

CAREGIVER CONSORTIUM NEWSLETTER



Summer 2022 | Volume 1, Issue 2

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Welcome to the summer issue of the Caregiver Consortium Newsletter, a collaboration between VA caregiver researchers, to keep you informed of research findings.

In this issue, we are highlighting results of three projects related to the impact of the COVID-19 pandemic on caregivers of Veterans. The first examines the use of secure text messages to support caregivers. The second and third projects examine the impact of COVID-19 on caregiver well-being, stress, and caregiving capacity.

We welcome your feedback! Please send your comments or information about relevant research for caregivers to julie.parishjohnson@va.gov

ANNIE AND COVID-19 - VA'S TEXT MESSAGING PROGRAM HELPS CAREGIVERS COPE



Annie is the Department of Veterans Affairs (VA) Office of Connected Care's automated short-message service (SMS) application for guided self-management. Annie was named after Lt. Annie G. Fox who was the first woman to receive the purple heart for combat. Veterans and Caregivers receive text messages on their phones. Messages are focused on a particular topic known as a protocol. Participants can respond to the messages in their own time or even go back and review messages when needed. Messages are mostly educational, motivational, activities or tips to help with a particular topic, or asking the Veteran to report back health related numbers like blood pressure or blood glucose levels.

As of February 2022, Annie had 43,229 participants and 363 different protocols focusing on education and self-care. In October 2019, Annie was opened to caregivers in addition to Veterans, and there are currently five protocols designed for caregivers that have had 6113 caregivers enrolled in them as of February 2022.

Protocol	Date Begun	# of caregivers
Stress Management	10/19	4315
Bereavement	03/20	256
Taking Care of You	05/21	1066
Dementia Behaviors	05/21	430
PTSD	01/22	46

In March 2020, a two-month COVID-19 Coronavirus Precautions protocol (CPP) Annie protocol for Veterans was rolled out. Caregivers can also be enrolled in the CPP and about 860 (7%) of participants are caregivers. The CPP is an interactive protocol that provides education on how to identify symptoms and actions to take.¹

Type of Message	Days Sent	Examples
Wellness checks	Monday, Wednesday, Friday, Sunday	Annie here. Are you feeling well today? Reply with keyword WELL and yes or no).
If the caregiver responds no, there is a follow-up message		Sorry to hear that. Symptoms of COVID19 include cough, fever, shortness of breath, fatigue, diarrhea, or loss of smell or taste. Do you have any of these? Reply HAVE Yes or HAVE No
Education messages	Monday, Wednesday, Friday	Annie here with another reminder. Keep hand sanitizer in your car and apply it before and after entering stores.

For Veterans, there is now a Coping during COVID protocol available, which is very similar to the Caregiver Stress Management protocol. During COVID, the stress management texts have

¹ For more information about the COVID-19 Veterans protocol, see: Saleem JJ et al. Veterans' response to an automated text messaging protocol during the COVID-19 pandemic. J Am Med Inform Assoc. 2020; 27(8):1300-1305. <https://doi.org/10.1093/jamia/ocaa122>

For Veterans, there is now a Coping during COVID protocol available, which is very similar to the Caregiver Stress Management protocol. During COVID, the stress management texts have been useful for caregivers, 47% of whom report that the texts have helped them manage their stress. As one caregiver said, "These texts are really helping me to come through this covid crisis. I was getting a lot of anxiety because of my husband allowing people to come over without mask." Caregivers have also requested, "More COVID-19 stress related topics." Caregivers who have completed anonymous feedback surveys on the various protocols report that they really appreciate the messages and don't want them to stop. Annie caregiver protocols will continue to help caregivers cope with new and continuing challenges.

If you have questions about Annie, you can email VHAMEMTextCare@va.gov



SHORT-TERM EFFECTS OF THE COVID-19 PANDEMIC ON WELL-BEING OF CAREGIVERS OF VETERANS

Author: Katherine Miller, Durham VAMC

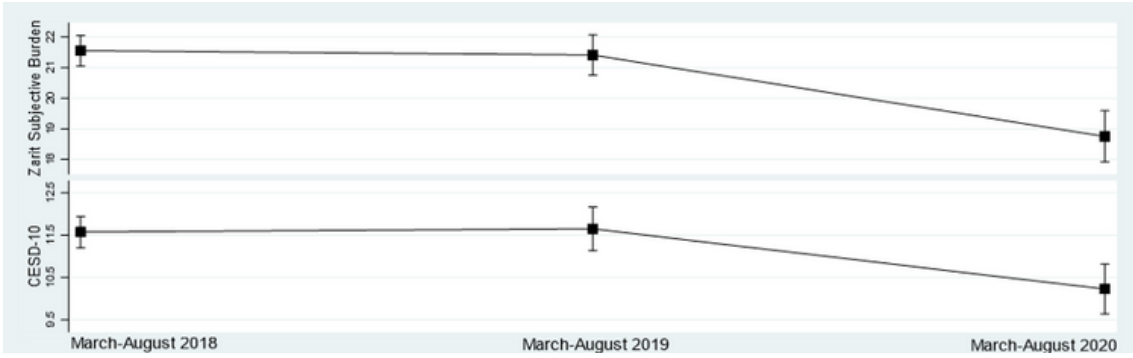
The VA Program of General Caregiver Support Services provides support to caregivers of Veterans through services including, but not limited to, peer-support mentoring, counseling, training, and education. Since 2018, VA Caregiver Support Program Partnered Evaluation Center has conducted telephone-based surveyed caregivers of Veterans on an annual basis. We collected data about caregiver well-being, e.g., subjective burden and depressive symptoms.

Because we collected data pre- and during the pandemic, we were able to measure how caregiver well-being changed during the pandemic compared to pre-pandemic. Using repeated observations of individual caregivers is a contribution to our understanding of the pandemic effects on caregivers because we do not rely on self-reported changes (which may be subject to recall biases), but rather rely on data collected from caregivers up to two years pre-pandemic.

We analyzed the surveys of 903 caregivers collected from March 2018-August 2018, March 2019-August 2019, and March 2020-August 2020. We examine caregiver subjective burden (Zarit Subjective Burden) and depressive symptoms (Center of Epidemiologic Studies Depression Scale). Because our data collected during the pandemic only includes March 2020-August 2020, our findings are limited to the immediate effects of the pandemic on caregivers of Veterans.

During the pandemic, we observed slight improvements for caregivers across well-being measures. Yet prior to the pandemic, we observed high scores (indicating worse outcomes). Prior to the pandemic, caregivers score positive for clinically significant caregiver burden and probable depression. While we do not observe worsening indicators of caregiver well-being during the pandemic, caregiver burden and depressive symptoms remain clinically significant during-COVID-19 pandemic.

Figure 1. Model Estimated Mean Outcome Values with 95% Confidence Intervals



These findings illuminate pandemic-related impacts of caregivers receiving support through the VA pre- and during the pandemic while caring for a population of frail, older care-recipients with a high burden of mental illness and other chronic conditions. Considering the long-term impacts of the pandemic to increase morbidity and the expected increased demand for caregivers in an aging population, these consistently high levels of distress despite receiving support highlight the need for interventions and policy reform to systematically support caregivers more broadly.

THE IMPACT OF COVID-19 PANDEMIC ON VETERAN CAREGIVERS

VETCORE

PROJECT BRIEFING: February 2022

The Impact of the COVID-19 Pandemic on Veteran Caregivers (VA HSR&D Pilot PP0 20-342)
PI: Lauren Penney, VetCORE@va.gov

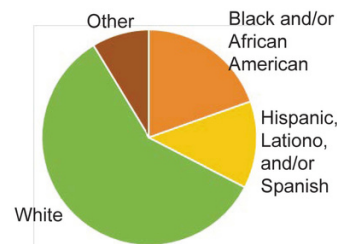
Survey Respondents: 46

----Interview Respondents: 26

Median age: 59 (range: 32-83)

Gender: 96% Female

83% are caregiver to a spouse



Survey Findings: Recent data aligns with data collected in summer 2022

Change in Stress

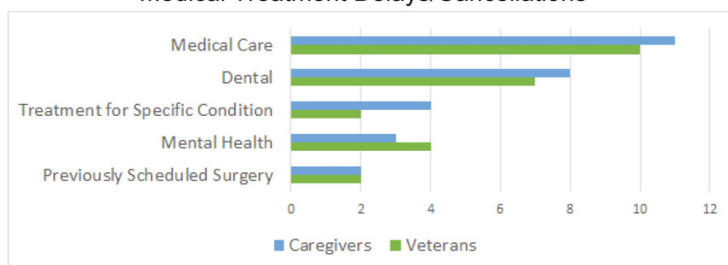
More Stressed (n=31)
About the same (n=14)
Less Stressed (n=1)

67% report increased stress

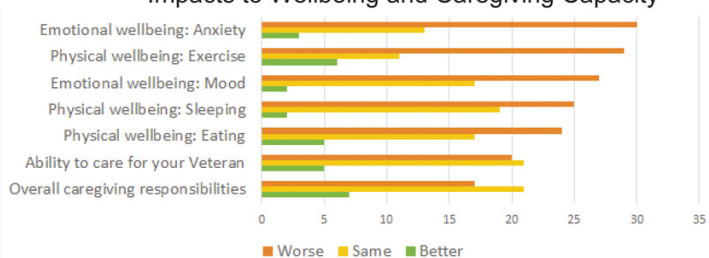
Top 5 Sources of Increased Stress

1. Worry about COVID-19 infection
2. Increased caregiving responsibility
3. Delayed access to care
4. Concern about vaccine safety
5. Employment or financial concerns

Medical Treatment Delays/Cancellations



Impacts to Wellbeing and Caregiving Capacity



Interview Findings: Themes observed in summer 2022 persist, plus new insights

We still see:

- Positive and negative impacts to health care access due to VA and caregiver COVID precautions/physical distancing
- Disruption of routines that may have been important anchors for Veterans or outlets for caregivers
- Declines in Veteran physical and/or mental health (including cognitive functioning)
- Largely positive experiences with Telehealth, some barriers with technology and/or getting timely assessment and treatment for new issues
- Increased caregiver centrality to Veterans' support and care, impacting Veteran-caregiver relationships in positive and negative ways

And have identified:

- Sense of normalization and hope with vaccines and return to more in-person activities ...
- But ongoing uncertainties concerning future surges and safe practices
- Mostly positive responses to enhanced caregiver support program, but frustrations about difficulty identifying services, managing respite care, and PCAFC denials
- Changes in work or living situation to address enhanced Veteran needs and/or reduce risk of exposure

Caregivers' Recommendations: not COVID-specific but reflect challenges often exacerbated by the pandemic

- Adopt policies and practices for meaningful inclusive care:**
 - Listen to caregivers, they know things staff/providers don't
 - Allow fuller access & participation while assuring veteran privacy
- Streamline processes for respite & community care:**
 - Reduce paperwork burden (e.g., multiple authorizations)
 - Relieve caregivers the task of coordinating & managing outside care
- Help caregivers navigate and problem solve offerings**
 - Someone they can call to help them understand requirements
- Strengthen CSP outreach for & accessibility**
 - Engage caregivers personally and earlier in their caregiving journey (e.g. through primary care)
 - Develop an online catalog of recordings of trainings
- Create opportunities for caregiver networking & peer support**
 - Reduce barriers to caregivers exchanging contact info in groups
- Make PCAFC more caregiver-friendly by assuring:**
 - PCAFC staff: caregiver advocates in assessment processes
 - Eligibility criteria: clear, meaningful, & applied consistently

Findings related to a caregiver well-being were shared at Academy Health's Annual Research Meeting in June 2022. View that presentation by going to <https://www.youtube.com/watch?v=e53GXpQTVjQ>