

Home- and Community-Based Service Use and Preferences among Post-9/11 Veterans With or at High Risk of Alzheimer's Disease and Related Dementia and their Caregivers: Protocol for a Mixed Methods Observational Study

Erin D. Bouldin, Amanda Cheney, Mary Jo Pugh, Kayla Morales, Roxana E. Delgado

Submitted to: JMIR Research Protocols
on: September 05, 2025

Disclaimer: © The authors. All rights reserved. This is a privileged document currently under peer-review/community review. Authors have provided JMIR Publications with an exclusive license to publish this preprint on its website for review purposes only. While the final peer-reviewed paper may be licensed under a CC BY license on publication, at this stage authors and publisher expressly prohibit redistribution of this draft paper other than for review purposes.

Table of Contents

Original Manuscript..... 5

Supplementary Files..... 23

 Figures 24

 Figure 1..... 25

 Figure 2..... 26

Home- and Community-Based Service Use and Preferences among Post-9/11 Veterans With or at High Risk of Alzheimer's Disease and Related Dementia and their Caregivers: Protocol for a Mixed Methods Observational Study

Erin D. Bouldin^{1,2} PhD, MPH; Amanda Cheney^{1,2} BS; Mary Jo Pugh^{1,2} PhD, RN; Kayla Morales³ PhD; Roxana E. Delgado³ PhD, MS

¹Informatics, Decision-Enhancement and Analytic Sciences Center Health Systems Research Department of Veterans Affairs Medical Center Salt Lake City US

²Division of Epidemiology Department of Internal Medicine University of Utah Spencer Fox Eccles School of Medicine Salt Lake City US

³Caring for the Caregiver Program School of Nursing UT Health San Antonio San Antonio US

Corresponding Author:

Erin D. Bouldin PhD, MPH
Informatics, Decision-Enhancement and Analytic Sciences Center
Health Systems Research
Department of Veterans Affairs Medical Center
500 Foothill Blvd
Salt Lake City
US

Abstract

Background: Veterans have an increased risk of developing Alzheimer's disease/Alzheimer's disease-related dementia (ADRD) due to military exposures such as traumatic brain injury (TBI). There is a lack of information on home and community-based service (HCBS) use among Veterans who served in the post-9/11 era and their caregivers.

Objective: To (1) quantify HCBS use among post-9/11 Veterans with or at higher risk of ADRD, (2) identify facilitators, barriers, and preferences for HCBS among Veterans and family caregivers, and (3) prioritize HCBS interventions with input from Veterans and family caregivers.

Methods: This study will include post-9/11 Veterans with early-onset Alzheimer's disease or frontotemporal dementia (current ADRD) and Veterans at elevated ADRD risk due to TBI or cognitive dysfunction. Veterans' family caregivers will also be recruited. Secondary data will come from the Department of Veterans Affairs (VA), the Department of Defense (DOD), and a previous neurotrauma study. Using VA data augmented with Centers for Medicare and Medicaid Services data, we will characterize HCBS utilization. We will calculate the cumulative frequency of use (i.e., number of unique service records) and the proportion of Veterans using a service (i.e., any versus no use) among Veterans with ADRD, and those at higher and lower risk for ADRD. We will compare groups using t-tests for continuous measures (number of services) and chi-square tests for categorical measures (any service use) to test whether Veterans with current ADRD have higher HCBS use. We will interview Veterans and caregivers to identify facilitators and barriers to HCBS use. We will use descriptive content analysis including rich descriptions, coding, and theme identification. We will use a modified Delphi approach to identify and rank HCBS modifications that would increase use. Using the ranking data, we will assess consensus on each item's importance. If 70% or more respond "important" or "very important", the consensus will be that the item has high importance. Participants for primary data collection will be recruited from prior studies of TBI, military-Veteran caregiver outcomes, VA health systems data, VA clinics, and Veteran- and caregiver-serving organizations. We intend to recruit a diverse sample across sex, race/ethnicity, and rural residence.

Results: This study was approved by the institutional review boards of the University of Utah, Salt Lake City Veterans Affairs, and UT Health at San Antonio. It was also reviewed by the Human Research Protection Office of the United States Army Medical Research and Development Command. Secondary data use approvals are complete.

Conclusions: This study will quantify current HCBS use and identify barriers and needs of Veterans with or at higher risk of

ADRD and their caregivers. The results will be used to increase the availability and use of acceptable HCBS for post-9/11 Veterans and their caregivers.

(JMIR Preprints 05/09/2025:83629)

DOI: <https://doi.org/10.2196/preprints.83629>

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**

Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.

Only make the preprint title and abstract visible.

No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain visible.

Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <https://preprints.jmir.org/preprint/83629>

No. Please do not make my accepted manuscript PDF available to anyone. I understand that if I later pay to participate in <https://preprints.jmir.org/preprint/83629>

Original Manuscript

Home- and Community-Based Service Use and Preferences among Post-9/11 Veterans With or at High Risk of Alzheimer's Disease and Related Dementia and their Caregivers: Protocol for a Mixed Methods Observational Study

Erin D. Bouldin, PhD, MPH^{1,2} <https://orcid.org/0000-0001-7550-309X>

Amanda Cheney^{1,2} <https://orcid.org/0009-0000-8391-9220>

Mary Jo Pugh, PhD, RN^{1,2} <https://orcid.org/0000-0003-4196-7763>

Kayla Morales, PhD³ <https://orcid.org/0000-0001-6863-7882>

Roxana E. Delgado, PhD, MS³ <https://orcid.org/0000-0002-8922-4857>

¹Informatics, Decision-Enhancement and Analytic Sciences Center, Health Systems Research, Department of Veterans Affairs Medical Center, Salt Lake City, Utah

²Division of Epidemiology, Department of Internal Medicine, University of Utah Spencer Fox Eccles School of Medicine, Salt Lake City, Utah

³School of Nursing, Caring for the Caregiver Program, UT Health San Antonio, San Antonio, Texas

Abstract

Background: Veterans have an increased risk of developing Alzheimer's disease/Alzheimer's disease-related dementia (ADRD) due to military exposures such as traumatic brain injury (TBI). There is a lack of information on home and community-based service (HCBS) use among Veterans who served in the post-9/11 era and their caregivers.

Objective: To (1) quantify HCBS use among post-9/11 Veterans with or at higher risk of ADRD, (2) identify facilitators, barriers, and preferences for HCBS among Veterans and family caregivers, and (3) prioritize HCBS interventions with input from Veterans and family caregivers.

Methods: This study will include post-9/11 Veterans with early-onset Alzheimer's disease or frontotemporal dementia (current ADRD) and Veterans at elevated ADRD risk due to TBI or cognitive dysfunction. Veterans' family caregivers will also be recruited. Secondary data will come from the Department of Veterans Affairs (VA), the Department of Defense (DOD), and a previous neurotrauma study. Using VA data augmented with Centers for Medicare and Medicaid Services data, we will characterize HCBS utilization. We will calculate the cumulative frequency of use (i.e., number of unique service records) and the proportion of Veterans using a service (i.e., any versus no use) among Veterans with ADRD, and those at higher and lower risk for ADRD. We will compare groups using t-tests for continuous measures (number of services) and chi-square tests for categorical measures (any service use) to test whether Veterans with current ADRD have higher HCBS use. We will interview Veterans and caregivers to identify facilitators and barriers to HCBS use. We will use descriptive content analysis including rich descriptions, coding, and theme identification. We will use a modified Delphi approach to identify and rank HCBS modifications that would increase use. Using the ranking data, we will assess consensus on each item's importance. If 70% or more respond "important" or "very important", the consensus will be that the item has high importance. Participants for primary data collection will be recruited from prior studies of TBI, military-Veteran caregiver outcomes, VA health systems data, VA clinics, and Veteran- and caregiver-serving organizations. We intend to recruit a diverse sample across sex, race/ethnicity, and rural residence.

Results: This study was approved by the institutional review boards of the University of Utah, Salt Lake City Veterans Affairs, and UT Health at San Antonio. It was also reviewed by the Human Research Protection Office of the United States Army Medical Research and Development Command. Secondary data use approvals are complete.

Conclusion: This study will quantify current HCBS use and identify barriers and needs of Veterans with or at higher risk of ADRD and their caregivers. The results will be used to increase the availability and use of acceptable HCBS for post-9/11 Veterans and their caregivers.

Introduction

Background

The National Institutes of Health summit on Alzheimer's Disease and Related Disorders highlighted that both Alzheimer's disease and frontotemporal Dementia (FTD) have significant lifelong consequences that are amplified in those with early-onset dementia.¹ Veterans are at an increased risk of developing Alzheimer's disease and related dementias (ADRD) as a result of exposures including traumatic brain injury (TBI).²⁻⁶ ADRD substantially impacts quality of life for Veterans experiencing it and their family and friends who help care for them (herein "caregivers").⁷⁻⁹ Caregivers of Veterans with ADRD often experience poorer health outcomes in their daily lives, including depression, anxiety, and physical injuries, along with financial burden, social isolation, and significantly long and demanding hours of care.¹⁰⁻¹³

Having a caregiver can help assure health and quality of life of people with long-term health conditions and disability, but caregivers need support to maintain their own health and fulfill their role, and this support needs to be tailored to their situation and needs. A broad array of services and supports is available outside of traditional healthcare settings to enable community living, known collectively as home- and community-based services (HCBS).¹⁴ HCBS may be used by Veterans to provide targeted, short-term assistance like home care following a hospitalization or long-term assistance with household management. The vast majority of caregivers for Veterans – about 10.5 million of the 14.3 million (74%) – are caring for a Veteran who is over the age of 60.¹⁵ Similarly, most (70%) VA-paid or VA-delivered HCBS are used by Veterans age 65 or older.¹⁶ Structurally, HCBS are administered by Geriatrics and Extended Care within the VA. Given that older adults have a higher prevalence of disability and care needs, it is reasonable that HCBS has primarily been tested in and designed for this segment of the population and that HCBS services are administratively centered alongside other services for older Veterans. But the needs for HCBS among younger Veterans is substantial; it is higher than among their civilian counterparts because of injuries like TBI.⁹ Also, these Veterans' caregivers are, on average, younger and thus may have different needs and preferences for services than older caregivers given their different developmental and life stages. These factors must be considered to develop effective and acceptable HCBS for Post-9/11 Veterans with early-onset dementia.

According to the U.S. Census in 2019, there are 3.8 million post 9/11 Veterans.¹⁷ Veterans are at heightened risk of developing AD/ADRD as a result of exposures including TBI and post-traumatic stress disorder (PTSD).²⁻⁶ Of the post-9/11 deployed Veterans, 11% to 23% experienced TBI, most of which were mild TBIs (mTBIs).¹⁸ Furthermore, having multiple conditions appears to increase the cumulative risk of AD/ADRD development^{19,20} and once someone develops AD/ADRD, a history of TBI may lead to more rapid impairments.²¹ Because Post-9/11 Veterans are more racially and ethnically diverse than older Veterans²² and the incidence of AD/ADRD is higher among people who are African-American or Hispanic,²³ there may be more cases of dementia among Veterans in the future than now. Taken together, the current evidence demonstrates that AD/ADRD is critical to plan for and, if possible, prevent among post-9/11 Veterans.

Previous studies revealed that tailored HCBS options are needed to fill unmet needs for Veterans with ADRD²⁴ but those studies did not address the issue of early onset dementia, which data suggest is a significant emerging trend.²⁵ Studies of HCBS among people with ADRD and other conditions have identified racial and ethnic disparities in HCBS use.²⁶⁻²⁸ Among Veterans with early-onset dementia, there also may be unique needs and preferences among those from different racial and ethnic backgrounds^{28,29} and those living in rural areas.³⁰⁻³²

Expanding access to HCBS for Veterans could potentially reduce institutionalization and the costs associated with it while improving quality of life among Veterans and their caregivers, honoring Veterans' preferences to remain at home, and achieving health equity. Although the literature is

mixed on the impact of HCBS on institutionalization and costs, especially among older adults,^{29,33} existing evidence and our own work suggests that HCBS could reduce caregiver burden and improve quality of life for post-9/11 Veterans with TBI, early-onset dementia and their caregivers. While caregivers of people with ADRD are a well-studied population overall, those caring for someone with ADRD subsequent to TBI, post-traumatic epilepsy (PTE), and other experiences common among Veterans have received less attention. Likewise, little research has focused on Veterans with early-onset dementia and sought to identify their needs and preferences – both present and projected – along with those of their caregivers.

Hypothesis & Objectives

The aims of this study are to: (1) quantify HCBS use among post-9/11 Veterans with or at higher risk of ADRD, (2) identify facilitators, barriers and preferences for HCBS among these Veterans and their family caregivers, and (3) prioritize HCBS interventions with input from Veterans and their caregivers. Based on published literature and our preliminary studies, we hypothesize that post-9/11 Veterans with early-onset AD/FTD or at higher risk of ADRD and their caregivers use HCBS with greater frequency than their peers at lower risk of ADRD. We also expect HCBS use to be less common in this cohort than among older Veterans with ADRD. We further hypothesize that Veterans and caregivers in our study will report unique barriers to and preferences for accessing and using HCBS compared to those of older adults with ADRD or non-Veterans. Therefore, we expect that based on feedback from Veterans and their caregivers, we will identify novel strategies to meet the HCBS needs of post-9/11 Veterans with early-onset AD/FTD or at higher risk of ADRD and their caregivers.

Methods

Conceptual Framework

Our study is guided by a theoretical framework based on the experiences of Veterans and their caregivers. This theoretical framework (Figure 1) incorporates Raina's conceptual model of the caregiving process and caregiver burden³⁴ along with the Military & Veteran Caregiver Journey Map developed by the Elizabeth Dole Foundation in partnership with the VA and Philips.³⁵ It also includes aspects of the Andersen and Newman Model of Behavioral Health to describe health services utilization.³⁶ Our theoretical framework therefore posits that personal characteristics, family structure, and health status of Veterans and caregivers along with the changing demands caregivers experience over time in the caregiving role create caregiver strain and unmet needs for Veterans. Either of these two experiences – i.e., caregiver strain or Veteran unmet needs – can result in seeking additional help, including using HCBS. Depending on whether that additional help is accessible and meets the caregiver and Veteran needs, they may experience positive or negative effects on their health and well-being.

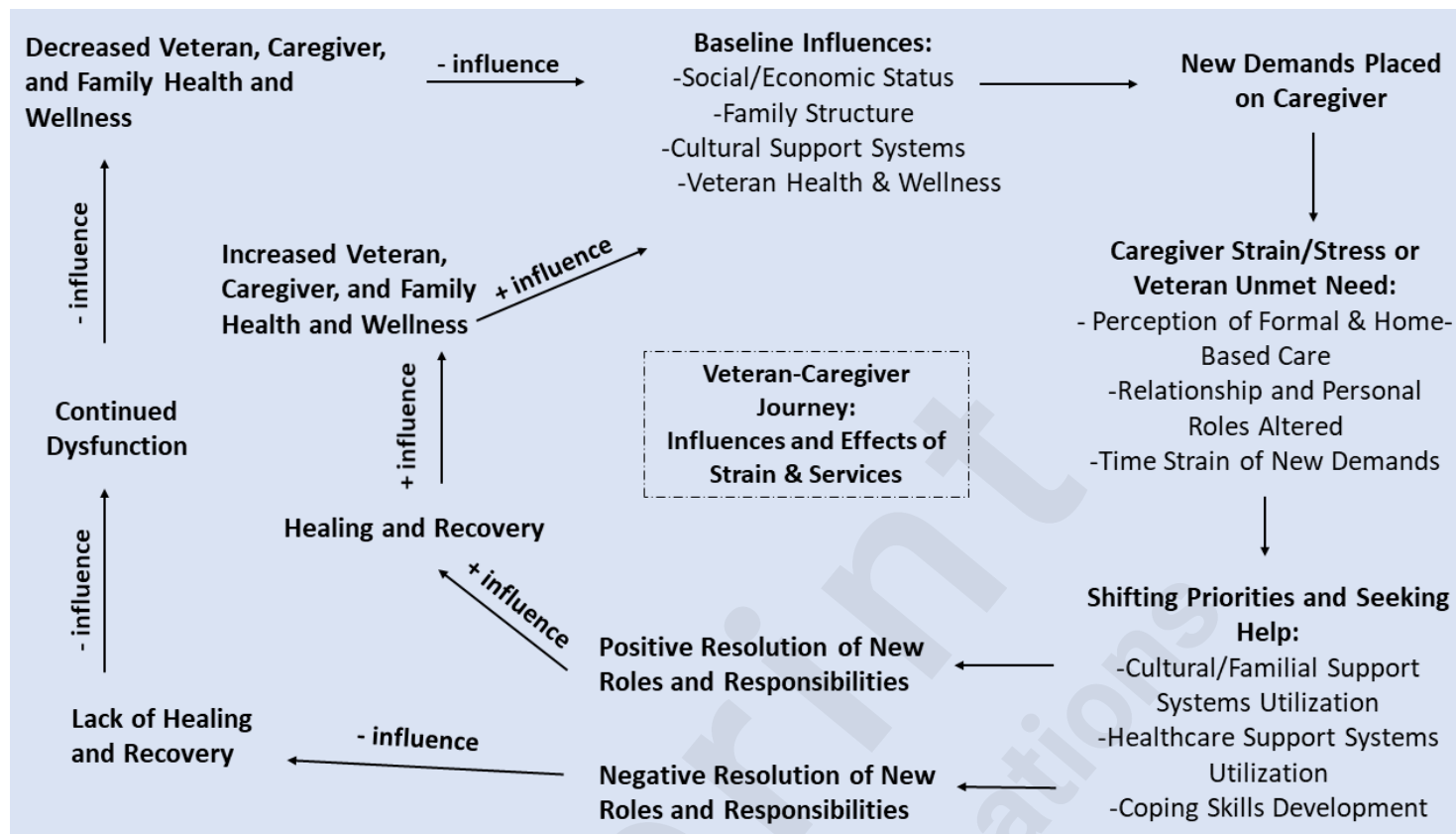


Figure 1. Conceptual framework, incorporating Raina's Theoretical Framework, MVC Journey Map, and Andersen Model of Behavioral Health.³⁴⁻³⁶

Study Design

In this sequential mixed-methods observational study, we will conduct a retrospective analysis of HCBS utilization; a qualitative study of facilitators, barriers and preferences related to HCBS use and design; and a modified Delphi survey among two groups of Veterans and their caregivers: those with early-onset AD/FTD or at higher risk of ADRD and those at lower risk of ADRD. We will leverage existing data from previous studies for the retrospective component. For primary data collection, we will recruit participants who agreed to be re-contacted from existing data and previous and ongoing studies of PTE/TBI and MVC outcomes conducted by the study team for the qualitative components, supplemented with additional recruitment strategies as needed. Whenever possible in analyses based on sample size, we will distinguish Veterans with early-onset AD/FTD from those at higher risk of ADRD to identify any differences between these two groups.

Study Population

For retrospective analyses, we will identify Veterans using data from the Characterizing Health Outcomes in post-9/11 Veterans (CHOP) repository which is the foundation for the Long-term Impact of Military Relevant Brain Injury Consortium (LIMBIC) Phenotype study. The LIMBIC dataset includes a longitudinal DoD and VA health record for >1.7 million post-9/11 Veterans with DoD health records and VA care from FY2000-FY2019. Using those data, we identified Veterans with diagnoses of AD or FTD before age 65 which represent our early-onset AD/FTD group (n=1,747). These data are available in the CHOP repository. We will compare them to a group of Veterans who are at high risk of developing early-onset AD/FTD; namely, Veterans with epilepsy; moderate, severe, or penetrating [msp]TBI; or other cognitive dysfunction (approximate n=75,000). We have found the positive predictive value of the algorithm for identifying AD and FTD diagnoses in administrative data was 0.88-0.96, much higher than other types of ADRD, and therefore these are the foci of this study.^{25,37}

Participants in the qualitative component of the study and the modified Delphi process will be

recruited from among members of the LIMBIC cohort; specifically, we will invite a diverse sample of Veterans with early-onset AD/FTD or at high risk of ADRD to participate. If we are unable to achieve target sample sizes using this cohort alone, we will recruit Veterans from other ongoing studies, VA healthcare users, and Veterans connected with organizations related to TBI and ADRD.

Inclusion and Exclusion Criteria

For Aim 1, all Post-9/11 Veterans in the dataset will be included as long as they can be classified into one of the three groups of interest: having early-onset AD/FTD, being at high risk for ADRD in the future (Veterans with epilepsy; moderate, severe, or penetrating [msp]TBI; or other cognitive dysfunction), or being at lower risk of ADRD in the future (i.e., not having early-onset AD/FTD, epilepsy, mspTBI, or other cognitive dysfunction). For Aims 2 & 3, post-9/11 Veterans with self-reported early-onset AD/FTD, epilepsy, mspTBI, or other cognitive dysfunction and their caregivers who are aged 18 years or older, can participate in English, and can consent to participate are eligible to do so.

Participants must provide informed consent to participate in the interviews or the Delphi surveys. To ensure that informed consent is obtained for this research, we plan to use a modified version of the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC). The UBACC helps investigators identify research participants who warrant more thorough decisional capacity assessment and/or remediation efforts prior to enrollment.³⁸ Specifically, we will ask Veterans with early-onset AD/FTD, epilepsy, mspTBI, or other cognitive dysfunction four questions before they participate: (1) “What is the purpose of the study that was just described to you?”; (2) “What makes you want to consider participating in this study?”; (3) “Do you have to be in this study if you do not want to participate?”; (4) “If you participate in this study, what are some of the things that you will be asked to do?” If a potential research subject does not provide a correct response to one or more of these questions, the investigator will conduct a remediation session to re-review the relevant portions of the consent language. We will then re-administer the UBACC to potential participants to assess their understanding. If the Veteran does not provide a correct response to one or more questions, they will not be eligible to complete the study.

Sample Size & Power

We expect to include 1,747 Veterans with early-onset AD/FTD (n=689 with early-onset AD, n=284 with early-onset FTD, and n=774 with early-onset AD & FTD diagnoses) and approximately 75,000 Veterans without early-onset AD/FTD who are at high risk of developing ADRD in the future in Aim 1 analyses. These numbers come from the existing LIMBIC dataset. For Aim 2, we will seek to reach saturation with the individual interviews and anticipate interviewing up to 20 Veterans and 20 caregivers, totaling up to 40 individuals. We will recruit only Veterans with early-onset AD/FTD or at high risk of ADRD and their caregivers since the primary purpose is to better understand their use of HCBS, barriers to this use, and preferences for HCBS that will inform future services and interventions. We intend to recruit and interview dyads – Veterans and their caregivers – but recognize that this will not always be possible and will interview only one member of the dyad if needed. Similarly, our goal in the modified Delphi process (Aim 3) is to include the perspectives of Veterans and caregivers to document all possible HCBS solutions and rank them. We therefore intend to recruit a diverse sample in terms of sex, race/ethnicity, and rural residence. We plan to consent up to 84 participants in the modified Delphi process, aiming for an equal number of Veterans and caregivers. The recommended sample size for online panels like this one is 40-60 participants³⁹ and the response rates between the first and second rounds of the modified Delphi process generally appears to be around 60%.^{39,40} Therefore, we anticipate that if 84 participants complete round one we will have 50 responses in round two.

We anticipate adequate statistical power for our planned Aim 1 analyses, even if we focus on only the Veterans with EO-AD/FTD. For example, in order to detect a mean difference in service use between the Veterans with and without early-onset AD/FTD of 1.0 with a standard deviation of 5.0 and 80% power (e.g., Veterans with early-onset AD/FTD use a service 7 times, on average, and

Veterans at high risk of early-onset AD/FTD use service 6 times, on average, with $SD=5.0$), we would need 392 Veterans with early-onset AD/FTD, assuming equal samples. Similarly, we would have 80% power to detect a 20% difference in the proportion of Veterans with and without early-onset AD/FTD using a service (e.g., 25% vs. 21%). These power calculations suggest that we will have adequate power to make most sub-group comparisons by sex, race/ethnicity, and geographic region for commonly used services as well. We anticipate a 25% response rate from the cohort overall for primary data collection efforts (Aims 2 & 3), and a 60% completion rate in the modified Delphi process.⁴¹ Therefore we expect to contact 500 Veterans and caregivers to enroll 124 in the individual interviews and the modified Delphi process.

Recruitment

For primary data collection we will contact Veterans with early-onset AD/FTD or at high risk of AD/FTD from the CHOP repository using the contact information available in VA databases. We will engage in purposive criterion sampling to recruit female Veterans; Veterans who are African-American, other races, and Hispanic; and Veterans who live in both rural and urban areas in the study.⁴² We will use a modified Dillman approach⁴³ for recruitment, using mailing and web-based surveys that has resulted in high participation levels in previous studies. This will include an introductory letter via mail, an electronic introductory letter via email, a second reminder about the study with details, and a final reminder with a request to participate. These introductory letters will include the purpose, the time required to participate, incentives for participating, a paper version of the pre-interview or Delphi survey, and a QR code to the electronic version of the survey. Contact information for the team will also be included. To encourage participation, we will provide an incentive of \$25 for each participant in an interview. Participant incentives for the modified Delphi process are up to \$30 for each participant (2 rounds; \$15 for each complete round).

In addition to this criterion sampling recruitment approach and if recruitment is slow, we will incorporate snowball recruitment in which prospective participants can share study information with others they know who may be eligible and interested.⁴² This approach has the advantage of efficiency and, when networks are broad, final recruits can be independent of initial recruiters.⁴⁴ Similarly, since we do not have contact information for caregivers, we will rely on Veterans to share information with them. Therefore, we may have difficulty engaging these caregivers because of indirect contact. If needed, we will expand our recruitment efforts to include Military, Veteran, and Caregiver groups like the Elizabeth Dole Foundation and the Red Cross Military and Veteran Caregiver Network, among other caregiving serving organizations. Additional recruitment strategies will include the use of community gatekeepers or leaders, especially within the caregiver community.⁴⁵

Service Member, Veteran, and Caregiver Stakeholder Input

We will work with existing Veteran Engagement Groups established at VA medical centers to receive feedback on this project and to share findings. Veteran Engagement Groups vary by site but typically include Veterans from diverse backgrounds, including those from different service eras, military ranks, sexes, and demographic groups. Several groups also include family members or family caregivers, who will be particularly important in this study. We plan to share draft study materials including documents and strategies related to recruitment, data collection (e.g., interview guides), and dissemination (e.g., framing results, lay audience summaries) with the Veteran Engagement Groups and incorporate their feedback. If needed, we will recruit additional lived experience advisors to guide us on this project to represent groups not reflected within the membership of the Veteran Engagement Groups.

Data Collection

Secondary data

LIMBIC data were derived from the Characterizing Health Outcomes for Post-9/11 Era Veterans (CHOP) repository. The VA manages the repository via VINCI in a secure data warehouse. As such,

we have requested access to CHOP data using procedures established by the CHOP repository standard operating procedures, via VINCI's secured environment. We also have requested VA and Centers for Medicare and Medicaid Services (CMS) data to link with the existing CHOP data so that we can explore HCBS use.

We will identify HBCS use as we are currently doing for older Veterans as part of an ongoing study funded by the VA and will utilize data on comorbidities including TBI and other health care utilization such as mental health, neurology, TBI, and other specialty care that may be relevant to understand the patient context.^{25,46}

Qualitative interview data

The interview guide was developed to align with our conceptual framework, and it will be revised based on input from Veterans and caregivers. Our goal is to interview both the Veteran with early-onset AD/FTD or at high risk of ADRD and their caregiver;⁴⁷ however, we will allow for single interviews, depending on interest in or ability to participate, preferences, and scheduling constraints. We will use a descriptive qualitative study design⁴⁸ to: 1) characterize the use of HCBS since the Veteran's diagnosis with early-onset AD/FTD or another condition that puts them at high risk of ADRD, including the type(s) of services used, the timing of service use relative to diagnosis and any injuries/other diagnoses, the reasons for stopping and starting service use, barriers to HCBS use, promoters of HCBS use, and knowledge/awareness about HCBS availability; and 2) identify preferences for HCBS (e.g., type(s) of service, eligibility requirements, timing, delivery mode, etc.). Both the Veteran's and caregiver's personal preferences and experiences will be detailed as part of this process. The interviews will be guided by the following research questions:

1. What unique facilitators and barriers to accessing and using HCBS do Veterans with early-onset AD/FTD or at high risk of ADRD and caregivers report that relate to their age, race/ethnicity, geographic residence, VA disability status, preferences for support, awareness of HCBS, and perceived usefulness of HCBS for their specific needs and situation?
2. What specific preferences do Veterans with early-onset AD/FTD or at high risk of ADRD and caregivers report for both the type of HCBS services and the service delivery method (e.g., timing, duration, format, and location) that include aspects relating to their life stage and family needs?

The goal of this component of the study is to describe the insights and experiences of Veterans with early-onset AD/FTD or at high risk of ADRD and their caregivers in accessing and using HCBS. Additionally, we seek to identify important elements of HCBS that will help develop strategies for increasing appropriate utilization of these services. To collect information on demographic characteristics and baseline influences in our framework (social/economic status, family structure, cultural support systems, and Veteran health and well-being), we will ask potential participants to take a brief survey administered through Qualtrics before the interview.

The semi-structured interviews will be conducted via web-based conferencing and will be audio recorded and transcribed. Audio recording will facilitate the verbatim transcription of these interviews and the subsequent content analysis. Initial transcription will be completed using the artificial intelligence (AI)-based program Otter (when a separate audio recorder is used) or the built-in transcription function of virtual meeting platforms (i.e., Teams and Zoom) and finalized by the research team in San Antonio, TX. The transcripts will be the main source of information during the analysis.⁴⁵ Field notes will also be taken by the interviewer/interview team and used in analyses. The interviewer will have training and experience in qualitative research. We estimate each interview will take approximately 60 minutes. The first two interviews will be used as pilots to assess the content and flow. Performing this pilot test will provide the opportunity to modify and add probes based on new information valuable for the aims of this study.⁴⁹ Data from the pilot interviews will be included in the final analyses.

We will use best practices in conducting qualitative data collection, management, and analysis. Interviews, including using clear and direct language to describe the study, allowing participants

extra time to complete the interviews, and allowing participants to take breaks during the interview if needed, as well as an audit trail of all the study activities.⁴⁷

Modified Delphi process

The Delphi method is a structured approach designed for reaching consensus using iterative rounds of anonymous surveys that ask experts to rate various topics or ideas.⁵⁰ It has been modified over time in various ways, including an adaptation to an online format. While the Delphi process is most used to gain input from subject matter experts like clinicians or researchers, in this study we believe the most relevant experts for informing HCBS modifications are the Veterans with early-onset AD/FTD or at high risk of ADRD and the caregivers themselves. The Delphi technique, especially the modified online approach, is increasingly being used to gain feedback from patients and caregivers in pursuit of developing more patient-centered care.^{41,51} Combining the RAND PPMD Patient-Centeredness Method (RPM)^{40,41} with recent successful work by Morbey, Harding, and colleagues to engage people with dementia in a Delphi process,^{52,53} we plan to conduct a 2-stage online modified Delphi process for Veterans with early-onset AD/FTD or at high risk of ADRD and their caregivers.

The goal of the modified Delphi process is to understand priorities among Veterans with early-onset AD/FTD and their caregivers regarding potential HCBS modifications, delivery strategies, or other aspects of HCBS interventions designed specifically to meet their needs. The modified Delphi process will be guided by the following research questions:

- 1) What specific adaptations to existing HCBS available through VA would make them more appealing and useful to Post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD and caregivers?
- 2) Is there consensus that several programs or approaches are important to Post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD and caregivers that can be tested in future intervention studies?

The data from Aims 1 and 2 along with information from the literature and our conceptual framework will be used to develop a list of HCBS approaches that would be useful to post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD and their caregivers. This list will form the basis for the first round of surveys (Figure 2). Each potential HCBS adaptation or program will be listed using plain language and begin with the phrase, "How important is it to...". For example, items may include, "*How important is it to create a program where younger Veterans can do physical exercise or projects together?*" or, "*How important is it to change respite so that caregivers can have a full day break on the weekend?*" Participants will be asked to rate the importance of each item as "1 - Not very important," "2 - Important," or "3 - Very important." This scale, while much more narrow than most Delphi rating scales which often range from 1-9, was developed by Morbey and colleagues in collaboration with people with dementia to make it easier for people with cognitive impairment to participate.⁵³ They demonstrated that it can still be used to evaluate consensus and that it was acceptable and feasible for people with cognitive impairment; furthermore, the responses from people with dementia and their caregivers varied meaningfully.⁵³

The survey will include text boxes to allow participants to describe why they rated each statement a certain way. Additionally, we will add a text box at the end of the survey to allow participants to identify any additional services or adaptations they would like to see that were not listed on the survey.

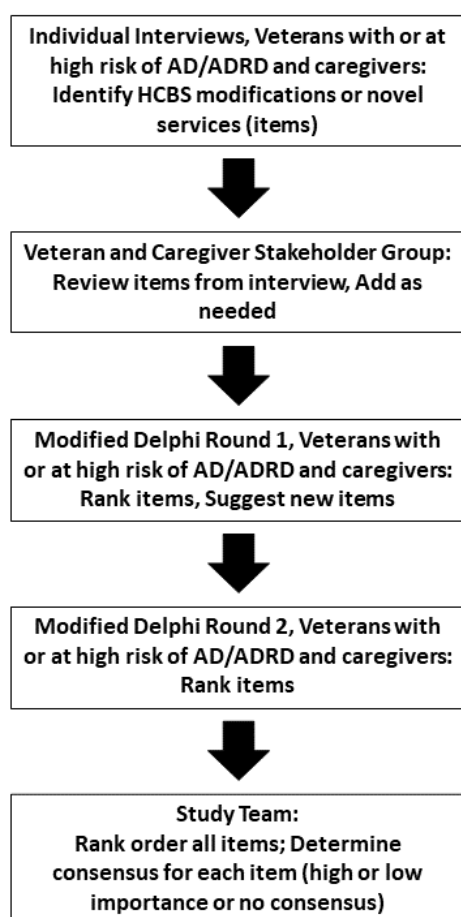


Figure 2: Flow diagram for primary data collection.

Once the first survey closes, responses will be summarized and provided to participants. Rankings will be summarized using bar charts to show the frequency of responses for each item. Each participant's response will be indicated in the bar chart so they can compare their rating to other participants' rankings. Based on difficulty interpreting these reports among some people with dementia in the study by Morbey et al.,⁵³ we will also audio-record a summary of the overall findings from round one. While this will not be tailored to each respondent, we will send each respondent a summary report showing their own answers along with the full-sample summary report. We will summarize written comments from round one by identifying themes within responses, using a descriptive content analysis approach similar to the process described for individual interviews above. Specifically, we will code free-text responses, identify themes, validate them, and summarize themes. This will be included in the summary report along with the bar charts and individual responses.

The first round Delphi survey will be available through Qualtrics, and a unique link will be sent to each participant's email address. The first-round survey will remain open for 4 weeks. Summary reports will be distributed within 4 weeks of the first round of the survey closing. Responses will be linked, allowing participants to recall their earlier answers in subsequent rounds of surveys. Also, linking emails to responses will enable participants with early-onset AD/FTD or at high risk of ADRD to respond over multiple sessions if they wish to do so; therefore, fatigue will be less of a barrier to participation.⁴⁷

Once participants have received their summary reports from the first round, approximately 4 weeks after the end of the first round, the second round of the modified Delphi process will begin. The second survey round will resemble the first round but will include any newly suggested items (adaptations or new services identified in the first round). We will not collect any new HCBS-related suggestions from the second round since it is the final round in this process. When completing round two, participants will be invited to review the summary report and consider the comments and ratings of other people then submit their ratings for each statement. The second round of the survey will again be linked to respondents' email addresses so they can complete it over multiple sessions if they like. The round two survey will close 4 weeks after it opens. The second round will form the basis of the final rankings and consensus determination (Figure 2). In our recruitment materials, we will make it clear that participants are welcome to get help from someone else when completing the surveys, though we want the opinions to be their own.

Measures

Diagnoses

We will identify AD and FTD diagnoses using inpatient and outpatient data, consistent with a previous completed study using the LIMBIC Phenotypes dataset.²⁵ Specifically, Veterans must have two or more diagnosis codes documented at least 7 days apart.¹⁹ We define early-onset AD/FTD as AD or FTD that occurs before age 65. We will consider Veterans to be at higher risk of developing early-onset AD/FTD or ADRD in the future⁵⁴ if they have epilepsy, mspTBI, or another cognitive dysfunction (e.g., cognitive disorder not otherwise specified, memory loss, mild

cognitive impairment). TBI status and severity is classified based on ICD-9/10 codes from both DoD and VA along with information from the comprehensive TBI evaluation (CTBIE), using the process established by the Chronic Effects of Neurotrauma Consortium epidemiology study and the Armed Forces Health Surveillance System.^{46,55,56}

Home- and community-based services. The VA offers eleven non-institutional programs that are delivered either in-home (homemaker home health aide, skilled care, hospice, respite, spinal cord injury and disability, home-based primary care, and telehealth) or in the community (VA, community, or state adult day care; residential care). We will use data from Geriatrics and Extended Care Data Analysis Center to classify service use within VA and will supplement this information with Medicare and Medicaid data, since Medicaid covers a substantial share of HCBS, including among VA users.

Data Analysis

Aim 1: Quantify HCBS use by post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD using data from VA and DoD and compare it to post-9/11 Veterans at lower risk of ADRD.

We will calculate both the cumulative frequency of use (i.e., number of unique service records) and the proportion of Veterans using a service (i.e., binary indicator for any versus no use) among Veterans with EO-AD/FTD, Veterans at high risk for EO-AD/FTD, and Veterans at lower risk of ADRD. We will make comparisons between these groups using t-tests for continuous measures (number of services) and chi-square tests for categorical measures (any service use) to test whether Veterans with EO-AD/FTD have higher HCBS use than other groups and whether there is variation by race and ethnicity. We will rank-order the services based on the total amount of services used and use t-tests to compare the difference across types among Veterans with early-onset AD/FTD or at high risk of ADRD.

We will calculate and report 95% confidence intervals for all estimates and will use a p-value less than 0.05 to indicate statistical significance in all analyses. In situations where data for a sub-group are sparse or when testing for interactions between groups, we will use a p-value of less than 0.10 to indicate a statistically significant difference. We will not report estimates for sub-groups if they have an individual cell size smaller than 5 Veterans. We will flag estimates that have a relative standard error greater than 30.0%. (Relative standard error is calculated as the standard error of the estimate divided by the point estimate, then multiplied by 100%.)

Aim 2: Identify HCBS-specific facilitators, barriers and preferences among Post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD and their caregivers.

We will conduct a descriptive content analysis using Atlas.ti (version 25.0.1) approach for the qualitative data analysis.^{45,48,57,58} Our approach will include an in-depth description of the information collected from the participants, including transcripts and field notes. We will then develop a coding system. The codes will be purposely and methodically assigned to specific statements and information. Next, we will cluster units of meaning (codes) to form themes. The data will be examined to identify common themes, extracting significant statements to compile a set of themes based on the research question, leading to the creation of meaning units and textual description. We will summarize each interview, creating text that incorporates all the themes elicited from the data gives a holistic context. The summary will include verbatim examples, also known as exemplars and/or quotes. Finally, once all interviews have been coded and summarized, we will synthesize across interviews to create a composite summary across interviews. This final synthesis will identify points of possible intervention for policy, programs and future research.

In addition to this descriptive content analysis, we will catalogue all suggestions for HCBS adaptations or development using data from the qualitative interviews. We will consider the codes and themes identified through the process above when deciding whether to combine responses across individuals. This list of suggestions will be part of the foundation for the next step, the modified Delphi approach.

Aim 3: Develop and prioritize specific HCBS interventions with input from post-9/11 Veterans

with early-onset AD/FTD or at high risk of ADRD and their caregivers.

The free response data from the Delphi process will be analyzed using a descriptive content analysis approach,^{45,48,57} similar to Aim 2. However, because this aim focuses on ranking interventions, we will not perform an exhaustive coding of the data. Instead, we will focus on identifying which aspects of HCBS the participants wanted to modify. We will catalogue all HCBS adaptations and ideas identified in individual interviews, any additional ideas suggested by lived experience consultants, and ideas generated during the first round of the Delphi process. This will constitute the final list of all potential adaptations to existing HCBS available through VA that would make them more appealing and useful to post-9/11 Veterans with early-onset AD/FTD or at high risk of ADRD and caregivers.

Using the ranking data, we will determine whether consensus was reached on the importance of each potential HCBS modification or new intervention. We will calculate descriptive statistics for each item: median, mode, and interquartile range. We will use the median scores to rank the importance of individual items. To determine whether there was consensus among participants, we will calculate the proportion of people who responded “important” or “very important” for each item. If 70% or more of respondents selected these answers, we will consider there to be consensus that the item has high importance. Similarly, if 70% of respondents report an item is “Not very important” we will consider this to represent consensus that the item has low importance. All other scenarios will be classified as not reaching consensus.

Ethical Approval

The University of Utah, Salt Lake City VA, and The University of Texas at San Antonio, approved this study. The study has been reviewed by the Human Research Protection Office of the United States Army Medical Research and Development Command. All data with protected health information or personal identifiable information will remain on a server that has federally approved encryption at VA Salt Lake City.

Results

We have received human subject and data access approvals to begin the study on January 24, 2023. We met with two Veteran Engagement Groups, and they recommended we modify study recruitment materials and the interview guides and develop an HCBS information sheet to provide to participants. We made these changes and had the new materials approved by local, VA, and DoD human subjects boards in June 2025. We plan to begin secondary data analysis in September 2025. While secondary analysis is ongoing, we will begin primary data collection by recruiting participants for interviews beginning in October 2025. This part of the data collection will continue for 6 months. Once secondary and interview data are analyzed, we will begin recruiting for the Delphi survey which contains 2 rounds of surveys. The project will be completed by September 30, 2027.

Discussion

The use of long-term supports for Veterans living in the community has the potential to enable them to remain at home while limiting financial and emotional distress for their families, especially when family members are also serving as caregivers. While previous work has measured HCBS use among post-9/11 Veterans whose caregivers had applied to or been accepted to the VA's Program of Comprehensive Assistance for Family Caregivers (herein referred to as the VA Caregiver Support Program),⁵⁹ no research has specifically addressed the use of HCBS among Post-9/11 Veterans whose caregivers are not enrolled in the program nor among those with or at high risk of ADRD. Similarly, we are not aware of any efforts to understand the needs and preferences among these Veterans and caregivers, which we do in this study.

Our long-term goal is to increase HCBS utilization and effectiveness. This collaboration allows us to utilize multiple modes of data collection and analytic methods to holistically assess the use of HCBS among Veterans with or at high risk of developing ADRD and to plan for interventions that will

improve HCBS quality and utilization. The study provides us a unique opportunity to lay the groundwork to develop evidence-based HCBS interventions for post-9/11 Veterans at high risk of developing ADRD and their caregivers that ultimately will improve quality of life and facilitate community living and participation. This study will help to develop programs based on the findings and disseminating findings to affect policy. We also will create summaries aimed at policymakers and DoD and VA staff who make decisions about HCBS funding and allocation.

Strengths

This study incorporates numerous data sources such as health system data from DoD, VA, and CMS including inpatient, outpatient, and HCBS utilization data along with VA TBI screening from CTBIE. We will leverage existing data and collect novel data to comprehensively evaluate HCBS use and potential strategies to increase uptake. The modified Delphi method we are using was developed for people living with ADRD, and this may be the first time it has been used with Veterans.

Limitations

This study may be limited in its ability to represent all geographic regions of the United States or all subgroups of Veterans. While we will aim to sample a diverse set of post-9/11 Veterans and caregivers, we will not capture the experiences of all groups and therefore the results may not generalize to all Veterans and caregivers.

Conclusion

This study will fill a critical gap to help understand the use of HCBS among Post-9/11 Veterans and their caregivers and to identify strategies that could improve access to these potentially helpful services. Because VHA is an integrated and learning healthcare system and already provides HCBS to eligible Veterans and caregivers, it is an ideal setting in which to test modifications to HCBS design and delivery in future studies.

Acknowledgments

This study is funded by the Department of Defense Congressionally Directed Medical Research Program: Peer-Reviewed Alzheimer's Research Program (PRARP) (W81XWH2210291). Dr. Pugh was also supported by the VA Health Systems Research, Research Career Scientist award (1IK6HX003762). Dr. Bouldin assumes primary responsibility for this project. This material is the result of work supported with resources and the use of facilities at the Salt Lake City VA medical center in Salt Lake City, UT. The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Conflicts of Interest

None Declared.

References

1. Schneider J, Leon S, Gladman JT, Corriveau RA. ADRD Summit 2019 Report to the National Advisory Neurological Disorders and Stroke Council. In: *National Institute of Neurological Disorders and Stroke*. 2019.
2. Yaffe K, Vittinghoff E, Lindquist K, et al. Posttraumatic stress disorder and risk of dementia among US veterans. *Arch Gen Psychiatry*. 2010;67(6):608-613. doi:10.1001/archgenpsychiatry.2010.61
3. Zhu CW, Sano M. Demographic, Health, and Exposure Risks Associated With Cognitive Loss, Alzheimer's Disease and Other Dementias in US Military Veterans. *Front Psychiatry*. 2021;12. doi:10.3389/fpsyt.2021.610334
4. Vincent AS, Roebuck-Spencer TM, Cernich A. Cognitive changes and dementia risk after traumatic brain injury: Implications for aging military personnel. *Alzheimer's & Dementia*. 2014;10(3S). doi:10.1016/j.jalz.2014.04.006
5. Kempuraj D, Ahmed ME, Selvakumar GP, et al. Psychological Stress-Induced Immune Response and Risk of Alzheimer's Disease in Veterans from Operation Enduring Freedom and Operation Iraqi Freedom. *Clin Ther*. 2020;42(6):974-982. doi:10.1016/j.clinthera.2020.02.018
6. Barnes DE, Byers AL, Gardner RC, Seal KH, Boscardin WJ, Yaffe K. Association of Mild Traumatic Brain Injury With and Without Loss of Consciousness With Dementia in US Military Veterans. *JAMA Neurol*. 2018;75(9):1055. doi:10.1001/jamaneurol.2018.0815
7. Välimäki TH, Martikainen JA, Hongisto K, Väättäin S, Sintonen H, Koivisto AM. Impact of Alzheimer's disease on the family caregiver's long-term quality of life: results from an ALSOVA follow-up study. *Quality of Life Research*. 2016;25(3):687-697. doi:10.1007/s11136-015-1100-x
8. Brickell TA, French LM, Lippa SM, Lange RT. Burden among caregivers of service members and veterans following traumatic brain injury. *Brain Inj*. 2018;32(12):1541-1548. doi:10.1080/02699052.2018.1503328
9. Brickell TA, Lippa SM, French LM, et al. Service needs and health outcomes among caregivers of service members and veterans following TBI. *Rehabil Psychol*. 2019;64(1):72-86. doi:10.1037/rep0000249
10. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Aff*. 2015;34(10):1642-1649. doi:10.1377/hlthaff.2015.0536
11. Carnahan JL, Judge KS, Daggy JK, et al. Supporting caregivers of veterans with Alzheimer's disease and traumatic brain injury: study protocol for a randomized controlled trial. *Trials*. 2020;21(1):340. doi:10.1186/s13063-020-4199-1
12. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2009;11(2):217-228. doi:10.31887/DCNS.2009.11.2/hbrodaty
13. McCabe M, You E, Tatangelo G. Hearing Their Voice: A Systematic Review of Dementia Family Caregivers' Needs. *Gerontologist*. 2016;56(5):e70-e88. doi:10.1093/geront/gnw078
14. Medicaid and CHIP Payment and Access Commission. Home- and community-based services. MACPAC.
15. Ramchand R, Dalton S, Dubowitz T, et al. America's Military and Veteran Caregivers: Hidden Heroes Emerging from the Shadows. *Rand Health Q*. 2024;12(1):7.
16. Government Accountability Office. Veterans' Use of Long-Term Care Is Increasing, and VA Faces Challenges in Meeting the Demand. US Government Accountability Office; <https://www.gao.gov/assets/710/704690.pdf>.
17. U.S. Census Bureau. Census Infographics & Visualizations: Memorial Day. U.S. Census Bureau; <https://www.census.gov/library/visualizations/2022/comm/memorial-day.html>.
18. Bouldin ED, Delgado R, Peacock K, et al. Military Injuries—Understanding Posttraumatic Epilepsy, Health, and Quality-of-Life Effects of Caregiving: Protocol for a Longitudinal Mixed Methods Observational Study. *JMIR Res Protoc*. 2022;11(1):e30975. doi:10.2196/30975
19. Barnes DE, Kaup A, Kirby KA, Byers AL, Diaz-Arrastia R, Yaffe K. Traumatic brain injury and risk

- of dementia in older Veterans. *Neurology*. 2014;83(4):312-319. doi:10.1212/WNL.0000000000000616
20. Yaffe K, Lwi SJ, Hoang TD, et al. Military-related risk factors in female veterans and risk of dementia. *Neurology*. 2019;92(3). doi:10.1212/WNL.0000000000006778
 21. Gilbert M, Snyder C, Corcoran C, Norton MC, Lyketsos CG, Tschanz JT. The association of traumatic brain injury with rate of progression of cognitive and functional impairment in a population-based cohort of Alzheimer's disease: the Cache County Dementia Progression Study. *Int Psychogeriatr*. 2014;26(10):1593-1601. doi:10.1017/S1041610214000842
 22. National Center for Veterans Analysis and Statistics. *Profile of Post-9/11 Veterans: 2016.*; 2018. Accessed July 28, 2025. https://www.va.gov/vetdata/docs/SpecialReports/Post_911_Veterans_Profile_2016.pdf
 23. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & Dementia*. 2016;12(3):216-224. doi:10.1016/j.jalz.2015.12.007
 24. Arai A, Matsumoto T, Ikeda M, Arai Y. Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *Int J Geriatr Psychiatry*. 2007;22(12):1255-1261. doi:10.1002/gps.1935
 25. Kennedy E, Panahi S, Stewart IJ, et al. Traumatic Brain Injury and Early Onset Dementia in Post 9-11 Veterans. *Brain Inj*. 2022;36(5):620-627. doi:10.1080/02699052.2022.2033846
 26. Fabius CD, Ogarek J, Shireman TI. Racial Disparities in Medicaid Home and Community-Based Service Utilization among White, Black, and Hispanic Adults with Multiple Sclerosis: Implications of State Policy. *J Racial Ethn Health Disparities*. 2019;6(6):1200-1207. doi:10.1007/s40615-019-00621-9
 27. Fabius CD, Thomas KS, Zhang T, Ogarek J, Shireman TI. Racial disparities in Medicaid home and community-based service utilization and expenditures among persons with multiple sclerosis. *BMC Health Serv Res*. 2018;18(1):773. doi:10.1186/s12913-018-3584-x
 28. Parker LJ, Fabius CD. Racial Differences in Respite Use among Black and White Caregivers for People Living with Dementia. *J Aging Health*. 2020;32(10):1667-1675. doi:10.1177/0898264320951379
 29. Gorges RJ, Sanghavi P, Konetzka RT. A National Examination Of Long-Term Care Setting, Outcomes, And Disparities Among Elderly Dual Eligibles. *Health Aff*. 2019;38(7):1110-1118. doi:10.1377/hlthaff.2018.05409
 30. Harrison AL, Hunter EG, Thomas H, Bordy P, Stokes E, Kitzman P. Living with traumatic brain injury in a rural setting: supports and barriers across the continuum of care. *Disabil Rehabil*. 2017;39(20):2071-2080. doi:10.1080/09638288.2016.1217081
 31. Siconolfi D, Shih RA, Friedman EM, et al. Rural-Urban Disparities in Access to Home- and Community-Based Services and Supports: Stakeholder Perspectives From 14 States. *J Am Med Dir Assoc*. 2019;20(4):503-508.e1. doi:10.1016/j.jamda.2019.01.120
 32. Mileski M, Kruse CS, Brooks M, Haynes C, Collingwood Y, Rodriguez R. Factors Concerning Veterans With Dementia, Their Caregivers, and Coordination of Care: A Systematic Literature Review. *Mil Med*. 2017;182(11):e1904-e1911. doi:10.7205/MILMED-D-16-00396
 33. Konetzka RT, Jung DH, Gorges RJ, Sanghavi P. Outcomes of Medicaid home- and community-based long-term services relative to nursing home care among dual eligibles. *Health Serv Res*. 2020;55(6):973-982. doi:10.1111/1475-6773.13573
 34. Raina P, O'Donnell M, Schwellnus H, et al. Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatr*. 2004;4(1):1. doi:10.1186/1471-2431-4-1
 35. Elizabeth Dole Foundation, Philips, US Department of Veterans Affairs. Caregiver Journey - Military and Veterans | Elizabeth Dole Foundation. Caregiver Journey. Elizabeth Dole Foundation. 2019. Accessed June 12, 2024. <https://caregiverjourney.elizabethdolefoundation.org/about/>
 36. Andersen R, Newman JF. Societal and Individual Determinants of Medical Care Utilization in the

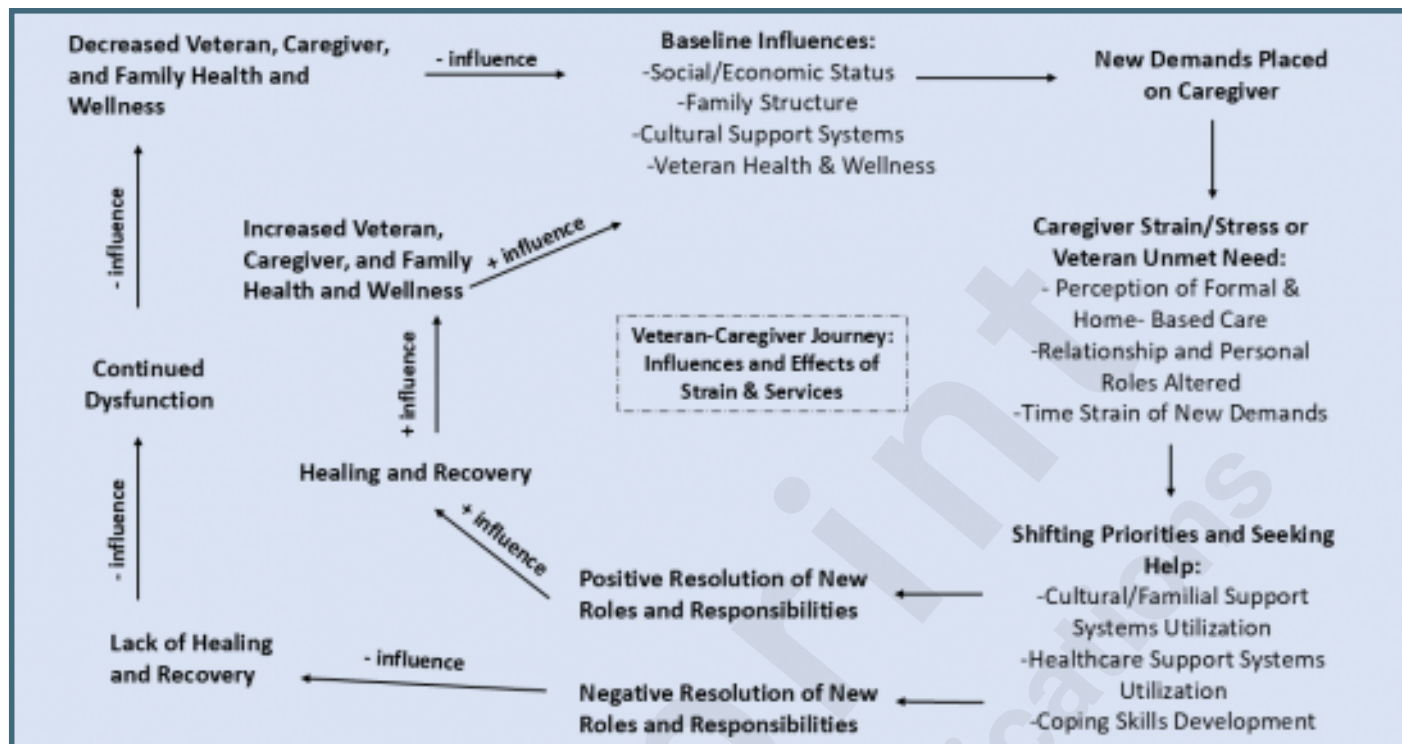
- United States. *Milbank Mem Fund Q Health Soc.* 1973;51(1):95-124. doi:10.2307/3349613
37. Marceaux JC, Soble JR, O'Rourke JJF, et al. Validity of early-onset dementia diagnoses in VA electronic medical record administrative data. *Clin Neuropsychol.* 2020;34(6):1175-1189. doi:10.1080/13854046.2019.1679889
 38. Jeste D V., Palmer BW, Appelbaum PS, et al. A New Brief Instrument for Assessing Decisional Capacity for Clinical Research. *Arch Gen Psychiatry.* 2007;64(8):966. doi:10.1001/archpsyc.64.8.966
 39. Khodyakov D, Hempel S, Rubenstein L, et al. Conducting Online Expert panels: a feasibility and experimental replicability study. *BMC Med Res Methodol.* 2011;11(1):174. doi:10.1186/1471-2288-11-174
 40. Khodyakov D, Denger B, Grant S, et al. The RAND/PPMD Patient-Centeredness Method: a novel online approach to engaging patients and their representatives in guideline development. *Eur J Pers Cent Healthc.* 2019;7(3):470-475.
 41. Khodyakov D, Grant S, Denger B, et al. Using an Online, Modified Delphi Approach to Engage Patients and Caregivers in Determining the Patient-Centeredness of Duchenne Muscular Dystrophy Care Considerations. *Medical Decision Making.* 2019;39(8):1019-1031. doi:10.1177/0272989X19883631
 42. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research.* 2015;42(5):533-544. doi:10.1007/s10488-013-0528-y
 43. Dillman DA, Smyth JD, Christian LM. *Internet, Phone, Mail, and Mixed-Mode Surveys: The Tailored Design Method.* 4th edition. John Wiley & Sons, Inc; 2014.
 44. Valerio MA, Rodriguez N, Winkler P, et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. *BMC Med Res Methodol.* 2016;16(1):146. doi:10.1186/s12874-016-0242-z
 45. Creswell JW, Poth CN. *Qualitative Inquiry & Research Design: Choosing among Five Approaches.* 4th edition. SAGE Publications, Inc; 2018.
 46. Pugh MJ, Swan AA, Amuan ME, et al. Deployment, suicide, and overdose among comorbidity phenotypes following mild traumatic brain injury: A retrospective cohort study from the Chronic Effects of Neurotrauma Consortium. *PLoS One.* 2019;14(9):e0222674. doi:10.1371/journal.pone.0222674
 47. Hellström I, Nolan M, Nordenfelt L, Lundh U. Ethical and Methodological Issues in Interviewing Persons With Dementia. *Nurs Ethics.* 2007;14(5):608-619. doi:10.1177/0969733007080206
 48. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health.* 2000;23(4):334-340. doi:10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
 49. Carlsson E, Paterson BL, Scott-Findlay S, Ehnfors M, Ehrenberg A. Methodological Issues in Interviews Involving People With Communication Impairments After Acquired Brain Damage. *Qual Health Res.* 2007;17(10):1361-1371. doi:10.1177/1049732307306926
 50. Murphy MK, Black NA, Lamping DL. Consensus development methods, and their use in clinical guideline development. *Health Technol Assess Winch Engl.* Published online 1998:1-88.
 51. Grant S, Armstrong C, Khodyakov D. Online Modified-Delphi: a Potential Method for Continuous Patient Engagement Across Stages of Clinical Practice Guideline Development. *J Gen Intern Med.* 2021;36(6):1746-1750. doi:10.1007/s11606-020-06514-6
 52. Harding AJE, Morbey H, Ahmed F, et al. Developing a core outcome set for people living with dementia at home in their neighbourhoods and communities: study protocol for use in the evaluation of non-pharmacological community-based health and social care interventions. *Trials.* 2018;19(1):247. doi:10.1186/s13063-018-2584-9
 53. Morbey H, Harding AJE, Swarbrick C, et al. Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development. *Trials.* 2019;20(1):12.

- doi:10.1186/s13063-018-3069-6
54. Alzheimer's Association. 2022 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2022;18(4):700-789. doi:10.1002/alz.12638
 55. The Management of Concussion-mild Traumatic Brain Injury WGroupVCPG for the M of CMTBInjury. *VA/DoD Clinical Practice Guideline for the Management of Concussion-Mild Traumatic Brain Injury. Department of Veterans Affairs and Department of Defense* <https://www.healthquality.va.gov/Guidelines/Rehab/Mtbi/MTBICPGFullCPG50821816.Pdf>. Department of Veterans Affairs and Department of Defense; 2016.
 56. Military Health System. Surveillance Case Definitions. Military Health System. 2020. Accessed June 12, 2024. <https://www.health.mil/Military-Health-Topics/Health-Readiness/AFHSD/Epidemiology-and-Analysis/Surveillance-Case-Definitions>
 57. Hsieh HF, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687
 58. ATLAS.ti Scientific Software Development GmbH. *ATLAS.ti Mac (version 2501)*. Preprint posted online 2024.
 59. Shepherd-Banigan M, Smith VA, Stechuchak KM, et al. Comprehensive Support for Family Caregivers of Post-9/11 Veterans Increases Veteran Utilization of Long-term Services and Supports: A Propensity Score Analysis. *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. 2018;55:004695801876291. doi:10.1177/0046958018762914

Supplementary Files

Figures

Conceptual framework, incorporating Raina's Theoretical Framework, MVC Journey Map, and Andersen Model of Behavioral Health.



Flow diagram for primary data collection.

