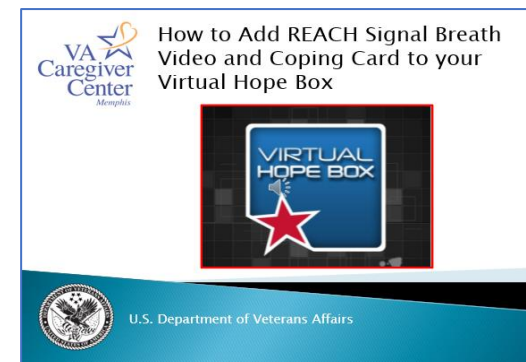




Successes to Date



- » **REACH Hope Caregiver Notebook** – an easy-to-use resource with 28 short chapters on managing behaviors and 16 chapters on reducing stress and burden
- » **Hope Box Users Guide** – screen shots and detailed descriptions for installation and use
- » **Twelve REACH Hope YouTube videos** – that caregivers can download into their personalized Hope Box app (e.g., stretching, problem solving)
<https://www.youtube.com/channel/UCT01GHg08qma66gZKYdOuCQ/videos>
- » **Databases** to track study activities – recruitment, data collection, and intervention
- » **Recruitment** on target ($n = 29$)





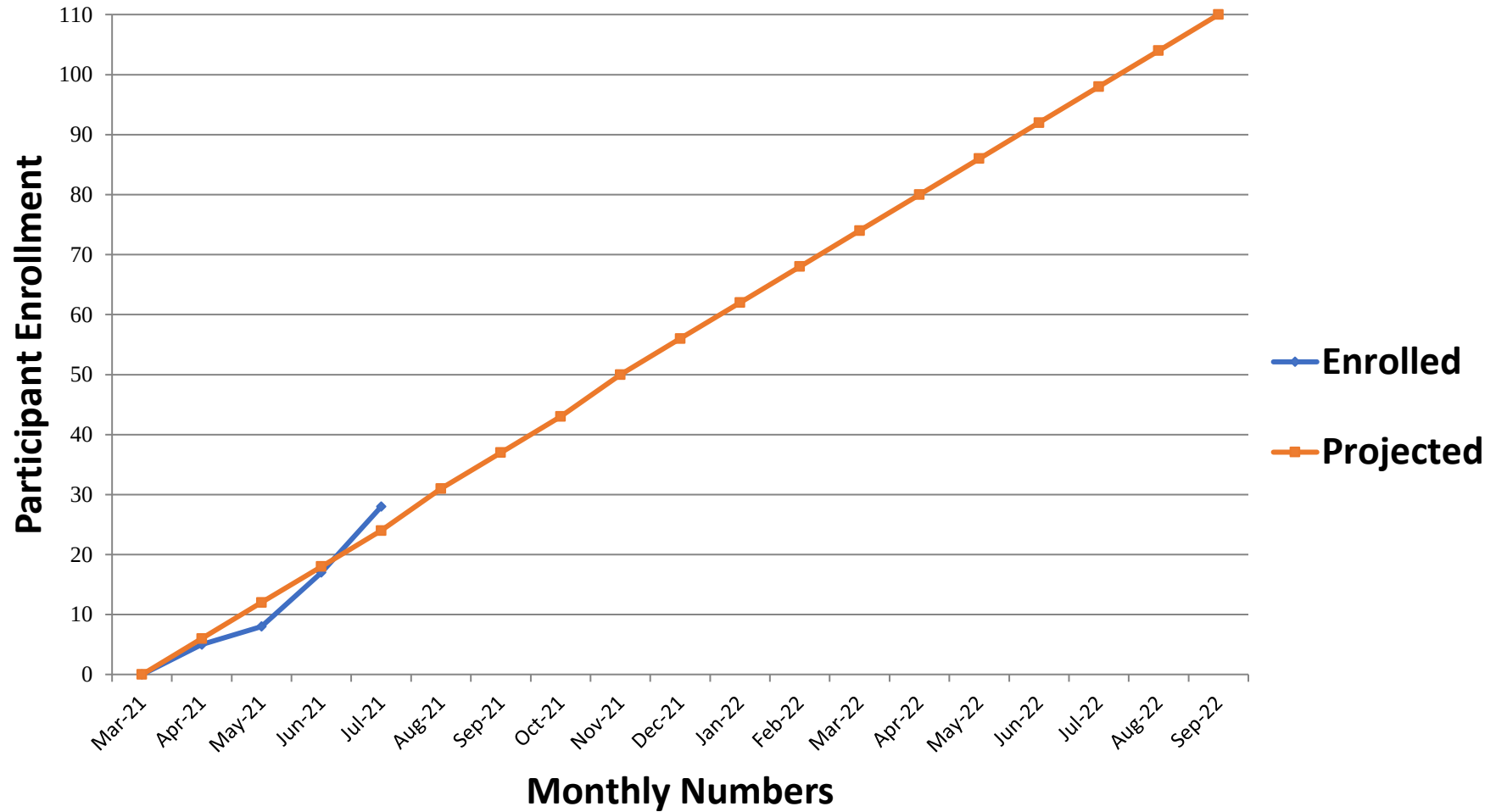
Challenges



- » **Problem:** Delay in hiring data analyst at Virginia Commonwealth University
 - » **Solution**
 - » Hired data consultant at Memphis who developed data bases
- » **Problem:** Caregiver difficulty downloading Hope Box app (19% have had a problem)
 - » **Solutions:**
 - » Developed detailed screen-shot instructions and four short YouTube videos to walk caregiver through process
 - » Discuss downloading app and assist during introduction and randomization call
 - » If caregiver continues having difficulty, ask-caregiver if they have someone to help them with downloading app



Recruitment





What's Next



During next project year, 15-Aug-21 through 14-Aug-22

- » Continue recruitment
- » Continue to provide intervention
- » Continue to collect data
- » Continue treatment fidelity checks, interventionist coaching, and data quality control

Future directions

- » Submission of grant to Department of Defense Traumatic Brain Injury and Psychological Health Research Program (TBIPHRP) – all 5 VA Polytrauma TBI Model Systems – Richmond, Minneapolis, Palo Alto, Tampa, and San Antonio, as well as Caregiver Support Program's Caregiver Center at Memphis



Possible DoD Applications



- » **Inclusion of REACH Hope as a virtual, personalized, evidence-based caregiver intervention for the VA:**
 - » Can be delivered by interventionists from the Caregiver Center and individual VAMC facilities
 - » Training materials for interventionists
 - » Interventionist manual and caregiver notebook to serve as intervention resources
 - » Hope Box app for caregivers to access and store personalized resources
 - » On-going update of user manuals and Hope Box app with new resources and materials
 - » Ongoing coaching support for interventionists through Caregiver Center
 - » Dissemination on Administration for Community Living evidence-based practice guidelines



» Preliminary

- » The REACH Hope virtual, personalized intervention can be successfully delivered to caregivers across many parts of the U.S. based on successful initiation and completion of caregiver intervention participants
- » Most caregivers (81%) appear able to access and use the Hope Box app successfully with reasonable assistance
- » We are slightly ahead of our projected recruitment goals, reflecting/validating the need for the intervention
- » Low study drop out rates and positive qualitative feedback from participants suggest that REACH Hope has potential as an effective, post-TBI dementia, caregiver intervention



Project Funding



	Current Budget	Expended Funds*	%
Current project year – 8/15/20-8/14/21			64%
All project years – 8/15/20-8/14/23			18.7%

*Last month (7/15/20-8/14/20) expenditures estimated



Summary of Key Findings



Study Highlights During First Project Year

- » Obtained regulatory approval
- » Hired and trained staff
- » Developed study protocol and Manual of Operations
- » Developed REACH Hope Coaches Manual and Caregiver Notebook
- » Developed detailed Hope Box installation and use guide
- » Developed videos for inclusion in Hope Box app
- » Began recruitment, which is on target
- » Developed access data bases for recruitment, data collection, and intervention
- » Began baseline and three-month data collection
- » Began intervention delivery

REACH Hope
BASELINE INTERVIEW (BL), Version 6

Completion Log		
	Person	Date
Data collected		___ ___/___ ___/___ ___
Data entered		___ ___/___ ___/___ ___
System ID		
Data verified and cleaned		___ ___/___ ___/___ ___
Subject ID		

BASELINE INTERVIEWIntroduction

Hello, my name is _____ from the Memphis VA Medical Center. It is time to complete your baseline interview. This interview will take about 30 to 45 minutes. Do you have time to complete the interview now?

() Yes () No

If no: When would be a better time for me to call you back?

Date: _____ Time: _____

If yes: I mailed you a response card that contains the answer choices for today's interview. Please get it out at this time.

Baseline Battery Table of Contents

Form Name	Form Abbreviation	Page
Introduction		4
Risk Assessment	RA	4
Activities of Daily Living/Instrumental Activities of Daily Living	AL	10
Health Conditions	HC	11
Health and Health Services Use	HS	12
Family Needs Questionnaire (FNQ)	FN	13
Financial Strain	FI	15
Zarit Burden Interview (ZBI-12)	ZB	16
Generalized Anxiety Disorder (GAD-7)	GA	17
Patient Health Questionnaire (PHQ-9)	PH	18
Caregiving Self-Efficacy, Revised	SE	19
Participant Sociodemographics	SO	22

Please Use This Form To Record The Amount Of Time Spent Doing The Interview

1. Date of form completion: ____/____/____
month day year

2. Interviewer's name: _____
Last, First

3. During which visit is this interview taking place?

- 1 () Baseline
2 () 3 month interview
3 () 6 month interview
4 () 9 month interview

4. Was the interview completed in one visit? 0 () No 1 () Yes

5. Interview date: ____/____/____
month day year

6. Start time (military time): ____:____
hours minutes

7. End time (military time): ____:____
hours minutes

For reporting Alert only:

8. Were any of the following alerts reported during the interview?

0 () No	1 () Yes	Caregiver PHQ-9 depression score greater than or equal to 15
0 () No	1 () Yes	Caregiver suicidal ideation or thoughts of harming self (#9 on PHQ-9)
0 () No	1 () Yes	Caregiver concern regarding Care Recipient access to gun
0 () No	1 () Yes	Caregiver concern regarding Care Recipient driving
0 () No	1 () Yes	Caregiver concern regarding Care Recipient aggression/violence
0 () No	1 () Yes	Caregiver concern regarding Care Recipient harming self

BASELINE INTERVIEW SCRIPT

Thank you for participating in the REACH Hope Project. The following questions will help us learn more about how to help people like yourself who are caring for someone with both dementia and TBI. The questions that I will ask take about an hour. There are no right or wrong answers; we are interested in your opinions and feelings. If you do not understand a question, please feel free to ask me to repeat or clarify, and if you would like to take a break at any time during the session, just let me know.

As a reminder, all of the information that you give me will be kept strictly confidential, and no information that could identify you will be available to anyone outside the study.

RISK ASSESSMENT (RA)

Please answer the following questions about your caregiving situations.

SAFETY

1. Can your loved one get to dangerous objects (e.g., gun, knife or other sharp objects)? 0 () No 1 () Yes
 - 1.1 If yes, is it a gun? 0 () No 1 () Yes ⚠️
2. (RC 1) Does your loved one drive? 0 () Never 1 () Sometimes ⚠️ 2 () Often ⚠️
3. Can your loved one respond to emergency situations? 0 () No 1 () Yes
4. (RC 1) Does your loved one try to leave the home and wander outside? 0 () Never 1 () Sometimes 2 () Often
5. Are there any safety concerns with your loved one smoking? 0 () No 1 () Yes
6. (RC 1) Are there any concerns about your loved one engaging in aggression or violence toward you or others or property? 0 () Never 1 () Sometimes ⚠️ 2 () Often ⚠️
7. Are there any concerns about your loved one harming self? 0 () No 1 () Yes ⚠️

HEALTH/PHYSICAL WELL-BEING

8. In the past month, have you lost or gained weight without meaning to? 0 () No 1 () Yes
9. In the past 3 months, have you missed any scheduled doctor's appointments? 0 () No 1 () Yes

10. In the past 3 months, have you experienced any alcohol or drug problems? 0 () No 1 () **Yes**
11. (RC 1) Have you cut back on your physical activities, like exercise and walking, because of caregiving? 0 () Never 1 () **Sometimes** 2 () **Often**
12. (RC 1) Do you miss taking your prescription medication on a regular basis? 0 () Never 1 () **Sometimes** 2 () **Often**
13. (RC 1) How often do you get a good night's sleep? 0 () **Never** 1 () **Sometimes** 2 () **Often**
14. (RC 1) Is providing support for your loved one negatively affecting your physical health in any way? 0 () Never 1 () **Sometimes** 2 () **Often**
15. (RC 2) In general, would you say your health is: Excellent Very Good Good Fair **Poor**
4 () 3 () 2 () 1 () 0 ()

SOCIAL AND EMOTIONAL SUPPORT

16. If you were unable to care for your loved one or yourself, do you have someone who would take over? 0 () **No** 1 () **Yes**
17. (RC 3) Overall, how satisfied have you been in the past month with the support you have received from family members, friends, or neighbors? 0 () **Not at all** 1 () **A Little** 2 () **Very**
18. (RC 1) Do you feel guilty about not providing good enough support to your loved one? 0 () Never 1 () **Sometimes** 2 () **Often**
19. (RC 1) Does your loved one appreciate your assistance? 0 () **Never** 1 () **Sometimes** 2 () **Often**
20. (RC 1) Does your loved one expect more than you can or are willing to do? 0 () Never 1 () **Sometimes** 2 () **Often**
21. (RC 1) Do you feel you and your loved one are able to communicate your needs openly and without conflict? 0 () **Never** 1 () **Sometimes** 2 () **Often**

CAREGIVER FRUSTRATIONS AND VIGILANCE

22. (RC 1) Is it hard or stressful for you to find resources to help or assist with your caregiving needs? 0 () Never 1 () **Sometimes** 2 () **Often**
23. (RC 1) Is it hard for you to get helpful information from your loved one's doctor or nurse? 0 () Never 1 () **Sometimes** 2 () **Often**
24. (RC 1) How often in the past three months, have you felt like screaming or yelling at your loved one because of the way he/she behaved? 0 () Never 1 () **Sometimes** 2 () **Often**
25. (RC 1) How often in the past month, have you had to keep from hitting or slapping your loved one because of the way he/she behaved? 0 () Never 1 () **Sometimes** 2 () **Often**

26. (RC 1) How often in the past three months have you cut back or avoided participating in joint activities with your loved one that you previously enjoyed? 0 () Never 1 () **Sometimes** 2 () **Often**
27. (RC 1) Within the past month, have you at any time...
- 27.1 Felt overwhelmed? 0 () Never 1 () **Sometimes** 2 () **Often**
- 27.2 Felt like you needed to cry? 0 () Never 1 () **Sometimes** 2 () **Often**
- 27.3 Been frustrated as a result of your caregiving? 0 () Never 1 () **Sometimes** 2 () **Often**
- 27.4 Felt cut off from your family/friends? 0 () Never 1 () **Sometimes** 2 () **Often**
- 27.5 Felt lonely or alone? 0 () Never 1 () **Sometimes** 2 () **Often**
28. On a scale of 1 to 10, with 1 being “not stressed” to 10 being “extremely stressed,” please rate your current level of stress. — —
29. About how many hours a day do you feel the need to "be there" or "on duty" to care for your loved one? [**24 hours acceptable**] — — hours
30. About how many hours a day do you estimate that you are actually doing things for your loved one? [**Subtract sleeping & other activity hours from 24 if Caregiver has difficulty**] — — hours

(RC 4) PROBLEMS/CONCERNS - The following is a list of problems individuals with TBI and dementia sometimes have. Please indicate if [CR] has had any of these problems during the past month. If Caregiver answers yes; then ask about Distress.

If Caregiver answers yes; also ask about caregiver distress.	Has it occurred? (in past month)		(If <u>yes</u>), Rate the DISTRESS you experience due to that symptom (how it affects <u>you</u> on a scale from 0 to 5 with 0 being not at all distressing and 5 being very severe/ extremely distressing)					
	NO	YES	Not at all	Minimal	Mild	Moderate	Severe	Very Severe
1. Have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
2. Hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3. Resistive to help from others at times, or hard to handle?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
4. Seem sad or say that he /she is depressed?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
5. Become upset when separated from you? have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
6. Appear to feel too good or act excessively happy?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
7. Seem less interested in his/her usual activities or in the activities and plans of others?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
8. Seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
9. Impatient and cranky? having difficulty coping with delays or waiting for planned activities?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
10. Engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

If Caregiver answers yes; also ask about caregiver distress.	Has it occurred? (in past month)		(If yes), Rate the DISTRESS you experience due to that symptom (how it affects <u>you</u> on a scale from 0 to 5 with 0 being not at all distressing and 5 being very severe/ extremely distressing)						
	NO	YES	Not at all	Minimal	Mild	Moderate	Severe	Very Severe	
11. Awaken you during the night, rise too early in the morning, or take excessive naps during the day?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
12. Lost or gained weight, or had a change in the type of food he/she likes?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
13. Have problems with bathing or refusing to bathe	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
14. Aggressive to others verbally	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
15. Trouble remembering recent events (e.g., items in newspaper or TV)	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
16. Trouble remembering significant past events	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
17. Lose or misplace things	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
18. Start, but not finish, things	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
19. Difficulty concentrating on a task	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
20. Have problems with dressing or refusing to get dressed	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
21. Accidents of the bowel or bladder	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
22. Ask the same question over and over	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
23. Inappropriate sexual behavior	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
24. Misuse alcohol or other substances	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
25. Get upset when friends or family visit	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
26. Difficulty communicating (forgetting/misusing words)	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
27. Wandering outside the home	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	
28. Disorientation/confusion about surroundings (e.g., thinking they are not home when they are, inability to recognize family in home)	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	

Questions 1-12 are the Neuropsychiatric Inventory (NPI). (© JL Cummings, 1994, all rights reserved; permission for commercial use required; npitest.net)

**ACTIVITIES OF DAILY LIVING/
INSTRUMENTAL ACTIVITIES OF DAILY LIVING (AL)**

Now, I will ask about tasks (CR) needs to perform in daily life and whether you help with any of these tasks.

Do you help (CR) with...?

ADLs

	No	Yes
1. Bathing	0 ☐	1 ☐
2. Dressing	0 ☐	1 ☐
3. Grooming	0 ☐	1 ☐
4. Toileting	0 ☐	1 ☐
5. Transferring in/out of bed, chair, wheelchair	0 ☐	1 ☐
6. Eating	0 ☐	1 ☐

IADLs

7. Shopping	0 ☐	1 ☐
8. Cooking	0 ☐	1 ☐
9. Managing medications	0 ☐	1 ☐
10. Doing housework	0 ☐	1 ☐
11. Doing laundry	0 ☐	1 ☐
12. Driving or using public transportation	0 ☐	1 ☐
13. Managing finances	0 ☐	1 ☐
14. Using the phone	0 ☐	1 ☐

HEALTH CONDITIONS (HC)

(RC 5) These are some questions about conditions that you and/or [CR] might have.

Has a doctor or other health professional ever told either of you that you have...*If yes, who has condition?*

	No	Yes	CG	CR	Both
1. hypertension or high blood pressure?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
2. congestive heart failure?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
3. a myocardial infarction or heart attack?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
4. heart arrhythmias?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
5. a stroke?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
6. emphysema or asthma or COPD?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
7. high blood cholesterol?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
8. diabetes, high blood sugar, or sugar in the urine?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
9. pneumonia?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
10. liver disease (such as hepatitis)?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
11. rheumatoid arthritis?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
12. osteoarthritis?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
13. sleep disorder like sleep apnea?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
14. cataracts?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
15. chronic pain?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
16. Parkinson's disease?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
17. alcoholism?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
18. drug addiction?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
19. depression?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
20. anxiety?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
21. panic attacks?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
22. bipolar disorder or manic-depression?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
23. attention deficit disorder (ADD)/attention deficit hyperactivity disorder (ADHD)?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
24. obsessive-compulsive disorder?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐
25. PTSD (post-traumatic stress disorder)?	0 ☐	1 ☐	0 ☐	1 ☐	2 ☐

HEALTH AND HEALTH SERVICES USE (HS)

The next questions are about your health and use of health services.

1. (RC 6) Compared with 12 months ago, would you say your health is better, worse, or about the same?

Better1 ☐**Worse**2 ☐**About the same**3 ☐*Unknown*-3 ☐*Refused*-4 ☐

During the past 3 months, have you seen or talked to any of the following health care providers about your own health?

2. ...A mental health professional such as a psychiatrist, psychologist, psychiatric nurse, or clinical social worker.

No0 ☐**Yes**1 ☐*Unknown*-3 ☐*Refused*-4 ☐

3. ...A medical doctor or nurse practitioner or physician assistant.

No0 ☐**Yes**1 ☐*Unknown*-3 ☐*Refused*-4 ☐

4. **During the past 3 months, how many times have you been to the hospital emergency room for your health? Number** _____

5. **During the past 3 months, how many times have you been admitted to the hospital for your health? Number** _____

5.1. How many days were you in the hospital? _____ days

6. **During the past 3 months, how many times has (CR) been to the hospital emergency room for his/her health? Number** _____

7. **During the past 3 months, how many times has (CR) been admitted to the hospital for his/her health? Number** _____

7.1. How many days was (CR) in the hospital? _____ days

8. **About how long has it been since you last saw or talked to a doctor or other health care professional about your own health? Include doctors seen while a patient in a hospital.**

_____ months

9. In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition? _____
10. In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition? _____

FAMILY NEEDS QUESTIONNAIRE (FN)

(RC 7) The following is a list of needs families sometimes have. Please indicate if this need has been met for your family. Answer N/A (Not applicable) if your family has not had this need.

Has the need...	...been met?	Yes	Partly	No	N/A
1. ...to be shown that medical, educational or rehabilitation staff respect the patient's needs or wishes...	1 ☐	2 ☐	3 ☐	-2 ☐	
2. to be told daily what is being done with or for the patient	1 ☐	2 ☐	3 ☐	-2 ☐	
3. to give my opinions daily to others involved in the patient's care, rehabilitation, or education	1 ☐	2 ☐	3 ☐	-2 ☐	
4. to be told about all changes in the patient's medical status	1 ☐	2 ☐	3 ☐	-2 ☐	
5. to be assured that the best possible medical care is being given to the patient	1 ☐	2 ☐	3 ☐	-2 ☐	
6. to have explanations from professionals given in terms I can understand	1 ☐	2 ☐	3 ☐	-2 ☐	
7. to have my questions answered honestly	1 ☐	2 ☐	3 ☐	-2 ☐	
8. to be shown that my opinions are used in planning the patient's treatment, rehabilitation or education	1 ☐	2 ☐	3 ☐	-2 ☐	
9. to have a professional to turn to for advice or services when the patient needs help	1 ☐	2 ☐	3 ☐	-2 ☐	
10. to have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery)	1 ☐	2 ☐	3 ☐	-2 ☐	
11. to have complete information on the patient's physical problems (e.g., weakness, headaches, dizziness, problems with vision or walking)	1 ☐	2 ☐	3 ☐	-2 ☐	
12. to have complete information on the patient's problems in thinking (e.g., confusion, memory, or communication)	1 ☐	2 ☐	3 ☐	-2 ☐	
13. to have complete information on drug or alcohol problems and treatment	1 ☐	2 ☐	3 ☐	-2 ☐	
14. to be told how long each of the patient's problems is expected to last	1 ☐	2 ☐	3 ☐	-2 ☐	
15. to be shown what to do when the patient is upset or acting strange	1 ☐	2 ☐	3 ☐	-2 ☐	
16. to have information on the patient's rehabilitative or educational progress	1 ☐	2 ☐	3 ☐	-2 ☐	
17. to have help in deciding how much to let the patient do by himself/herself	1 ☐	2 ☐	3 ☐	-2 ☐	
18. to have enough resources for the patient (e.g., rehabilitation programs, physical therapy, counseling, job counseling)	1 ☐	2 ☐	3 ☐	-2 ☐	

Has the need...	...been met?	Yes	Partly	No	N/A
19. to have enough resources for myself or the family (e.g., financial or legal counseling, respite care, counseling, nursing or day care)	1 ☐	2 ☐	3 ☐	-2 ☐	
20. to have help keeping the house (e.g., shopping, cleaning, cooking, etc.)	1 ☐	2 ☐	3 ☐	-2 ☐	
21. to have help from other members of the family in taking care of the patient	1 ☐	2 ☐	3 ☐	-2 ☐	
22. to get enough rest or sleep	1 ☐	2 ☐	3 ☐	-2 ☐	
23. to get a break from my problems and responsibilities	1 ☐	2 ☐	3 ☐	-2 ☐	
24. to spend time with my friends	1 ☐	2 ☐	3 ☐	-2 ☐	
25. to pay attention to my own needs, job or interests	1 ☐	2 ☐	3 ☐	-2 ☐	
26. to have my significant other understand how difficult it is for me	1 ☐	2 ☐	3 ☐	-2 ☐	
27. to have my partner or friends understand how difficult it is for me.	1 ☐	2 ☐	3 ☐	-2 ☐	
28. to have other family members understand the patient's problems	1 ☐	2 ☐	3 ☐	-2 ☐	
29. to have the patient's friends understand his/her problems	1 ☐	2 ☐	3 ☐	-2 ☐	
30. to have the patient's employer, coworkers or teachers understand his/her problems	1 ☐	2 ☐	3 ☐	-2 ☐	
31. to discuss my feelings about the patient with someone who has gone through the same experience	1 ☐	2 ☐	3 ☐	-2 ☐	
32. to discuss my feelings about the patient with other friends or family	1 ☐	2 ☐	3 ☐	-2 ☐	
33. to be reassured that it is usual to have strong negative feelings about the patient	1 ☐	2 ☐	3 ☐	-2 ☐	
34. help getting over my doubts and fears about the future	1 ☐	2 ☐	3 ☐	-2 ☐	
35. help in remaining hopeful about the patient's future	1 ☐	2 ☐	3 ☐	-2 ☐	
36. help preparing for the worst	1 ☐	2 ☐	3 ☐	-2 ☐	
37. to be encouraged to ask others to help out	1 ☐	2 ☐	3 ☐	-2 ☐	

FINANCIAL STRAIN (FI)

1. (RC 8) How much of a financial strain would you say that caring for your loved one is on a scale from 1 to 5 with 1 being Not a strain at all and 5 being Very much a strain?

Not a strain at all

Very much a strain

1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
----------------------------	----------------------------	----------------------------	----------------------------	----------------------------

2. How much do you estimate you spend out of pocket per month for your loved one's care? Include medical/dental/vision expenses, household expenses, personal care items expenses, education, legal, travel, and other expenses, caregiver personal expenses/respite (aides, help, etc.) _____

Have you had to do any of the following as a result of caregiving?

	No	Yes
3. Dip into your personal savings to cover expenses	0 ☐	1 ☐
4. Dip into your retirement savings to cover expenses	0 ☐	1 ☐
5. Reduce how much you save for retirement	0 ☐	1 ☐
6. Take out a loan, borrow from a friend or family member or assume other debts to cover expenses	0 ☐	1 ☐
7. Cut back on personal spending to cover expenses, such as trips, your children's education	0 ☐	1 ☐
8. Cut back on spending for your own health care, such as going to the doctor or buying medicine	0 ☐	1 ☐

ZARIT BURDEN INTERVIEW (ZB)

(RC 9) Please choose the response that best describes how you feel currently.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
DO YOU FEEL...					
★ 1. that because of the time you spend with (CR) that you don't have enough time for yourself?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
★ 2. stressed between caring for (CR) and trying to meet other responsibilities (work/family)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
3. angry when you are around (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
4. that (CR) currently affects your relationship with family members or friends in a negative way?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
★ 5. strained when you are around (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
6. that your health has suffered because of your involvement with (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
7. that you don't have as much privacy as you would like because of (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
8. that your social life has suffered because you are caring for (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
9. that you have lost control of your life since (CR's) illness?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
10. uncertain about what to do about (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
★ 11. you should be doing more for (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
12. you could do a better job in caring for (CR)?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

★ = items for Program Coach to note

GAD-7 (GA)

(RC 10) Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
★ 1. Feeling nervous, anxious or on edge	0 ☐	1 ☐	2 ☐	3 ☐
★ 2. Not being able to stop or control worrying	0 ☐	1 ☐	2 ☐	3 ☐
3. Worrying too much about different things	0 ☐	1 ☐	2 ☐	3 ☐
4. Trouble relaxing	0 ☐	1 ☐	2 ☐	3 ☐
5. Being so restless that it is hard to sit still	0 ☐	1 ☐	2 ☐	3 ☐
6. Becoming easily annoyed or irritable	0 ☐	1 ☐	2 ☐	3 ☐
7. Feeling afraid as if something awful might happen	0 ☐	1 ☐	2 ☐	3 ☐

★ = items for Program Coach to note

PHQ-9 (PH)

(RC 10) Over the last 2 weeks, how often have you been bothered by the following

	Not at all	Several days	More than half the days	Nearly every day
★ 1. Little interest or pleasure in doing things	0 ☐	1 ☐	2 ☐	3 ☐
★ 2. Feeling down, depressed, or hopeless	0 ☐	1 ☐	2 ☐	3 ☐
3. Trouble falling or staying asleep, or sleeping too much	0 ☐	1 ☐	2 ☐	3 ☐
4. Feeling tired or having little energy	0 ☐	1 ☐	2 ☐	3 ☐
5. Poor appetite or overeating	0 ☐	1 ☐	2 ☐	3 ☐
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0 ☐	1 ☐	2 ☐	3 ☐
7. Trouble concentrating on things, such as reading the newspaper or watching television	0 ☐	1 ☐	2 ☐	3 ☐
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0 ☐	1 ☐	2 ☐	3 ☐
9. Thoughts that you would be better off dead, or of hurting yourself in some way problems?	0 ☐	1 ☐	2 ☐	3 ☐

★ = items for Program Coach to note

Add columns: _____ + _____ + _____

Total: _____ 
(cumulative total of all columns)

10. Is the score of the PHQ-9 ≥ 15 ? No 0 () Yes 1 () 

11. Is the answer to #9 anything other than Not at all? No 0 () Yes 1 () 



If a Caregiver reports “nearly every day” for “Thoughts that you would be better off dead, or of hurting yourself in some way” and the interviewer feels that the Caregiver is in immediate danger, the interviewer will stop the interview at that question and start the Suicide Caller protocol (Yellow Suicide Card). Interviewer should have a Yellow Suicide Caller Card (see example in VOL III/4) in his/her office.

If interviewer feels that the Caregiver is NOT in immediate danger, the interviewer can finish the interview and notify the data manager that the Caregiver needs to be given immediately to a Program Coach.

CAREGIVING SELF-EFFICACY (SE)

(RC 11) Please think about each one and tell me how confident you are that you could do each item. Rate your degree of confidence from 0 to 100 where a 0% confidence means that you cannot do it at all, a 50% confidence means that if you gave it your best effort, chances are about 50-50 that you could perform the activity, and a 100% confidence means you are certain you can do it. You can use any score between 0 and 100 (10, 20, 30, etc.) to express your confidence.

Self-Efficacy for Obtaining Respite

How confident are you
that you can ask a
friend/family member
to...

	Cannot do at all				Moderately certain can do				Certain can do			
	0	10	20	30	40	50	60	70	80	90	100	
1. stay with [CR] for a day when you need to see the doctor yourself?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
2. stay with [CR] for a day when you have errands to be done?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
3. do errands for you?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
4. stay with [CR] for a day when you feel the need for a break?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
5. stay with [CR] for a week when you need the time for yourself?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

Self-Efficacy for Responding to Disruptive Patient Behaviors

	Cannot do at all				Moderately certain can do				Certain can do			
	0	10	20	30	40	50	60	70	80	90	100	
6. When [CR] forgets your daily routine and asks when lunch is right after you've eaten, how confident are you that you can answer him/her without raising your voice? (Clarify that "answer" can be direct or a distraction.)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
7. When you get angry because [CR] repeats the same question over and over, how confident are you that you can say things to yourself that calm you down?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
8. When [CR] complains to you about how you're treating him/her, how confident are you that you can respond without arguing back? (e.g., reassure or distract him/her?)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
9. When [CR] asks you 4 times in the first one hour after lunch when lunch is, how confident are you that you can answer him/her without raising your voice?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	
10. When [CR] interrupts you for the fourth time while you're making dinner, how confident are you that you can respond without raising your voice?	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	

Self-Efficacy for Controlling Upsetting Thoughts about Caregiving

All caregivers sometimes have negative thoughts about their situation. Some thoughts may be brief and easy to get rid of. Other times, thoughts may be hard to put out of your mind, just like a silly tune is sometimes hard to get out of your mind. We would like to know how well you can turn off any of the following thoughts. Use the same confidence rating. Don't be concerned about how often the thoughts come up. We want you to rank your confidence that you can turn off or get rid of each type of thought when it does come up." (Administrator: When caregivers state that they have absolutely never had the thoughts in one of the items, put "N/A" (not applicable) on the line for rating confidence.)

How confident are you
that you can control...

	Cannot do at all				Moderately certain can do				Certain can do			
11. thinking about unpleasant aspects of taking care of [CR]?	0 ☐	10 ☐	20 ☐	30 ☐	40 ☐	50 ☐	60 ☐	70 ☐	80 ☐	90 ☐	100 ☐	
12. thinking how unfair it is that you have to put up with this situation (taking care of [CR]?	0 ☐	10 ☐	20 ☐	30 ☐	40 ☐	50 ☐	60 ☐	70 ☐	80 ☐	90 ☐	100 ☐	
13. thinking about what a good life you had before [CR]'s illness and how much you've lost?	0 ☐	10 ☐	20 ☐	30 ☐	40 ☐	50 ☐	60 ☐	70 ☐	80 ☐	90 ☐	100 ☐	
14. thinking about what you are missing or giving up because of [CR]?	0 ☐	10 ☐	20 ☐	30 ☐	40 ☐	50 ☐	60 ☐	70 ☐	80 ☐	90 ☐	100 ☐	
15. worrying about future problems that might come up with [CR]?	0 ☐	10 ☐	20 ☐	30 ☐	40 ☐	50 ☐	60 ☐	70 ☐	80 ☐	90 ☐	100 ☐	

SOCIODEMOGRAPHIC QUESTIONS (SO)

Finally, some general information about you and your loved one.

1. Sex of the CR: 1 ☐ Male 2 ☐ Female 3 ☐ Other Specify _____

2. Is CR's primary ethnic group Latino/Hispanic?

No
0 ☐

Yes
1 ☐

Unknown
-3 ☐

Refused
-4 ☐

3. What is CR's racial group?

- 1 ☐ White/Caucasian
- 2 ☐ Black/African American
- 3 ☐ American Indian/Alaska Native
- 4 ☐ Asian
- 5 ☐ Native Hawaiian/Pacific Islander
- 6 ☐ More than one race
- 7 ☐ Other

3.1 If "More than one race" or "Other," specify race(s): _____

4. What is CR's age? _____

5. How many years did CR serve in the military? _____

6. Which branch of the military did CR serve?

- 1 () Army
- 2 () Navy
- 3 () Air Force
- 4 () Marines
- 5 () Coast Guard

7. Did CR receive a medical discharge from the military?

No
0 ☐

Yes
1 ☐

Unknown
-3 ☐

Refused
-4 ☐

8. (RC 12) What level of education did CR complete?

0 () No formal education	9 () Grade 9
1 () Grade 1	10 () Grade 10
2 () Grade 2	11 () Grade 11
3 () Grade 3	12 () Grade 12/High School Diploma/GED
4 () Grade 4	13 () Vocational/training school after high school
5 () Grade 5	14 () Some college/associate degree
6 () Grade 6	15 () College graduate (4 or 5 year program)
7 () Grade 7	16 () Master's degree (or other post-graduate training)
8 () Grade 8	17 () Doctoral degree (PhD, MD, EdD, DVM, DDS, JD etc)

9. (RC 12) What level of education did you complete?

0 () No formal education	9 () Grade 9
1 () Grade 1	10 () Grade 10
2 () Grade 2	11 () Grade 11
3 () Grade 3	12 () Grade 12/High School Diploma/GED
4 () Grade 4	13 () Vocational/training school after high school
5 () Grade 5	14 () Some college/associate degree
6 () Grade 6	15 () College graduate (4 or 5 year program)
7 () Grade 7	16 () Master's degree (or other post-graduate training)
8 () Grade 8	17 () Doctoral degree (PhD, MD, EdD, DVM, DDS, JD etc)

10. What is your relationship to (CR)? i.e., the CG is CR's _____

- | | |
|-----------------------|------------------------------|
| 1 () Wife | 10 () Husband |
| 2 () Daughter | 11 () Son |
| 3 () Daughter-in-law | 12 () Son-in-law |
| 4 () Sister | 13 () Brother |
| 5 () Niece | 14 () Nephew |
| 6 () Granddaughter | 15 () Grandson |
| 7 () Step daughter | 16 () Step son |
| 8 () Mother | 17 () Father |
| 9 () Partner | 18 () Other, specify: _____ |

11. (RC 13) What is your current marital status?

- 1 () Married
 2 () Single
 3 () Divorced
 4 () Separated
 5 () Widowed
 6 () Single, living as married
 7 () Other: _____

12. (RC 13) What is CR's current marital status?

- 1 () Married
- 2 () Single
- 3 () Divorced
- 4 () Separated
- 5 () Widowed
- 6 () Single, living as married
- 7 () Other: _____

13. Does CR live with you?

- | | | | |
|----------------------------|----------------------------|-----------------------------|-----------------------------|
| No | Yes | <i>Unknown</i> | <i>Refused</i> |
| 0 ☐ | 1 ☐ | -3 ☐ | -4 ☐ |

13.1 If no, where does CR live (with friends, by self, with spouse, facility, etc)?

14. (RC 14) What is your current employment status?

- 1 () Employed at a job for pay, full-time
- 2 () Employed at a job for pay, part-time
- 3 () Homemaker, not currently working for pay
- 4 () Not currently employed, retired
- 5 () Not currently employed, not retired
- 6 () Not currently employed, disabled

15. (RC 14) What is CR's current employment status?

- 1 () Employed at a job for pay, full-time
- 2 () Employed at a job for pay, part-time
- 3 () Homemaker, not currently working for pay
- 4 () Not currently employed, retired
- 5 () Not currently employed, not retired
- 6 () Not currently employed, disabled

16. What is your current monthly household income before taxes? _____

17. (RC 15) How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:

- | | | | |
|---------------------------------|-------------------------------|-------------------------------|----------------------------|
| Not at all
Difficult | Not Very
Difficult | Somewhat
Difficult | Very
Difficult |
| 0 ☐ | 1 ☐ | 2 ☐ | 3 ☐ |

18. Are you receiving services as part of the VA's Family Caregivers program (stipend, home visit)?

No	Yes	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	-3 ☐	-4 ☐

18.1 *If yes*, in the last 6 months, has the amount...

Increased	Stayed Same	Decreased	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	2 ☐	-3 ☐	-4 ☐

19. Do you have any injuries/conditions that make it difficult to care for your loved one?

No	Yes	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	-3 ☐	-4 ☐

20. (RC 16) At what point did you begin providing care for your loved one?

- 1 () As soon as your loved one returned injured
- 2 () When your loved one could no longer care for him/herself
- 3 () When a previous Caregiver could no longer care for your loved one
- 4 () Other: _____

21. Would you like to know the results of this research once the study has finished?

No	Yes	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	-3 ☐	-4 ☐

21.1 *If yes*, how would you like to be contacted?

☐ Email ☐ Postal Mail

22. Have you and/or (CR) tested positive for COVID-19?

No	Yes	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	-3 ☐	-4 ☐

22.1 *If yes*, who tested positive?

CG	CR	Both	<i>Unknown</i>	<i>Refused</i>
0 ☐	1 ☐	2 ☐	-3 ☐	-4 ☐

23. Has the COVID-19 pandemic caused you any challenges for your caregiving?