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Veterans Health Administration

Health Services Research & Development Service

Commentary

VA's Commitment to Caregiver Support in Action

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VHA first implemented its Caregiver Support Program in 2007, to support Public Law 109-461,¹ which instructed VA to “carry out a pilot program to assess the feasibility and advisability of various mechanisms to expand and improve caregiver assistance services.” Implementation of these pilots occurred against the backdrop of early National Alliance for Caregivers (NAC) and AARP studies² that illustrated the growing number of family caregivers, particularly as the U.S. population ages. From 2007-2011, thousands of caregivers participated in various VA programs, and VA eventually implemented Resources to Enhance All Caregivers Health (REACH) and Building Better Caregivers³ to support Veterans, and their families and caregivers.

The wars in Iraq and Afghanistan resulted in a new cohort of Veterans with catastrophic injuries, many of whom are now being cared for by family members at home. These caregivers worked with Congress to pass Public Law 111-163,⁴ the Caregivers and Veterans Omnibus Health Services Act of 2010, which provides an unprecedented level of direct services and supports to family caregivers of Veterans. VHA quickly pivoted from piloting a few programs to implementing two full-scale national programs – the Program of Comprehensive Services for Family Caregivers (PCAFC) and the Program of General Support Services for Caregivers (PGCSS). In 2018, Congress expanded

availability of PCAFC to all family caregivers of eligible Veterans, regardless of the era when they served.

VA's work to operationalize caregiver support has not been without challenges. One key challenge is balancing the requirements of a given program with the specific needs of the family caregivers. While the original pilot programs focused on supporting caregivers without requiring caregivers to complete an application or undergo an assessment, the implementation of PCAFC has required a strong focus on assessing Veterans and their individual needs for assistance. Because the level of assistance an individual Veteran requires is not always indicative of how much assistance or support a family caregiver requires, this can lead to frustration and confusion on the part of the family caregiver, and can even create, on occasion, an adversarial relationship between the caregiver and the Caregiver Support team.

As an example, in the early stages of Alzheimer's or other related illnesses, a caregiver is likely working full time, may not understand the disease or its trajectory, and may also struggle to share the news with other family members. The care recipient is likely confused, focused on their independence, and significantly less worried about their safety than the caregiver. In this circumstance, the caregiver may need many more resources, additional support, or extra training. On the

other hand, a caregiver who has somewhat mastered the daily tasks of caring for an individual in the later stages of the disease may need grief support.

The support needed by a family caregiver is very individualized and having to implement a “one size fits all” approach has had operational challenges. These challenges continue to be met, however, through partnership, innovation, an expansion of the PGCSS, and a much deeper understanding by VA of the role of family caregivers. The recent addition of “caregivers” to VA's Mission Statement, “to fulfill President Lincoln's promise to care for those who have served in our nation's military and for their families, caregivers, and survivors,” demonstrates VA's commitment to supporting not only Veterans, but also their caregivers.

An additional challenge in meeting the needs of caregivers is to ensure a balance of support services for family caregivers. Caregiver support programming can be divided into two buckets. The first bucket involves support programming that addresses the challenges associated with the new role and responsibilities placed on family members, i.e., “how” to be a family caregiver. Programs that offer support, either professional mental health or peer support, fall into this bucket. In addition, programs that teach goal setting, communication skills, anger management, and self-care often help caregivers at various

DIRECTOR'S LETTER



VA's original mission is reflected in our motto taken from Lincoln's second inaugural address: "to care for him who shall have borne the battle and for his widow, and his orphan."

This motto, however, is no longer sufficient. Due to the increasing number of Veterans who suffer from dementia, other problems of aging, or severe wartime injuries, and

who need extensive home support, VA recognizes that Veterans' caregivers are also in need of support. As outlined by Meg Kabat in the lead commentary article, efforts began with programs to assist caregivers of patients with dementia, then got a significant boost with the creation of the comprehensive caregiver support program in 2011 in response to legislation allowing VA to support caregivers for Veterans wounded in conflicts in Iraq and Afghanistan. The logic of supporting caregivers seemed straightforward: Veterans prefer care at home, yet care takes significant economic, emotional, and physical tolls on family caregivers. Few family members know how to handle the complex medical and psychological needs of

ill Veterans. But because institutional care is costly, investing in caregiver support could be cost-neutral if it even modestly reduced the need for institutionalization. The economics and logistics of delivering effective caregiving support has proven complicated. Providing caregiver support involves determining the unique needs of patients and their families and developing effective education or training programs to meet those needs.

The innovation, testing, and revision needed to create effective programs would not be possible without the careful qualitative and quantitative information produced by our research community. Because of their efforts, we have a clearer picture of how to deliver high quality, Veteran- and caregiver-centered support. The work described in this issue is a testament to the power of an embedded research program with strong program partnerships. VA leads the nation not only in our caregiver support programs but in research on caregiving. This research will not only improve the lives of Veterans and their caregivers, it will also help pave the way for health systems across the country to do the same.

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transition points during their caregiver journey. The other bucket is more focused on the "what," i.e., the actual hands-on skills needed to support their loved ones. Programs in this bucket include teaching skills through hands on training and videos; examples include supporting a transfer from a wheelchair, wound care, how to take a blood pressure, when to call the doctor, when to call 911, how to manage difficult behaviors, including de-escalation, and suicide prevention. Many programs offered by VA, such as Building Better Caregivers,⁵ include approaches that incorporate both the "how" of becoming a family caregiver and the "what" in terms of skills training.

An important area of focus for VA researchers should be on how we can better support the Veterans in our care who are caregivers themselves. A recent AARP study found that almost one in five Americans is a family caregiver.⁶ As a large, integrated healthcare system, VA treats more than nine million Veterans – therefore, we can assume that

many Veterans must be caring for their spouse, or adult disabled child, neighbor, or friend. For example, is there a screening question we should be asking during primary care visits? While we may be limited in what supports and services we can provide to Veterans who are caregivers, are there community resources we can provide? Are there policy changes we can make so that Veterans who are caregivers can get access to some of the world class caregiver programming VA offers?

In summary, VA has led the United States in developing and implementing comprehensive programming to support family caregivers. VA research can help to individualize supports and services to better meet the needs of family caregivers and tailor programming to caregivers versus the needs of the Veterans they care for. In addition, VA research can lead in identifying ways to support family caregivers within healthcare systems through identifying interventions to support Veterans as they support their family members.

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Supporting the Needs of Caregivers through Research

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In this issue's lead article, Meg Kabat, LCSW-C, CCM, Principal Senior Advisor, Office of the Secretary, outlines the history of legislative actions that created important and innovative programs to support caregivers of Veterans, including the Program of Comprehensive Services for Family Caregivers (PCAFC) and the Program of General Support Services for Caregivers (PGSSC). With the implementation of these programs, and the more general expansion of VA's mission to include families, caregivers, and survivors, the VA Health Services Research & Development (HSR&D) program vigorously supports research related to caregivers of Veterans, enabling the VA research community to partner with operational and policy leaders, and provide them with data to ensure that programs have maximal impact. The Elizabeth Dole Center of Excellence for Veteran and Caregiver Research, the VA CARES partnered evaluation program, and the VA Caregiver Center are all examples of research initiatives that are closely partnered with operations.

VA CARES has partnered with the Caregiver Support Program (CSP) to evaluate the PCAFC, an effort that has identified important program impacts. First, the evaluation found that PCAFC increases Veteran use of high-value care, though overall costs of Veteran care in this program have also increased. Second, the program has significantly reduced caregiver self-reported financial strain, and has led to increased interactions between caregivers, and VA staff and clinicians. VA researchers found that 40 percent of program participants between 2011 and 2016 were discharged, identifying subgroups of Veterans more likely to be discharged, and enabling CSP leadership to adapt the program in ways that could improve equity. VA CARES researchers also noted persistently high caregiver emotional strain during the COVID-19 pandemic, potentially mitigated by VA's rapid implementation of virtual services.

Ms. Kabat notes the difficulties that program leaders may have in understanding the

daily challenges and care gaps experienced by caregivers of Veterans, and how these challenges evolve over time. These gaps include both home-based supports provided by VA and its community partners, as well as trainings to enable caregivers themselves to be as effective as possible. Researchers in the Elizabeth Dole Center of Excellence have used multiple approaches to understand caregivers' experiences over time; interviews and focus groups conducted by this team generated important new insights including the following findings:

- Veterans and caregivers agree on key strengths of VA care, notably the broad scope of services and communication with clinicians.
- Challenges and unmet needs include coordination, communication, navigation, and misalignment between needs and services, such as:
 - Difficulty coordinating and navigating complex care in a large system;
 - Barriers to communication across VA; and
 - Difficulty with managing and balancing daily tasks, particularly household or childcare-related tasks.
- Veterans and caregivers view strengths and challenges as related to the implementation of needed services and increasing the need for coordination and navigation across the system.

A longitudinal survey of Veterans and their caregivers has provided additional insights regarding unmet needs.

- 16 percent of Veterans report having unmet needs in activities of daily living (ADLs), with as many as three ADLs not met.
- 26 percent report unmet needs related to instrumental activities of daily living (IADLs), again with as many as three IADLs not met.

- Caregivers provided feedback regarding available VA resources, including their awareness of services and how helpful those services are (Figure 1). Responses indicate a persistent gap in knowledge of existing services.
- Almost 40 percent of caregivers do not feel fully prepared for the caregiving tasks in which they are engaged; this finding is consistent with Ms. Kabat's observation that VA needs to develop more caregiver skills training programs.

Despite improvements in service awareness, more work is needed to ensure that Veterans, their caregivers, and clinicians are aware of relevant programs.

Ms. Kabat speaks to the need to better understand the home environment, family systems, and lived experiences of caregivers of Veterans. Researchers in the Elizabeth Dole Center of Excellence have laid the groundwork for this program of research.

- We developed policies and strategies for including youth < age of 18 in VA-funded research studies, and partnerships to facilitate their recruitment.
- We provided a narrative review of interventions to support caregivers as they transition to survivors, noting key gaps in the types of multi-pronged, family-system based interventions that are more likely to be successful.
- We completed an environmental scan of measures of home and community-based services, comparing existing measures with caregivers' priorities for assessment, and identifying the following measurement gaps:
 - Caregiver involvement in Veteran care
 - Impact of stipends and financial support on caregivers

Partnered Evaluation of the Enhanced Program of General Caregiver Support Services

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Over 5.5 million family caregivers provide often unpaid care to aging and disabled Veterans across the United States.¹ Given increasing reliance on family caregivers to maintain the highest quality and least restrictive care for Veterans, VA is expanding services offered through the Caregiver Support Program (CSP), including its Program of General Caregiver Support Services (PGCSS). PGCSS includes peer support mentoring, skills training, coaching, telephone support, online educational programs, referrals to mental health services and other resources, and respite care for eligible caregivers. In FY21, CSP enhanced PGCSS by providing funding to support one PGCSS staff member at every VA site, setting minimum practice standards, and rapidly delivering new supports and services.

Amid national expansion, rigorous evaluation of PGCSS enhancement is critical to optimize services and ensure high quality, inclusive, personalized, and holistic support for caregivers.

Formative Evaluation of Enhanced PGCSS Services and Supports

As part of an ongoing evaluation of CSP, in FY21 – FY22 the VA Quality Enhancement Research Initiative (QUERI) VA Caregiver Support Program Partnered Evaluation Center (VA CARES) evaluated the delivery and impact of two evidence-based PGCSS enhancement services.

- VA S.A.V.E Training for Caregivers – a one-time, locally delivered suicide prevention training for people who work, live with, and/or care for a Veteran.²
- Resources for Enhancing All Caregivers Health (REACH) VA Program – a one-on-one, or group based coaching program for caregivers focused on stress management, problem solving, self-care, and support for diagnosing specific issues.³

The VA CARES research team designed a qualitative evaluation to understand caregivers' experiences with these two services and factors that might have impacted those experiences. The design included collecting information from enrolled caregivers and PGCSS staff implementing these new services. The team engaged a total of 39 caregivers who participated in VA S.A.V.E. and/or REACH VA in a one-time, semi-structured phone interview. The team purposively sampled staff from seven sites that had high or low enrollment volume of new caregivers in early FY21, and invited them to participate in a series of two virtual interviews and a virtual focus group. Eight PGCSS staff members participated in initial semi-structured interviews, six participated in a second interview, and six participated in a single focus group. The VA CARES team analyzed the interviews using rapid qualitative methods.

The team identified three overarching themes through this analysis.

- *Services are valued but the timing of offering services is important and caregiver engagement can be challenging.* Participants articulated positive benefits of the trainings (e.g., improved knowledge and awareness about suicide, personal support, and practical caregiving skills). However, caregivers also described a lack of awareness of programming, and discussed their readiness to engage supports. Findings suggest that multiple types of caregiver engagement patterns exist and understanding factors that influence engagement may assist staff in tailoring approaches to increase caregiver engagement.
- *Connection and social support are valued, but so are practical skills.* Caregivers and staff recognized the importance of helping caregivers feel they are not alone, but caregivers also emphasized the utility

Key Points

- Over 5.5 million family caregivers provide care to aging and disabled Veterans.
- VA has expanded services offered through the Caregiver Support Program (CSP), including peer support mentoring, training, coaching, and educational programs through the Program of General Caregiver Support Services (PGCSS).
- A recent evaluation of PGCSS offers valuable feedback and illuminates the program's future directions.

of practical knowledge and skills, and indicated that advanced skill-based and refresher classes would be welcome.

- *Uneven initial implementation leveled out in year two of the PGCSS enhancement, but challenges remain.* PGCSS staff pointed to tensions between the movement toward more national uniformity and the desire to tailor services using their clinical expertise and understanding of local needs. They also expressed concerns about not having the appropriate resources to keep up with new program expectations.

Caregivers and staff in this evaluation offered the following suggestions for improvement.

- Ensure the availability of continuing opportunities for engagement and inform caregivers of these opportunities after time-limited trainings have ended.
- Help staff develop messaging to different groups of caregivers to improve engagement in VA S.A.V.E.
- Assure additional one-on-one time with caregivers to provide personalized touch points to bring up the topic of suicide.

- Continue to provide and expand venues for staff to share best practices and to problem solve specific issues around engaging caregivers in PGCSS programming (e.g., shared resources, adaptable scripts).
- Obtain better understanding of caregiver engagement types and develop targeted efforts aimed at different types of caregivers.

Overall, caregivers and staff offered suggestions for improving VA S.A.V.E. and REACH VA, while clearly articulating the value of those trainings for caregivers.

Future Directions

Building on the formative evaluation, VA CARES will conduct evaluations of two other pivotal PGCSS enhancement services: the Caregiver Health and Wellbeing Coaching Initiative (CHWC) and respite care.

Built upon the VA Whole Health framework, the CHWC is a six-day training course designed to equip CSP staff with Whole Health Coaching skills, knowledge, tools, and self-care skill building techniques to better support caregivers on their caregiving journey. The CHWC will be expanded over the next

two years with the goal of having at least one CHWC trained staff member at every VA facility by the end of FY23. In partnership with CSP, VA CARES will examine the effectiveness and implementation of the CHWC expansion. Guided by the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) framework and the Consolidated Framework for Implementation Research (CFIR), this evaluation will demonstrate impacts of the CHWC on caregivers and elucidate strategies to improve delivery of these services.

Respite care is designed to provide caregivers a short break from caregiving responsibilities through both formal supports (e.g., paid home-based and nursing home care) and informal supports (e.g., respite goal planning, self-care resources, other members of the caregiver’s social support network). CSP is currently enhancing respite services through innovations such as site-specific respite champions and self-guided respite planning tools for caregivers. Using mixed methods approaches, combined with rapid feedback from CSP, VA CARES will evaluate barriers to use of respite care and identify areas to optimize respite services offered through PGCSS.

The formative evaluation of PGCSS expansion acts as a stepping stone to determine the reach, delivery, and quality of other expanded caregiver services. Knowledge gained from this multipronged PGCSS evaluation will be used to improve support for caregivers across VA.

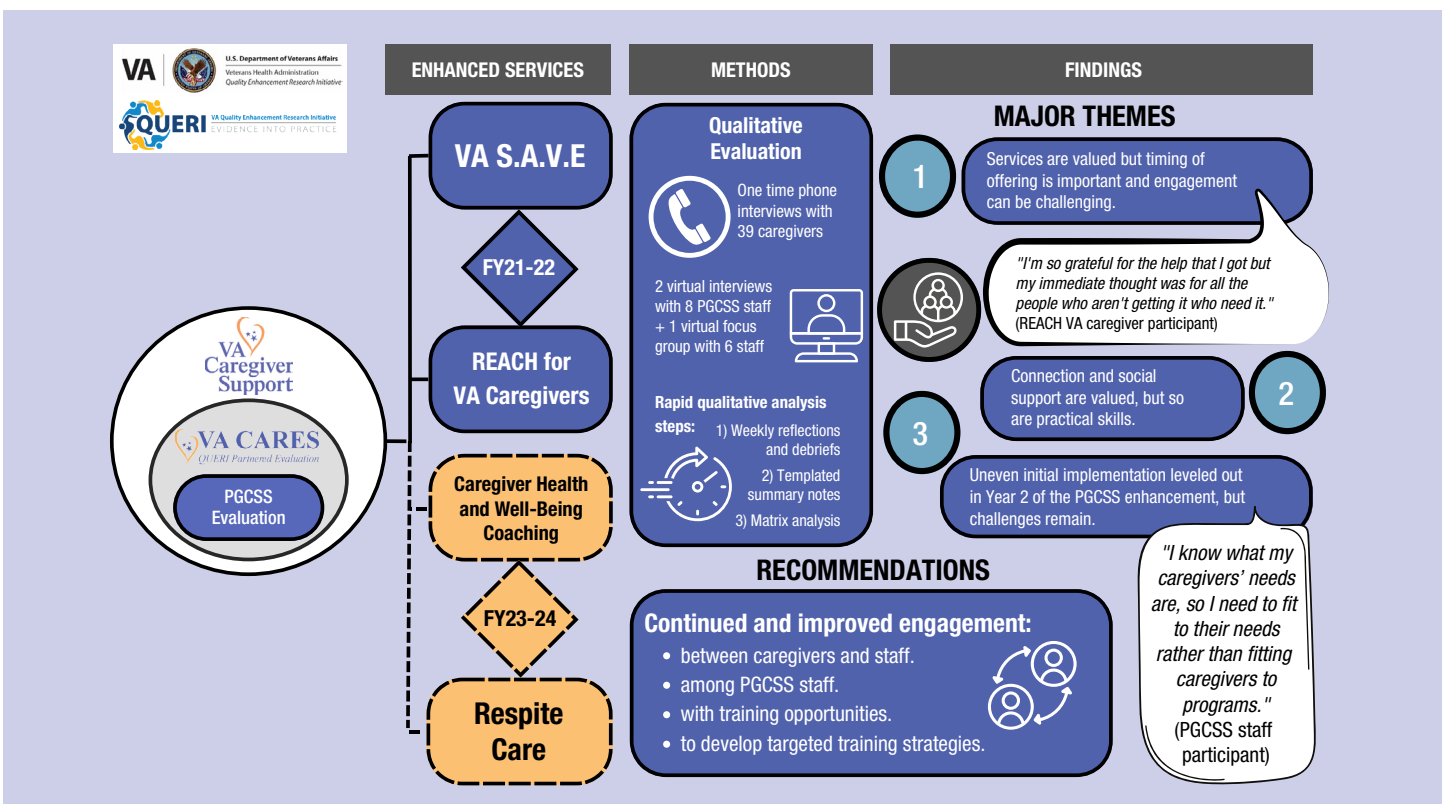
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Figure 1. PGCSS Evaluation



Unleashing the Power of Caregivers

Mark E. Kunik, MD, MPH, HSR&D Center for Innovations in Effectiveness, Quality and Safety (COIN), and the South Central Mental Illness Research Education and Clinical Center, Michael E. DeBakey VA Medical Center, Houston, Texas, and Molly Horstman, MD, MS, also with the HSR&D COIN

Family and friend caregivers (i.e., caregivers) are critical to good health, especially for older adults. Yet their roles, needs, and well-being are largely ignored within healthcare delivery.^{1,2} Caregivers decrease depression,³ support activities of daily living (including medical adherence), preserve autonomy, and improve medical outcomes.⁴ This support also delays or even prevents use of congregate living. Upwards of 55 million Americans provide unpaid care to an adult age 50 or older (National Alliance for Caregiving and AARP, 2020), caring for persons with chronic medical and mental illnesses, dementia, and traumatic brain injuries. The number of caregivers has dramatically risen in recent years because of the shortage of direct care workers, which is expected to continue.

Less than 50 percent of caregivers are asked about their roles and needs.¹ One essential goal of the RAISE Family Caregiving Advisory Council's 2022 National Strategy to Support Family Caregivers is for healthcare teams to recognize, integrate, and support family caregivers. To make this a reality, clinicians need new and better tools, such as culturally sensitive caregiver needs assessments that can be embedded into routine care. There are national efforts to acknowledge the critical role of the caregiver. Supported by AARP, 44 states have adopted the Caregiver Advise, Record, Enable (CARE) Act. The CARE Act requires hospitals to 1) record the name and contact information of the caregiver in the medical record, 2) inform the caregiver of the discharge date, and 3) provide the caregiver with education and instruction about medical tasks expected to be performed following discharge. As a federal agency, VHA does not fall under the jurisdiction of these state laws.

The Vital Need to Collect Information on Caregivers

Though VHA offers substantial support for Veteran caregivers, it does not routinely or systematically identify caregivers. When the caregiver's name and contact information is collected, the information is listed in different locations as unstructured data not readily accessible to clinicians.¹ Within the electronic health record, there is no structured field to designate and identify the caregiver. Veterans may choose to identify a next of kin or secondary next of kin, yet the next of kin should not be assumed to be the Veteran's caregiver. Caregiving relationships are complex, and many Veterans may have different caregivers who assume different roles. Veterans may also designate a durable power of attorney for healthcare, but this too may not be the caregiver who provides day-to-day assistance. To integrate caregivers into the Veteran's care, frontline clinicians need easy access to each caregiver's name and role.

Efforts exist within VHA to identify the needs of Veteran caregivers, yet this information also is not accessible. VHA has a caregiver self-assessment tool, but the tool is online and is not integrated into any VA data source (Caregiver: Self-Assessment (va.gov)). The VA Caregiver Support Program offers substantial support services to Veterans' caregivers, but the evaluation and supports provided through the program are separate from the healthcare teams that care for Veterans. Caregivers must refer themselves or be referred by their healthcare team to the Caregiver Support Program. Needs assessments completed by the Caregiver Support Program can offer rich information about the experiences of both the Veteran and the caregiver. However, this information is recorded in unstructured notes in the electronic health record.

Key Points

- While caregivers play a critical role in supporting patient activities of daily living and improving medical outcomes, their well-being is largely ignored by the healthcare system.
- RAISE Family Caregiving Advisory Council's 2022 National Strategy to Support Family Caregivers aims for healthcare teams to recognize, integrate, and support family caregivers.
- Changes are needed within VHA to integrate caregivers into Veterans' care and to connect them to the evidence-based resources available through the Caregiver Support Program.

Thus, frontline clinicians are left to search through years of clinical encounter records to determine whether anyone has ever assessed and documented the caregivers' roles, responsibilities, and needs and to determine whether those needs have ever been addressed.

HSR&D Funded Caregiver Research

HSR&D is a leader in funding caregiver research, including Partners in Dementia Care, a care consultant intervention. Partners in Dementia Care assessed the needs of persons with dementia and their caregivers and then created action plans and coached them to connect with resources to meet their needs and build their support network. The research established that the intervention was effective in decreasing unmet needs, stress and strain, and symptoms of depression for both caregivers and the persons receiving care. The research was foundational in its recognition by the Administration for Community Living and has been implemented in more than 50 sites in and outside VHA.

To support Veteran caregivers, VHA must identify how best to engage caregivers in all clinical environments. Hospital GamePlan4Care: A Web-Based Delivery System for Dementia Caregiver Support, a recently funded career development award jointly funded through VA and the National Institute on Aging, seeks to support and engage caregivers of hospitalized Veterans living with dementia. The intervention will adapt a community-based dementia caregiver support program to incorporate tailored care transitions training and support for caregivers. In addition to dementia research, HSR&D has funded caregiver research to address those with other chronic neurological and medical conditions.

VHA Must Integrate Caregivers

Structural changes in VHA are critical to integrate caregivers into Veterans' care and to connect them to the evidence-based

resources available through the Caregiver Support Program and ongoing research studies. Implementing the CARE Act within VHA would be an important first step, but alone, this step is insufficient to meet the goals of the 2022 National Strategy to Support Family Caregivers. As the largest integrated healthcare system in the United States, VHA can be a leader in ensuring that frontline clinicians have the information needed to connect caregivers to evidence-based services, supports, and clinical trials. Additional steps should include 1) ensuring that caregiver information is collected and recorded in a format that is easy for frontline clinicians to access, 2) developing a systematic assessment of caregiver needs and consistent facilitation of action plans across clinical settings, and 3) integrating the caregiver into the healthcare team.

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- Assessment of caregivers' ability to actually provide the care Veterans need
- Caregiver burden
- Caregiver perceptions of care delivered in the home

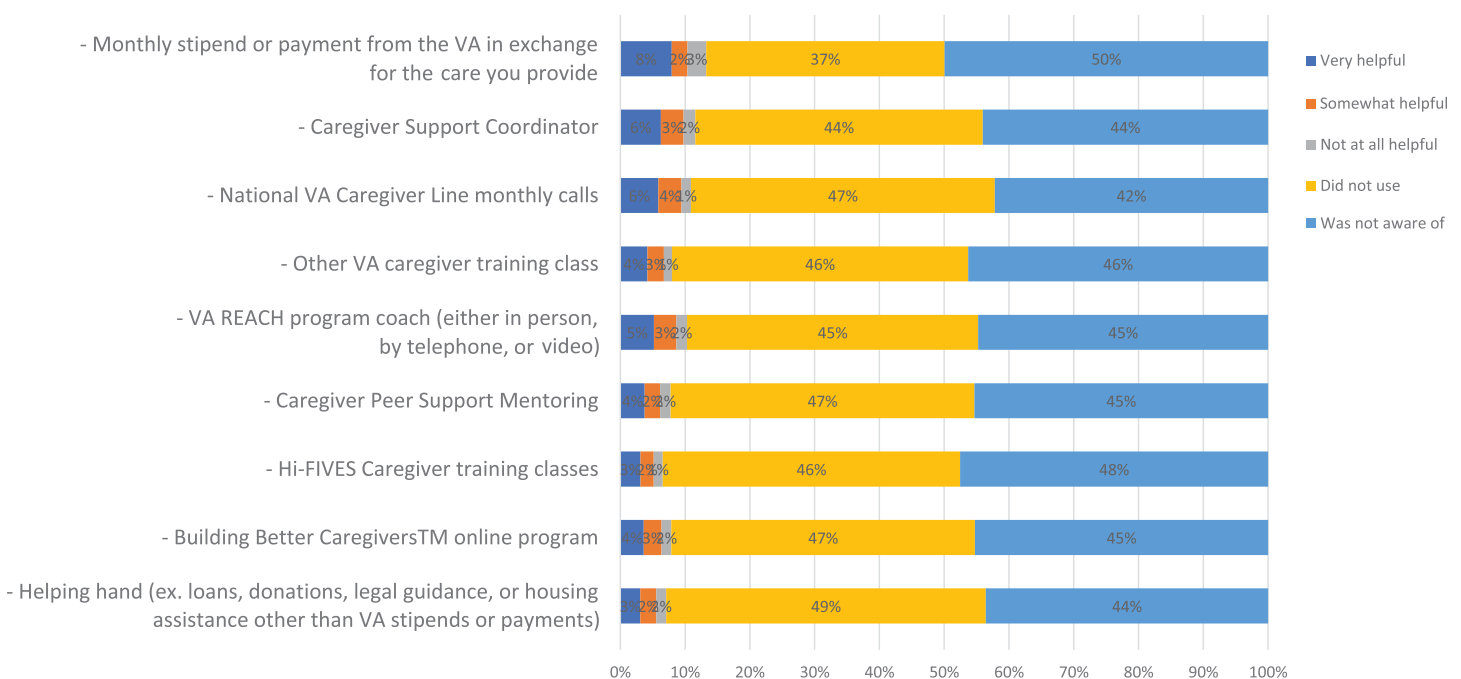
Additionally, Ms. Kabat notes the need to develop more interventions to support the varied and individualized needs of caregivers.

The VA Caregiver Support Program, through its national VA Caregiver Center, is assessing the use and impact of Annie, the VA Office of Connected Care's automated short-message service for guided self-management. During the COVID-19 pandemic, stress-management texts were deployed through Annie. In fact, 47 percent of caregivers found these texts to be helpful and wanted them to continue post-pandemic. These text protocols are being

expanded in response to this feedback. There are currently eight caregiver-focused protocols with over 14,000 caregivers enrolled to date.

Finally, Ms. Kabat highlights the need to identify Veterans who are caregivers (and vice versa) – including those Veterans who are part of the VA workforce. VA research teams are developing strategies to provide this important information for leadership.

Figure 1. Caregiver Awareness and Perceptions of VA Services



Testing the Impact of a Spanish Online and Telephone Intervention for Hispanic Caregivers of Veterans with Stroke

Magaly Freytes, PhD, Janet Lopez, PhD, and Melanie Orejuela, BS, all with the North Florida/South Georgia Veterans Health System, Gainesville, Florida

Stroke is one of the leading causes of death and long-term disability in the United States. Hispanics have a higher risk of stroke-related death compared to non-Hispanics.¹ Projections for 2030 indicate a 21 percent increase in prevalence of stroke among Hispanics compared to 2012.¹ Those who survive a stroke often rely on informal caregivers for care and support, thus family caregivers play an important role during the stroke recovery process. Due to the abrupt nature of strokes, many caregivers experience unexpected changes and demands that they are unprepared to assume. Hispanic caregivers report higher rates of negative caregiver outcomes.²

Caregiver education and support have been recognized as important factors that help facilitate the transition home for individuals following a stroke. Providing caregivers with information, support, and skills has the potential to reduce negative caregiver outcomes and increase the likelihood that stroke survivors can remain at home.

Culturally Relevant Interventions

Recognizing the important role that socio-cultural factors play in enhancing the skills of caregivers of stroke patients, and to fulfill a need for culturally relevant caregiver programs, we adapted an intervention and used a previously developed and tested Spanish-language web site: Resources and Education for Stroke Caregivers' Understanding and Empowerment (RESCUE). This intervention has the potential to reduce caregiver depressive symptoms and burden by teaching them a creative and optimistic approach to solving caregiving related problems. To ensure cultural relevancy, we employed a rigorous cultural adaptation consisting of a dynamic and reiterative process with stakeholders. We used several sources to inform the adaptation of the RESCUE en Español intervention, including reaching a consensus among an

interdisciplinary team of experts in stroke caregiving and Hispanic Veterans and families. To guide our efforts, we included input from Hispanics throughout the duration of the project, including an advisory panel. We incorporated culturally specific graphics using low-literate and appropriate language, and verified the translations by Spanish-speaking experts.

Framework and Methods

The study tests a telephone problem-solving intervention that uses modules, factsheets, and tools available on our RESCUE Stroke Caregiver website, Programa "RESCUE en Español." The intervention is based on the relational/problem-solving model of stress and integrates concepts of stress appraisal and coping theory, and is based on the COPE (Creativity, Optimism, Planning, and Expert Information) framework. All study procedures and supporting materials are in Spanish.

This two-arm parallel randomized controlled trial with repeated measures and mixed methods tests the effect of a telephone/online problem-solving intervention for Spanish-speaking stroke caregivers and examines caregivers' perceptions of the value, facilitators, and barriers to participating in the intervention. The primary outcome measure is caregiver depression. Secondary outcome measures are caregivers' burden, self-efficacy, problem-solving, and health-related quality of life and Veterans' functional abilities. Outcome measures are conducted at baseline and one and 12-weeks post-intervention. A budgetary impact will be conducted at the end of the study. Target enrollment is 227 stroke caregivers from three VA medical centers: San Juan, Puerto Rico, and Orlando and Tampa, Florida. Eligible caregivers who agree to participate in the study complete baseline measures and then are randomized into two groups. Participants in the intervention arm receive a nurse-led eight-session telephone problem-solving intervention and online

Key Points

- This ongoing study (IIR 15-117) seeks to test the efficacy of a telephone and online problem-solving intervention in Spanish for caregivers of Veterans post-stroke.
- This study is the first known randomized controlled trial to test a Spanish-language telephone and online intervention for caregivers in VA and addresses the need for culturally appropriate health information for an understudied population.
- The long-term goal is to partner with leaders to implement a culturally relevant, accessible, and cost-effective intervention for caregivers of Veterans post-stroke throughout VA.

education. Participants in the standard care arm receive normally provided VA care.

All caregivers of Veterans with a primary diagnosis of stroke who have received services from the VA Caribbean Healthcare System, Orlando VA Medical Center, or the James A. Haley Veterans' Hospital are eligible for participation if they meet the following criteria: 1) are the self-identified primary caregiver and provide the majority of care for a Veteran who received a diagnosis of stroke (ICD 10 codes I60.0-I69.998) within the last year and who has at least two activity of daily living deficits; 2) have Internet access and ability; 3) are reachable by cell or home phone; 4) indicate Spanish is their preferred language; 5) have moderate to severe stress; 6) self-identify as Hispanic; and 7) agree to random assignment to the intervention or standard care group. We exclude caregivers whose Veterans have a life expectancy of less than six months or are enrolled in home-based primary care or a telehealth program.

To date, we have enrolled 192 participants with 120 completed and 51 withdrawn participants. Reasons for withdrawal include Veteran's death or placement into a

Technology-Enabled Dyadic Intervention Can Meet the Needs of Both Patients and Caregivers

Dyadic behavioral interventions are designed to support both individuals with chronic health conditions and their informal caregivers in coping with emotional and practical challenges of chronic illness self-management. Well-designed, dyadic programs can improve patients' adherence to self-management recommendations, quality of life, and self-efficacy, while reducing hospitalization rates.² Unfortunately, dyadic interventions that simultaneously improve outcomes for patients and caregivers are rare. Furthermore, most dyadic interventions require communication between participants and facilitators in real-time. Compared to facilitated coaching, technology-enabled dyadic interventions have the potential to decrease the number of resources needed per patient-caregiver dyad, resulting in programs that are more personalized and scalable.²

We sought to develop such an intervention by adapting our telephone-based, facilitated, dyadic self-management program called Self-care Using Collaborative Coping Enhancement in Diseases (SUCCEED)¹ into a self-guided, web-based version (web-SUCCEED). SUCCEED was theoretically derived from our Dyadic Behavior Change Model. Semi-structured interviews with Veteran-caregiver dyads and an environmental scan of existing programs allowed us to identify three core components of SUCCEED: 1) skills to manage both individual and dyadic stress, 2) skills to manage the interpersonal stress in the Veteran-caregiver relationship, and 3) skills to build a fulfilling life for both Veterans and caregivers while managing chronic conditions. Participants of our successful SUCCEED pilot study as well as Veteran and caregiver stakeholders recommended that we create a self-guided, web-based version of SUCCEED. In this current study, we describe our process of adapting the format of the facilitated SUCCEED program into a self-guided, web-based version that would deliver the dyadic content of SUCCEED.

We developed web-SUCCEED in the following six steps (Figure 1).⁴

- 1. Ideation.** We determined content for web-SUCCEED based on the pilot test of SUCCEED, and with input from our multidisciplinary content experts.
- 2. Prototyping.** We developed the wireframes illustrating the look and feel of the website. We ensured the accessibility of web-SUCCEED for individuals with visual, hearing, and/or motor disabilities. The PI and web designers iteratively developed prototypes that included inclusive design elements (e.g., larger font size).
- 3. Prototype refinement via feedback from focus groups.** We elicited feedback on these prototypes from two focus groups of Veterans with chronic conditions (n=13). Rapid thematic analysis identified two themes: 1) online interventions can be useful for many, but should include ways to connect with other users, and 2) prototypes were sufficient to elicit feedback on the aesthetics; but a live website allowing for continual feedback and updating would be better. Focus group feedback was incorporated into building a functional website.
- 4. Finalizing the module content and scripts.** Our multidisciplinary team of content experts worked in small groups to adapt SUCCEED content so that it could be delivered in a didactic, self-guided format. Each module comprised three components: psychoeducation, skills training, and an action plan to practice skills. The final modules included the following.
 - Introduction and How to Create an Action Plan
 - Module 1: Skills to Reduce Stress and Improve Positive Emotions
 - Module 2: Skills to Reduce Relationship Stress and Improve Interpersonal Relationships

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Key Points

- Technology-enabled dyadic interventions can decrease the resources needed for both patients and their caregivers, resulting in programs that are more personalized and scalable.
 - The authors developed such an intervention by adapting a telephone-based, facilitated, dyadic self-management program called Self-care Using Collaborative Coping Enhancement in Diseases (SUCCEED)¹ into a self-guided, web-based version (web-SUCCEED).
- Module 3: Building a Fulfilling Life and Maintaining Behavioral Change
 - 5. Computer programming web-SUCCEED.** We chose WordPress which is both Section 508 compliant and widely used to support behavioral interventions in VA. We developed audio recordings of key exercises that could be accessed in the Resources section. Our team reviewed 600 stock photographs to choose those that represented a diversity of skin tones to suggest different races, ages, and a diversity of relationships (e.g., older woman-younger woman, two men and a child, Black man-Black woman). To allow user access while ensuring system security, each participant was required to have an e-mail address which served as their default User ID, which could not be changed. Users could change their display names after the initial logon. In addition to unique IDs, each user set their own password.
 - 6. Usability testing.** Sixteen participants – evenly divided amongst Veterans and caregivers – participated in usability testing. All participants completed at least one module and the usability survey. All Veterans were male, while all caregivers were female. Most participants identified as White, had at least a high school education,

Helping Informal Caregivers Navigate the Serious Illness of Older Veterans

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How care partners are supported is a significant concern in VA and beyond. Care partners – those friends and families called upon to provide daily care for Veterans – face challenges in that complex role. Care partners’ social and practical needs (e.g., food, clothing, transportation, utilities, housing/yard maintenance) present challenges, and health systems are not necessarily prepared to provide these types of support. Trained navigators may be able to help care partners connect to available services and supports in VA and in their respective communities.

Our 2021 study examined the feasibility of using navigators to support Veteran care partners. The study looked at the work of nine virtually trained human navigators who remotely helped 38 (30 completed 12-week intervention) care partners negotiate resources within VA and their communities across 12 North Carolina counties. In terms of demographics, 57 percent of the navigators were African American and 63 percent were 65 years or older. The 38 care partners

involved in the study cared for Veterans 65 years or older with serious illnesses, including advanced stage congestive heart failure (CHF), chronic obstructive pulmonary disease, dementia, and solid tumor cancer (~25 percent of each diagnosis enrolled). Half of the care partners were enrolled in a formal Caregiver Support Program; half were not.

Table 1 lists examples of navigator support provided to care partners during our pilot. Navigators provided this support by telephone due to COVID-19 and distance, an approach that was well-received by study participants. Table 2 shows representative feedback from care partners and navigators in the pilot.

Care partners rated satisfaction highly (mean: 4.6/5 at six wks; 4.7/5 at 12 wks) and navigator-care partner bonding highly as well (mean: 4.5/5 at 6 wks; 4.5/5 at 12 wks). Caregiving burden on the Caregiver Reaction Scale was 1.96 (base), 1.82 (6 wks), and 1.62 (12 wks). Results of the Zarit Burden Interview were 31.2 (base), 27.4 (6 wks.), and 27.3 (12 wks). Each navigator worked with three to four assigned care partners per

week over the study course. Time per week spent by navigators on the phone with a care partner or related to a specific care partner (including contacting agencies on the care partner’s behalf) averaged 32 minutes per week. Internet time researching services and supports for a specific care partner averaged 23 minutes per week. Overall, the navigation pilot provided 86 hours of phone time to care partners by navigators and 45 hours of online time gathering information for care partners. During weekly check-ins within the 12-week study period, navigators reported connecting care partners to needed supports ~80 percent of the time.

This study showed the feasibility of using trained navigators to support care partners of Veterans with serious illness. The next step is to show that this intervention is effective in meeting care partner needs and in decreasing their caregiving burden. Dr. Boucher is currently applying for VA funding to conduct a randomized controlled trial of this intervention model in the Durham VA Health Care System.

Table 1. Examples of Support Provided by Navigators to Care Partners in the Pilot Intervention

Home modifications	Arthritis exercises	Heart failure education
Weight loss resources	Respite	Coping with PTSD
Vegetarian restaurants	Home companions	Dealing with family deaths
Assistive devices	Public transportation options	COVID resources
Behavioral challenges/coping	Help with car repairs	Reimbursement forms for VA
Perioperative stress on family	Grants to cover household expenses	Encouragement/supportive conversation
College advice for children	Thrift shopping	Memory care
Exercise/Dieting resources	Chaplain referral	Coping for dementia

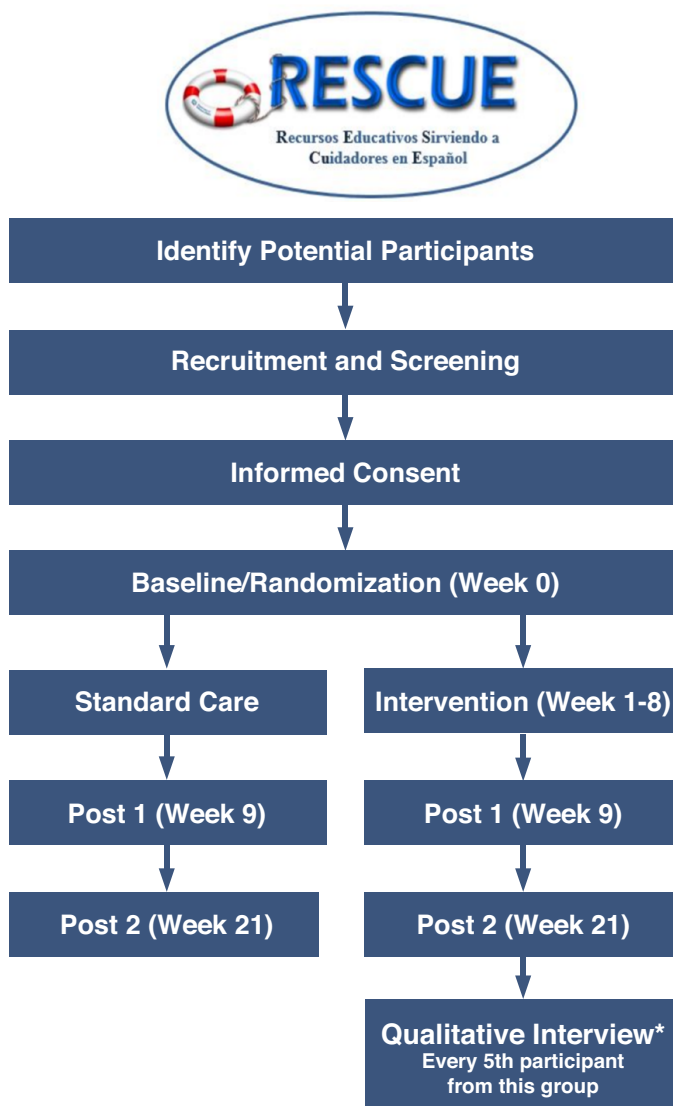
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Table 2. Examples of Pilot Participant Feedback

Care Partner Feedback	Navigator Feedback
“The program was wonderful.”	“We seemed to function as a team and everybody seems to be interested in everybody’s success”
“...makes you think about things you don’t normally do or need”	“Felt prepared; weekly meetings were useful to gain perspectives on techniques”
“...was beneficial to this new caregiver.”	“Workload was fine, allowed time to give to each caregiver.”
“I hope the program can expand.”	“My mother passed away but I was able to manage the workload.”
“The navigator helps reduce stress.”	“Have another way to give updates other than the weekly meeting, for when you cannot make it.”
	“The research staff support was great.”
	“Extra information [asked for by navigator] was delivered by study staff so the program could be fast-paced and I appreciated that.”

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Figure 1. RESCUE Study Timeline



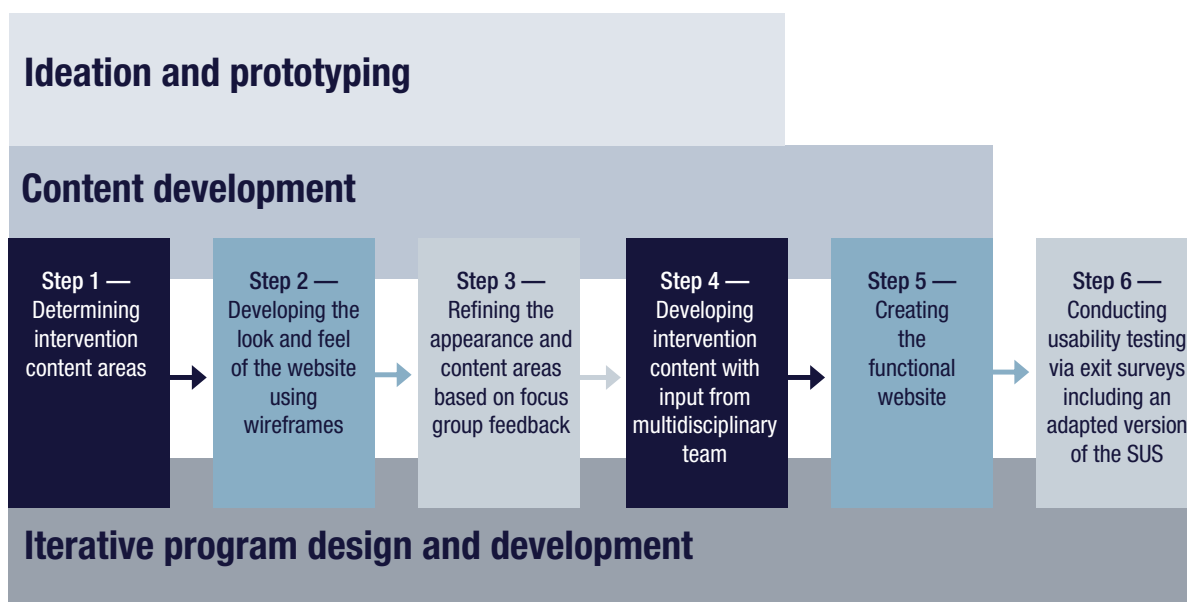
residential facility, or inability to contact the caregiver. Five project modifications have been implemented to address challenges associated with natural disasters and the COVID pandemic, including the addition of two new recruitment sites (Orlando and Tampa, Florida) and extending the duration of the project to make up for recruitment and enrollment shortages. Data analysis will begin in April 2024.

Implications

If effective, the intervention has the potential to reduce stroke caregiver depression, improve recovery of Veterans post-stroke, enable Veterans to remain in their homes, and reduce healthcare costs. This study will help identify novel interventions that can be implemented to reduce disparities for caregivers of Veterans with stroke that are sustainable in routine clinical practice and improve access to high-quality health care for minority Veterans.

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Figure 1. Web-Succeed Development

and reported that they could afford to pay their bills. Veterans and caregivers rated web-SUCCEED high on usability, noting that the website was easy to understand, easy to use, easy to complete, and they could learn to use the site quickly. Caregivers' mean scores on each usability item were lower than Veterans' although we did not test for statistical differences. Verbal feedback from Veterans included "it was helpful to me," "it was pretty easy, my wife helped me with it; I'm not that good with computers, [but] it wasn't that hard to use," and, "I've saved the URL and hope to access it in the future as a resource." Caregivers were also positive in their feedback noting, "I thought it was pretty user-friendly," and "overall, a good program." Veterans noted that they would use an intervention like this and would recommend this intervention to others, and noted that if permitted, they would continue to use web-SUCCEED beyond their study participation. Most participants completed modules in multiple sittings. We found that despite being self-guided, our program required engagement of the study team to encourage completion, answer questions, and provide technical assistance.

Estimated Cost

The software development phase accounted for \$100,000 in direct costs paid to the Washington, D.C.-based team including a project manager and a web designer (ideation and prototyping: \$25,000; programming the website: \$75,000). The other significant

contributor to cost was personnel. Project staff (excluding PI time) involved .5 FTEE Masters' level staff during the software development phase who served as the overall project coordinator and helped design the content and guides, and a total of 2.25 FTEE for the usability testing. All personnel were part-time on this project, which may have increased the time needed to carry out the project.

In conclusion, we successfully adapted web-SUCCEED using a systematic and rigorous process involving a multidisciplinary team of experts, Veteran and caregiver stakeholders, and human-centered design principles. We demonstrated the usability of this adapted web-based program for both Veterans and caregivers. Having dedicated, paid personnel for this project from a common source of funding may reduce both the cost and the time required to adapt existing programs into a web-based format.

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