

SUPPORTING STATEMENT - PART A

Military Caregiver's Program: Heart of Recovery. Caregiver's Assessment of Responsibility Evaluation

1. Need for the Information Collection

U.S. Army Regulation 40-5 "Preventive Medicine" (pg. 14, 2-19) requires MEDCOM to conduct evaluations of regional and local programs in support of the Department of the Army Surgeon General (DASG) oversight responsibilities. This regulation is included in the submission package and is entitled "Army Regulation 40-5, Preventive Medicine."

A 2014 RAND study titled "Hidden Heroes, America's Military Caregivers" (RAND Corporation, Santa Monica, CA) assessed the unique needs of wounded, ill, or injured service members (incl. Veterans, National Guard, Reservists, and Active Duty) and the Military Caregivers who support them. Military Caregivers are friends, family, and others who provide unpaid assistance to services members and this report estimated that there are a total of 5,499,253 Military Caregivers in the United States. Many Caregivers receive little to no emotional, physical, social, or financial support for the duties they perform, and this can affect their physical and mental wellbeing. Currently, there is no comprehensive and coordinated program that specifically helps our Army Caregivers navigate caregiving responsibilities safely and effectively.

In support of AR 40-5 and the Department of Defense's mandate for the proper and proactive care of its service members, DASG has sponsored a Commander's Initiative Group (CIG) initiative for an in-depth, focused assessment of the Army's Military Caregiver population, which will inform the creation of the Military Caregiver's Program Heart of Recovery. Using background information from the RAND study as a baseline, the focus of this assessment will be to identify and measure levels of burden Military Caregivers experience in their overall personal health and wellbeing. The overall intent of this information collection effort is to provide program managers with data that can be used to continue to develop programs and support that will improve outcomes for wounded, injured, or ill Soldiers and their Caregivers.

2. Use of the Information

Data will be collected from Military Caregivers who serve Service Members at one of four locations: Joint Base San Antonio (JBSA), Texas; Joint Base Lewis McChord (JBLM), Washington; Fort Sill, Oklahoma; or Fort Bragg, North Carolina. These four locations were purposively chosen with stakeholder input as strategic sites that potentially have a large number of Army caregivers and because each has unique attributes related to potential caregiver populations and available resources. For example, JBSA and JBLM are joint bases with joint service resources; Fort Bragg has a very large Warrior Transition Unit and military treatment facility. Fort Sill does not have a Warrior Transition Unit and is a training location. Most importantly, these sites were chosen because they will be locations where a concerted caregiver initiative (based on these survey findings) will be initially put in place. The intent of this survey is to perform a needs assessment of a purposive sample of the population, from which the needs of

Military Caregivers can be derived and then addressed. This survey is not meant as a research study that will be generalizable to an entire population. For the purposes of this evaluation, Military Caregivers are defined as: anyone who provides unpaid care and assistance or receives Special Compensation for Assistance with Activities of Daily Living (SCAADL) benefits) for, or manage the care of, someone who is at least 18 years old and has an illness, injury, or condition for which they require outside support. Support may include help with tasks such as personal care, bathing, dressing, feeding, giving medicines or treatments, help with memory tasks for someone with brain injury, help coping with symptoms of Posttraumatic Stress Disorder (PTSD), transportation to doctors' appointments, or arranging for services, etc. A Military Caregiver is not required to live with their care recipient. Care and assistance are considered unpaid if you provide services without receiving financial compensation in exchange for doing so.

It is requested that Military Caregivers respond to data collection efforts because their first-hand experiences are necessary to determine the needs of this Military Caregiver population. Without directly surveying Military Caregivers, it would be impossible to understand the level of caregiver burden Military Caregivers experience and the training and other assistance they would like to receive in future. Understanding current caregiver burden, and Military Caregiver needs, is crucial to the development of the "Heart of Recovery: Military Caregiver's Program," as it will ensure that the program will be utilized and is set up to be potentially effective.

The data collection instrument, entitled the Caregiver's Assessment of Responsibility Evaluation (CARE), was created using a combination of validated questionnaires and subject matter expertise from stakeholders. Question 1, which asks about caregiver tasks, was adopted from the U.S. Veterans Affairs (VA) Caregiver Support website

(United States Department of Veterans Affairs, 2016). Question 11, which asks about the time spent caregiving, was evidence-informed by nearly 13 studies (Arora & Wolf, 2014; Brinda, Rajkumar, Enemark, Attermann, & Jacob, 2014; Dumont, Jacobs, Turcotte, Anderson, & Harel, 2010; Franche, Pole, Hogg-Johnson, Vidmar, & Breslin, 2006; Gaugler et al., 2003; Kate, Grover, Kulhara, & Nehra, 2013; Li et al., 2013; Marin et al., 2000; Pressler et al., 2013; L. Smith et al., 2014; van den Berg & Spauwen, 2006) examining the amount of time spent caregiving. The resulting question responses in hours came from a study by Doser et al. (Doser & Norup, 2014). Similarly, response options on Question 13, which asks about the amount of money spent caregiving, was informed by an article written by van Houtven et al. (Van Houtven et al., 2012).

Question 14 includes items from the Zarit Burden Inventory (Zarit, Reever, & Bach-Peterson, 1980), and question 15, which includes two items from the “personal gain” section of a validated gerontology questionnaire (L. I. Pearlin et al., 1990; Skaff & Pearlin, 1992). The entirety of *Section E: Health Status of the Caregiver* was also derived from validated self-report scales. Question 20 was taken verbatim from the first question of the Medical Outcomes Study 36-Item Short Form (SF-36); Question 21 used the Michigan Department of State Public Health Physician’s Statement of Examination; Questions 22-24 came from the Physical Function, Fatigue, and Sleep Disturbance scales of the PROMIS-29, which is a short-form health questionnaire validated repeatedly by the National Institute of Health (NIH); and Questions 25-26 originally came from Littman et al. (Littman, White, Satia, Bowen, & Kristal, 2006), but were later requested to change to the current response options during the process of gaining OMB approval.

In addition, both the above caregiver literature and Army expert knowledge was used to create the CARE survey. Soldiers deployed multiple times helped inform the language used for Question 17, and scientists in the Epidemiology and Surveillance Directorate (EDS) of the Army Public Health Center provided data on the most common ailments and medical diagnoses for Soldiers in the Army, which guided response options for Question 18. The resources and services listed in Questions 27-28 came directly from the initial Caregiver White Paper (Campano, 2016) or from personnel on each of the pilot installations. The rationale for asking questions about the length of training was also derived from stakeholder subject matter expertise; stakeholders expressed concerns that often Caregivers have very limited time because they spend most of their waking hours caring for their Care Recipient and need to better understand the amount of time that Caregivers are willing to spend in training to develop materials most relevant to them and their needs. Lastly, subject matter experts from the Public Health Information Directorate provided response options for Question 43 (Watkins & Santo, 2015).

The CARE survey will be an online survey, programmed into Verint Enterprise Feedback Management (EFM) 15.2 software, which can be completed on any electronic device that has access to the internet, once they have been provided with the link. Verint EFM 15.2 has been approved as a method of administering this survey through MEDCOM's Networthiness program, in coordination with the Army Public Health Center's (APHC's) Information Management Division. When Verint is employed, the option to collect IP addresses will be disabled, so that no Military Caregiver can be identified or traced via their IP address. No part of the CARE survey is mandatory, and Military Caregivers can exit the survey at any time, or

continue to the end of the survey and press the submit button once they have finished the survey. Screenshots of the entire online survey have been included in the submission package, and that document is entitled "Screenshots for Heart of Recovery Survey." Of particular note is page 3 of "Screenshots for Heart of Recovery Survey," which shows the consent process.

Caregivers are initially provided all the information about the survey collection, and then are given the chance to press the "next" button if they agree to participate in the survey, and the only way to proceed with the survey is to press "next." Military Caregivers will be reached by a number of different communication means regarding their participation in the CARE survey, including the social media sites of Facebook and Twitter; advertisement on the Heart of Recovery's program website; local advertisement on the four installations of interest via the Public Affairs Office (PAO); local advertisement on the four installations at the Military Treatment Facilities (MTFs); contact with the local Family Readiness Groups (FRGs) and Community Health Promotion Councils (CHPCs); and through local Caregiver organizations on or near the four installations. The messaging plan for the survey has been included in the submission package, and is entitled "Care Messaging Plan." Military Caregivers who participate in the survey will not be given a unique identification number, in order to ensure anonymity and to keep the amount of burden to a minimum. However, at the beginning of the survey, Caregivers will be asked not to take the survey more than once and the risk of Caregivers taking the survey more than once is deemed more acceptable than the risk of making Caregivers uncomfortable or overburdened by requiring a unique identification number.

Once all data have been collected via online survey, data will be downloaded from Verint to a Microsoft Excel spreadsheet and then will be imported into Statistical Analysis Software (SAS)

version 9, where they will be further processed and analyzed. These data files will only be accessed by program evaluators in the APHC Public Health Assessment Division. As a public health organization, APHC has the regulatory authority to obtain Protected Health Information (PHI) (see HIPAA 1996 and DoD Regulation 6025.18r), though no PHI is being collected within this survey. As APHC employees, these program evaluators were provided the proper training to ensure maintenance of confidentiality during data collection, analysis, and reporting. All members of the evaluation team have taken the following mandatory trainings: HIPAA, Information Assurance, and Ethics. All data will only be stored and accessed on APHC's secure S:\ drive, which is a restricted network space designated by APHC's Information Management Division for this purpose. Records will be stored securely for 5 years before destruction.

The end result of data collection from Military Caregivers via the CARE survey will be to inform the creation of the Heart of Recovery Military Caregiver's Program, which will be based on actual Military Caregiver level of burden and needs. The program will be put in place initially at the four locations from which we are collecting these survey data with the intent of ultimately implementing Army-wide if initial pilots suggest the program is meeting Caregiver needs and effective at improving outcomes such as reduced caregiver burden and improved quality of life. This program will ideally be comprehensive and well-coordinated so that other resources for Military Caregivers are utilized to their fullest extent.

Before administering the CARE survey to everyone, it was pilot tested in 2016 with 9 Caregivers (3 parental Caregivers, 3 spousal Caregivers, and 3 friends/extended family Caregivers) to determine readability and appropriateness. This pilot testing consisted of a semi-structured interview; however, since it was done with 9 participants or less, it does not count as

a collection. Caregivers received the survey via an email requesting their participation in this pilot testing, as shown in AADA File 5, page 2, lines 13-20 and appendices C-D. Caregivers were only asked to read the survey, not complete it, and no data from the survey was collected in the pilot-testing/review phase. After the Caregiver consented to review the survey, a time was scheduled to have a non-recorded telephone call for the semi-structured interview. One evaluator asked the questions detailed in appendix D, while the other evaluator took notes by hand once consent to review the survey and participate in the interview was obtained. No personal identifying information was obtained during these interviews and the notes from each telephone interview were transcribed and then saved to APHC's secure S:\ drive, which is a restricted network space designated by APHC's Information Management Division for this purpose. Records will be stored securely for 5 years total (3 years from now) before destruction. The end result of pilot testing was that minimal changes were made to the CARE survey to ensure it was appropriate, relevant, and readable to the target audience. Caregivers who participated in the pilot all indicated that that they found the survey appropriate and did not cause them any harm. The survey under current OMB review reflects changes made based on pilot participants.

3. Use of Information Technology

All responses (100% of survey data) will be collected electronically via an Army-controlled electronic system (Verint EFM 15.2). Survey respondents will visit <http://militarycaregiver.health.mil/survey> which will direct them to the survey, which is housed on the Army Public Health Center server. Results will collected and housed on the Army Public

Health Center server, manually loaded into Microsoft Excel, and then imported into SAS for processing and analysis.

4. Non-duplication

The information obtained through this collection is unique and is not readily available for use or adaptation from another cleared source.

5. Burden on Small Businesses

This information collection does not impose a significant economic impact on a substantial number of small businesses or entities.

6. Less Frequent Collection

This information collection is a one-time collection only. This is the most infrequent collection interval possible, without jeopardizing the intent of this information collection as a way to assess Military Caregivers' burden level and needs. Without the collection of this information, the Heart of Recovery Military Caregivers' Program will not be created based on the evidence-based needs of the population and therefore may fail in its implementation and purpose.

7. Paperwork Reduction Act Guidelines

This collection of information does not require collection to be conducted in a manner inconsistent with the guidelines delineated in 5 CFR 1320.5(d)(2).

8. Consultation and Public Comments

Part A: PUBLIC NOTICE

A 60-Day Federal Register Notice for the collection published on Thursday, January 5, 2017.

The 60-Day FRN citation is Vol. 82, No. 3 FRN 1327.

One comment was received during the 60-Day Comment Period. It is included below, as well as our Agency's response to the comment.

Comment: "I am the wife of an Army Vietnam Vet with a disability rating of 50% or more for PTSD. He is prone to depression, addictive behavior, vivid re-living of events from Vietnam while asleep. It often involves vocalizations, movements such as running, swinging, pushing and fighting all while asleep. The depression has affected his job performances and his ability to function normally. I am also the daughter of a WWII Marine who saw combat on Guam, Okinawa and Fiji. I cared for my father for the last eighteen months of his life. He also exhibited PTSD symptoms. He cried while discussing his service or anything service related. He would have very similar symptoms to my husband in terms of calling out, thrashing, and engaging in combat with unseen assailants. I would here him calling out for someone to identify themselves and then engage the phantom person in his sleep, breaking lamps or otherwise damaging things in the bedroom in the process. I remember him being depressed and talking about recon operations that occurred during the war when he was in his fifties. IN his eighties he developed cancerous lesions on his scalp where he had experienced severe sunburns while on Guam. These required excisions, and the wounds needed to be cleaned and redressed. Later there were chemotherapy creams that blistered the scalp tht had to be applied at home per a protocol. At almost ninety, when he passed he, was feeling that God no longer could forgive

him and love him. It was a victory for him when he suffered his final stroke to tell me that "God loved him, because he knew that he did his best." Finally he could rest from his internal struggle. Perhaps it was the stroke. My role as a caregiver for both of these important men involves organizing medications and putting pills into a daily dose container, refilling medications, cleaning, laundry, meals, general homemaking...and at times driving them to appointments when they are impaired to the point that they cannot drive. My father suffered auditory nerve degeneration and needed a cochlear implant, I changed batteries, arranged for appointments, called and arranged for replacement parts and reprogramming of the receiver as needed. When necessary, I restricted his driving for safety reasons, and took on the role of chauffeur. During the time I was away from home caring for my father, my husband became depressed, and I was away for two months because of my father's last hospitalization, caring for his older sister, and being present for the attorney appointments. We were discussing the will with an attorney when my husband called and told me he had lost his job while I was there. I feel that the day to day emotional support is an essential part of care giving and keeping these important men healthy emotionally, psychologically and physically. When I returned I found a number of things broken or missing which indicates the severity of his symptoms in my absence, He did not apply for a disability rating until last year, and the response with a rating was fairly rapid. My narrative not only outlines the day to day tasks of a caregiver for veterans, but also the necessity to keep a consistent presence. Once when we had full time care come in for my father to replace me, it cost \$9800 for one month through an agency called Comfort Keepers. My father at that time was tending to all of his own care, medications, dressing and meal preparation. As time went on he required more support, and this consideration needs to

be written into any disability payments, respite care for an unrelated caregiver is essential. I hope this will assist you in your data collection for caregiver needs.

I am a 61 yr old female with the following health problems, 1- degeneration of the hip socket and sacral spine, which limits how long I can keep going physically, but if I break my time up and rest my hip, I can easily perform the tasks needed as a caregiver. 2-asthma and allergies, 3-diabetes (A1C says it is currently in remission) I am in need of health care benefits as I cannot work and provide care at the same time with my limitations.”

Response: Thank you for your dedication to caring for our Service Members. It is for people like you that the Army is establishing the Military Caregivers Heart of Recovery Program.

Part B: CONSULTATION

No additional consultation apart from soliciting public comments through the 60-Day Federal Register Notice was conducted for this submission.

9. Gifts or Payment

No payments or gifts are being offered to respondents as an incentive to participate in the collection.

10. Confidentiality

A Privacy Act Statement is not required for this collection because we are not requesting individuals to furnish personal information for a system of records.

A System of Record Notice (SORN) is not required for this collection because records are not retrievable by PII.

A Privacy Impact Assessment (PIA) is not required for this collection because PII is not being collected electronically.

Although a Privacy Act Statement, SORN, and PIA are not required, a privacy advisory statement has been added to the survey collection to ensure communication about data usage and the voluntary nature of the survey. This can be found under the header “What information am I required to provide and what is voluntary?” in the survey introduction.

For the Record Schedule, the data collected will be consolidated and collated into an overall analysis with the source documentation destroyed after five years of the assessment's end. All data will only be stored and accessed on APHC's secure S: drive, which is a restricted network space designated by the Information Management Division for this purpose.

11. Sensitive Questions

Yes, this survey asks about race/ethnicity; personal financial matters, including annual household income and the amount of personal funds spent to provide Caregiver support in the past 12 months; biological sex; age; and health status. All sensitive questions are in compliance with DoDI 3216.02 “Protection of Human Subjects and Adherence to Ethical Standards in DoD-Supported Research” (08NOV2011) and with “Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race and Ethnicity” (15DEC2000). It is necessary to ask

about demographics information in order to address the extent to which demographic disparities could exist within caregiver burden, as evidenced by the RAND report, and caregiver needs may be different based on demographic information as well. It is therefore important we understand the population's demographic makeup before tailoring a program to them. Similarly, it is necessary to ask about health status and level of caregiver burden, as these factors will ultimately shape the resource(s) made available to Military Caregivers through the Heart of Recovery: Military Caregiver's Program.

12. Respondent Burden and its Labor Costs

a. Estimation of Respondent Burden

1. Caregiver Assessment of Responsibility Evaluation

- a. Number of Respondents: 5,000
- b. Number of Responses per Respondent: 1
- c. Number of Total Annual Responses: 5,000
- d. Response Time: 30 minutes
- e. Respondent Burden Hours: 2,500 hours

3. Total Submission Burden (Summation or average based on collection)

- a. Total Number of Respondents: 5,000

- b. Total Number of Annual Responses: 5,000
- c. Total Respondent Burden Hours: 2,500 hours

b. Labor Cost of Respondent Burden

1. Caregivers Assessment of Responsibility Evaluation

- a. Number of Total Annual Responses: 5,000
- b. Response Time: 30 minutes
- c. Respondent Hourly Wage: \$16.00
- d. Labor Burden per Response: \$8.00
- e. Total Labor Burden: no more than \$40,000.00

3. Overall Labor Burden

- a. Total Number of Annual Responses: 5,000
- b. Total Labor Burden: no more than \$40,000.00

The Respondent hourly wage was determined by using the Department of Labor Wage Website (<https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-income-people.html>).

13. Respondent Costs Other than Burden Hour Costs

There are no annualized costs to respondents other than the labor burden costs addressed in Section 12 of this document to complete this collection.

14. Cost to the Federal Government

a. Labor Cost to the Federal Government

1. Caregivers Assessment of Responsibility Evaluation (CARE)

- a. Number of Total Annual Responses: 5,000
- b. Processing Time per Response: 10 minutes
- c. Hourly Wage of Worker(s) Processing Responses: \$43.00
- d. Cost to Process Each Response: \$7.17
- e. Total Cost to Process Responses: \$35,850

2. Overall Labor Burden to Federal Government

- a. Total Number of Annual Responses: 5,000
- b. Total Labor Burden: No more than \$35,850

b. Operational and Maintenance Costs

- a. Equipment: \$0.00

- b. Printing: \$500.00 for printing and shipping brochures to market the survey
- c. Postage: \$0.00
- d. Software Purchases: \$0.00
- e. Licensing Costs: \$0.00
- f. Other: \$5,200.00 for marketing survey via cable and targeted social media advertisements.
- g. Total (P: add A through F in this section): \$5,700.00

- 1. Total Operational and Maintenance Costs: \$5,700.00
- 2. Total Labor Cost to the Federal Government: \$35,850
- 3. Total Cost to the Federal Government: \$41,550

15. Reasons for Change in Burden

This is a new collection with a new associated burden.

16. Publication of Results

The results will be published in the form of a DoD technical report, entitled “A Needs Assessment for the Military Caregiver’s Program: Heart of Recovery.” Results will be published because this information may be useful to other Military programs attempting to meet the needs of Military Caregivers and provides background on an underserved population of the Military Family. Note: The intent of this survey is not to generalize findings but is rather to

summarize the experiences and needs of the caregiver respondents who participate in this collection. To that end, the publication of findings will use language such as, “Among the survey sample of XX respondents, YY% indicated...”

17. Non-Display of OMB Expiration Date

We are not seeking approval to omit the display of the expiration date of the OMB approval on the collection instrument.

18. Exceptions to “Certification for Paperwork Reduction Submissions”

We are not requesting any exemptions to the provisions stated in 5 CFR 1320.9.