

Creating Better Support for our Nation's Hidden Heroes

A Research Blueprint for Military and Veteran Caregivers

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Creating Better Support for Our Nation's Hidden Heroes: A Research Blueprint Military and Veteran Caregivers

Testimony of Terri Tanielian¹
The RAND Corporation²

Before the Special Committee on Aging
United States Senate

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Thank you, Chairman Collins, Ranking Member Casey, and distinguished committee members for inviting me to testify today. My name is Terri Tanielian and I am a senior behavioral scientist at the RAND Corporation, where I have studied issues that impact military servicemembers, veterans, their families, and their caregivers for the past 17 years. During this time, and with funding support from the Elizabeth Dole Foundation, I have led three sequential studies focused on the individuals who provide care and assistance to our nation's wounded, ill, and injured veterans.

The three studies conducted at RAND have been critical in shining a light on the number and characteristics of military and veteran caregivers, as well as the burdens they face.³ Before I outline the recommendations from our newest report designed to inform future research on military and veteran caregivers, I would like to provide a bit of context about why focusing on this population is so important.

¹ The opinions and conclusions expressed in this testimony are the author's alone and should not be interpreted as representing those of the RAND Corporation or any of the sponsors of its research.

² The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest.

³ Rajeev Ramchand, Terri Tanielian, Michael P. Fisher, Christine Anne Vaughan, Thomas E. Trail, Caroline Batka, Phoenix Voorhies, Michael Robbins, Eric Robinson, and Bonnie Ghosh-Dastidar, *Hidden Heroes: America's Military Caregivers*, Santa Monica, Calif.: RAND Corporation, RR-499-TEDF, 2014. We use the term military and veteran caregiver to include both those caring for a current member of the military (including active-duty, reserve, and National Guard members) and those caring for a former member of the military (commonly referred to as a veteran).

The Caregiving Context

There are more than 20 million veterans living in the United States today, many of whom have service-connected conditions or disabilities that require ongoing support and care. Supporting these wounded, ill, and injured warriors are the nation's "hidden heroes"—caregivers who provide unpaid, informal support with activities that enable current and former U.S. servicemembers to live fuller lives. They are an essential component of the nation's care for returning warriors. Recently, these caregivers have been the subject of much national attention. Starting in 2010, new federal programs were created to ensure improved support for caregivers; however, at the time, little was known about the characteristics and needs of this population.

In 2014, the RAND Corporation published work supported by the Elizabeth Dole Foundation titled *Hidden Heroes: America's Military Caregivers*.⁴ This study was the first to rigorously assess how many caregivers were aiding current and former servicemembers, their characteristics, the value they contribute to society, and the risks they face as a result of their caregiving roles. The RAND study also examined the existing programs and policies that support military and veteran caregivers and highlighted gaps in that support landscape.

Four of the study findings were of particular importance and serve as context for our newest report. First, of the 5.5 million individuals who were providing care and assistance to a current or former member of the U.S. armed forces, 20 percent (1.1 million) were supporting an individual who served after the terrorist attacks of September 11, 2001 (9/11). Second, the study found that post-9/11 caregivers were different from caregivers for persons who served before 9/11. Most significantly, they were younger, more were spouses, and more were in the labor force themselves. Third, while there were many programs designed to support caregivers, post-9/11 caregivers were ineligible for many of them because the person they were caring for was too young; they were not related to the servicemember; or they were caring for a person with a condition such as posttraumatic stress disorder or traumatic brain injury, and existing programs were for caregivers of persons with cancer or Alzheimer's. Fourth, the study identified significant threats to the future of military caregiving—based, most notably, on aging parents serving as caregivers who may need caregivers themselves, as well as the increasing stress faced by young spouses.

Based on these and other findings, the 2014 RAND report outlined recommendations for ensuring better support for military and veteran caregivers in the future. Among these recommendations was a call for increased investment in research on the population. Specifically, the recommendation was to:

- Ensure continued research into the evolving need for caregiving assistance among U.S. servicemembers and veterans, particularly for post-9/11 servicemembers as they age, and the resulting evolving demands on their caregivers.
- Conduct additional and continued research to document the needs of and outcomes for caregivers so that interventions can be better tailored or targeted to reduce or mitigate the negative consequences associated with caregiving.

⁴ Ramchand et al., 2014.

- Increase the amount of research that identifies the efficacy (i.e., whether an intervention has the intended effect under ideal circumstances) and effectiveness (i.e., whether an intervention has the intended effect in usual, real-world conditions) of caregiver support programs and policies to ensure that resources are being used efficiently and that evidence-based programs and policies are promulgated. Where programs and policies have not been rigorously assessed, they should nevertheless be rooted in relevant outcome data and the best available research findings.

Since the release of the 2014 study, there has been action on many of the recommendations, including additional research funded to evaluate military and veteran caregiver support programs. For example, the Department of Veterans Affairs (VA) launched an evaluation of its Comprehensive Caregiver Support Program, and the Bristol Myers Squibb Foundation funded an evaluation of the Military Veteran Caregiver Network. While these studies will yield valuable insights on whether specific programs have been effective, longitudinal research is still needed to inform our understanding of how caregiver needs evolve over time as caregivers age and their care recipients' needs change, how specific programs are working, and how caregiving affects specific subgroups of caregivers.

The Need for a Research Blueprint

Recognizing the need for future research on caregiving, the Elizabeth Dole Foundation requested that RAND develop a research blueprint to guide future national investments in this area. To craft this research blueprint, we reviewed the literature, conducted a survey, and solicited information in a structured, web-based exercise from several groups of stakeholders: policy and program officials, government officials, researchers, clinicians, funders, advocates, care recipients, and caregivers. Through these processes, more than 175 individual stakeholders provided input to guide the development of the blueprint and generate consensus around the research priorities. The blueprint is intended to convey a vision for future research that will build more effective support for military and veteran caregivers. There are many potential ways this blueprint can be used by different stakeholder groups, but by sharing it with you, we hope it will serve as a guide for understanding existing gaps in the knowledge base about military and veteran caregivers and inform your thoughts about opportunities for how to invest in new research initiatives that affect our nation's veterans and their caregivers.

The Blueprint: Ten High Priority Research Objectives

We identified ten high-priority research objectives to further the field of research into military and veteran caregiving. These are:

- 1. Who are the nation's military and veteran caregivers?** There are gaps in the existing knowledge about certain groups of military and veteran caregivers, as well as caregivers more broadly—for example, children serving as caregivers, caregivers for whom English is not a first language, male caregivers, caregivers with preexisting or chronic medical conditions, college-aged caregivers, caregivers with disabled children, and caregivers for those who served in the military before 9/11. As the needs of care recipients change,

demographic trends shift, and the landscape of care for families continues to transform, describing caregivers will become increasingly important.

2. **What societal cost savings can be attributed to caregivers?** Caregivers play a critical role in supporting the needs of their care recipients, often enabling them to live in noninstitutionalized settings. The reliance on informal caregivers often defrays costs associated with formal caregiving. Smaller families, an increasingly aging population, and women's growing participation in the workforce are among the trends that will change not only who assumes the role of a caregiver but also the cost savings attributed to caregiving. Understanding who military and veteran caregivers are and the benefits they convey to society can help guide programs and policies for caregivers that would lead to a more direct effect.
3. **How does caregiving affect caregivers?** Little is known about the longer-term impact of caregiving on military and veteran caregivers. Understanding how caregiving affects caregivers could help inform programs and policies designed to mitigate any adverse effects. In particular, it is important to focus on health (particularly mental health), employment (and associated loss of income or loss of job opportunities), and family well-being (including family strain, divorce, and abuse). However, there are also positive consequences of caregiving, and studies should seek to identify these effects as well.
4. **How does caregiving affect the children of caregivers?** Most stakeholders who participated in our data collection identified the effects of caregiving on children as a vital topic, but we identified no study documenting this effect. The following aspects merit attention: children directly serving as caregivers, the impact of being a child in a home with someone (usually a parent) caring for an individual with a mental health issue, the impact of caregiving on parenting and the associated effect on children, and both short-term (e.g., school performance, attachment issues, socialization, adverse behavior, and mental health) and long-term effects of caregiving on children.
5. **How does caregiving affect care recipients?** Caregivers play an essential role in supporting the recovery and reintegration of our wounded, ill, and injured veterans by helping coordinate medical care, administer medications, and provide supportive environments. More studies are needed to examine the impact of caregiving on care recipient outcomes, particularly long-term outcomes. Such research is critical for justifying continued support for programs and services for caregivers.
6. **How do care recipient needs change over time?** As individuals age or recover, their needs and demands for caregiving may change, and this may affect the duties and strain on the caregiver. However, only two studies published to date have examined how care recipients' needs change over time. Future research in this area could ensure that caregiver skills and knowledge keep pace with the changes in care recipient needs over time.
7. **What factors are associated with caregiver and care recipient harm (that is, any situation in which a care recipient is abusing the caregiver or vice versa)?** Fraud, harm, and abuse are often unpopular topics of discussion, but research with civilian populations indicates that this area deserves serious attention. The effort is complicated by the stigma associated with admitting that a caregiver or care recipient is abusive in some way, but understanding the extent to which these issues occur and why they occur is important for safeguarding caregivers and care recipients and minimizing adverse consequences.

8. **What strategies make effective programs more accessible to more caregivers?** Few studies have focused on the accessibility of caregiver programs, and no research has been conducted to understand the efficacy or effectiveness of workplace policies to support caregivers.
9. **How effective are programs and policies for ensuring caregiver well-being?** Knowing what works and for whom is an important consideration, not only for ensuring that caregivers' needs are being met but also for developing sound policies and funding worthy efforts. Many programs and policies have been promulgated in health care settings, in the workplace, and in the social support arena with the intent of improving caregiver well-being. The vast majority of research is on the effectiveness of programs enhancing caregivers' abilities to provide care, including informal and formal education and training, assessments of caregiver knowledge and information programs, and programs using new technologies (e.g., telehealth, smartphones) to help with caregiving tasks. More research is needed to focus on proving the effectiveness of specific caregiver interventions.
10. **How effective are programs and policies for supporting caregivers' ability to provide care?** Caregivers who contributed to our data collection felt that they did not have the information they needed to provide required care and were unaware of research on the effectiveness of key programs. They also criticized the ongoing, exhausting, and often disorganized bureaucratic aspects of programs and policies.

Setting the Conditions for Success

Just as in architecture, a research blueprint is only a vision or plan. Multiple conditions must be met to conduct studies designed to fulfill the research blueprint. Two of the more important conditions are ensuring consistency in terms and definitions and creating an environment conducive to research.

Ensuring consistency in terms and definitions. Variations in terms and definitions about who and what constitutes caregiving can lead to different inclusion and exclusion criteria for studies which can, in turn, lead to differences in estimates and conclusions about the needs of the population. For example, the definition we use does not necessitate that a military and veteran caregiver have a familial relationship with the care recipient or provide assistance for specific activities of daily living. We define military and veteran caregivers as:

Anyone who provides unpaid care and assistance for, or manages the care of, a current or former member of the U.S. military, National Guard, or reserves who has an illness, injury, or condition for which they require outside support.

It is also essential to have well-defined outcomes of interest and to use accepted, validated measures. Doing so will enable more-rigorous comparison of studies and evaluation of program outcomes.

Creating an environment conducive to research. For additional research on military and veteran caregivers to proceed, other enablers will be necessary. These include ensuring an environment that is conducive to facilitating, conducting, and using research. Enablers of such an environment include:

- *Funding.* Funding can come from many sources across the public and private sectors. Most of the research to date on military and veteran caregivers has been funded by either the federal government (e.g., the VA and Department of Defense) or the nonprofit, philanthropic sector. However, other funders may be interested in and amenable to supporting research on military and veteran caregivers. Such funding will be necessary to ensure that sufficient resources are available to support rigorous research on the population.
- *Research workforce.* Conducting research requires appropriately trained individuals to perform studies with rigor and to contribute their findings to the knowledge base. Many types of researchers from multiple disciplines will be needed to implement a research blueprint. Whether researchers are quantitatively or qualitatively focused, it is important that they use methods appropriate to the research objective and publish their findings so they are available to the research, advocacy, and decisionmaking communities. The process of technical peer review often helps to ensure the quality of the research and should be incorporated both at the time of funding or research implementation and at the publication or reporting phase. As more funding becomes available and research priorities are articulated, more researchers may be drawn to the field and help expand and strengthen the science.
- *Community participation.* Ultimately, successfully implementing studies of military and veteran caregivers will require participation from relevant parties, whether these are caregivers or the programs or settings designed to support caregivers. Ensuring that the perspectives of these constituencies are appropriately considered and addressed in the design and conduct of research can be instrumental in facilitating successful implementation. Thus, it is important to establish mechanisms to formally engage members of the military and veteran caregiver stakeholder community in identifying research questions, implementing studies, and using research findings. This could happen at the individual study level or, perhaps, at the portfolio-management level within a funding organization. An additional strategy would be to draw on Participatory Action Research, which is an established, mutually beneficial framework for systematically incorporating the views and needs of advocates and the communities of people they seek to help. Given the existing knowledge and zeal among Elizabeth Dole Foundation fellows, Participatory Action Research would be an effective means of leveraging advocates' strengths in future research efforts.
- *Vocal champions.* The imperative to increase the knowledge base and research funding to support such studies can be generated and influenced by the affected community. Those who advocate better support for military and veteran caregivers can be important vocal champions in encouraging policymakers across the government and nongovernment sectors to increase their support for and reliance on research. This can include increases in research budgets, as well as increased demand for policymakers and program officials to require rigorous evidence to inform decisionmaking. Thus, policymakers are also important champions and ambassadors for research. Making stakeholders and advocates an integral part of the research process increases the salience of the work and facilitates better dissemination and implementation of the findings.
- *Translating research into practice.* Generating new knowledge will be important, but enhancing support for military and veteran caregivers will require translating findings into practice. Without specific dissemination or facilitation efforts, it can often take more

than a decade for new findings to influence routine practice. It is possible to shorten this timeline, but it requires specific intention to do so. Past RAND research has identified ten strategies that often promote the translation of research into practice; those strategies include creating incentives for implementing new findings in practice and using evaluation findings in decisionmaking.⁵ These tasks are typically outside the scope of individual researchers and may require stakeholder groups to take the lead in facilitating them.

Using the Blueprint

Ideally, the research blueprint we have created will become a common reference point for the various stakeholder communities as they work toward a common goal of improving support for military and veteran caregivers. Two strategies for gaining support for, adopting, and implementing the blueprint are establishing partnerships and creating a caregiving research center of excellence.

Establish partnerships. The military and veteran caregiver stakeholder community should partner with some of the many organizations that are interested in research on various aspects of caregiving. For example, the National Academies of Science, Engineering, and Medicine's Committee on Family Caregiving for Older Adults released a report in September 2016 outlining recommendations aimed at addressing the health, economic, and social issues facing family caregivers of older Americans.⁶ Among other recommendations, the committee suggested that the VA and the Department of Health and Human Services create a public-private, multistakeholder fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families. The research objectives that we evaluated and arrayed within this blueprint can all be nested within these larger objectives and used as a basis for informing how the VA and Department of Defense in particular can support and implement this recommendation.

Additional partnerships and consortia with other caregiver organizations could be established to call for increased research investment across the governmental and nongovernmental sector, encourage the research community to focus on caregiving, and demand more evidence-based decisionmaking for future caregiver support programs and policies.

Create a research center of excellence. A research center of excellence specifically focused on military and veteran caregiving could foster the strategic pursuit of the research blueprint and begin to address the knowledge gaps outlined in our report, thus promoting better support for military and veteran caregivers. Such a center of excellence could be implemented within a federal agency or be established in the private sector. Ultimately, it will be important for such a research center of excellence to have broad, multidisciplinary expertise as well as a broad focus to ensure that all of the research objectives and special populations of importance to the military and veteran caregiving community are included in its mission.

⁵ Ramchand et al., 2014.

⁶ National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*, Washington, D.C.: National Academies Press, 2016.

Conclusion

As I noted in my introduction, the role of this blueprint is to convey a vision for future research that will build support for military and veteran caregivers. In essence, the blueprint becomes a guide for the community to use in prioritizing and facilitating future research. It is not a manual for how research should be pursued; stakeholders may use the blueprint differently as they craft their own specific activities. For example, caregivers and their advocates can use the blueprint as a reference point to encourage funding organizations to expand research opportunities in each of the areas outlined. The funding community can use the blueprint as a reference or guide to creating research priorities for allocating their research budgets. Policy makers can also use the blueprint as a guide for understanding existing gaps in the knowledge base and to inform investment for new research initiatives as they consider changes to existing programs and portfolios. As researchers design future studies, they can refer to the blueprint as a source of stakeholder-endorsed research objectives. In this manner, it is our intent that the blueprint becomes a mechanism and common reference point as we all work toward a common goal of improving support for military and veteran caregivers by conducting rigorous research.

Thank you for the opportunity to share this testimony with the committee.