Improving Support for America’s Hidden Heroes

A MILITARY CAREGIVER RESEARCH BLUEPRINT

The Elizabeth Dole Foundation commissioned the RAND Corporation to develop a research blueprint to inform future efforts to improve support for military and veteran caregivers. To construct this blueprint, researchers inventoried currently available research on caregiving for disabled adults, children, and the elderly and gathered stakeholder input by conducting a survey and facilitating an online panel where stakeholders rated and debated key research priorities to improve the well-being of military and veteran caregivers. The analysis highlights the need for research that specifically examines how well programs for caregivers and care recipients are working; how caregiving affects specific subgroups, including children; and how caregiver and care recipient needs evolve over time. The resulting blueprint conveys a vision for future research and should serve as a guide for the caregiver support community to use in prioritizing and facilitating future research.
There are more than 20 million veterans living in the United States today, a significant portion 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. service members to live fuller lives. These estimated 5.5 million caregivers are an essential component of the nation’s care for returning warriors.
Blueprint Components

In the construction world, a site plan shows the footprint of the building on a lot, or how it fits onto a given space. In caregiving research, an analogous construct is research that examines how caregiving and caregivers fit within the context of society at large. Such research quantifies how many caregivers there are and describes who they are and for whom they provide care. It may also quantify social benefits associated with caregiving—for example, by estimating societal cost savings attributed to unpaid, informal caregiving.

A floor plan describes the relationships between rooms and spaces on one floor of the building. In caregiving research, an analogous construct is research that examines the impacts of caregiving on caregivers, care recipients, and their families. For example, it may include studies that assess how caregiver demands change as the needs of those they are caring for change, as well as how caregiving may affect the children of caregivers. It may also examine factors associated with caregiver and care recipient harm (for example, any situation in which a care recipient is abusing the caregiver or vice versa).

An elevation shows the building from the outside. In caregiving research, an analogous construct is research that examines how external factors may influence caregiving. For example, such research may identify strategies for supporting caregivers through new policies or programs, making current programs more available to caregivers, or evaluating the effectiveness of policies or programs.
Blueprint Stakeholders

To guide our project, we turned to the field from which the term blueprint originates: architecture and construction. Before a new house is constructed, an architect investigates where it will be built, talks with the owners about what their needs will be, and investigates the laws and regulations that guide what can be designed. The architect then creates a design for the new house and displays it in a blueprint that communicates the design intent to both the owners and the builder. The blueprint also functions as the contract among these parties, documenting and specifying the decisions about what is to be constructed.

A blueprint for caregiving research can be considered in the same way. With support from the Elizabeth Dole Foundation, input from key stakeholders, and a review of caregiving research to date, RAND researchers serve as the architects, conveying a vision for research needed to build the house (in this case, ensure better support for military and veteran caregivers). Members of the research community serve as the builders, as they will be responsible for executing the research.

The owner of the research—that is, who will ultimately live in and benefit from the house—is the public, including caregivers and care recipients, as well as those who support them. An architect should design a building with the owners’ needs at the forefront of her mind, not her own interests or those of the builder. In designing this blueprint, we pursued a similar goal: to keep caregivers, care recipients, and those who support them in the forefront of our minds, prioritizing research that will best serve their needs.

In addition to the architects, builders, and owners in this blueprint metaphor, we can think of program leaders as the suppliers, who ensure that the house is built with the best available materials, and we can think of policymakers as the inspectors, who ensure that it has been examined and approved.
Assembling the Expertise

To gather a full picture of the gaps in research on military and veteran caregivers, we collected data from multiple sources and experts. We took advantage of opportunities offered at the September 2016 “Empowering Hidden Heroes: Pathways to Innovation” summit, cosponsored by the Elizabeth Dole Foundation and the U.S. Department of Veterans Affairs (VA). Attendees included the range of stakeholders whose input we sought: policy and program officials, government officials, researchers, clinicians, funders, advocates, care recipients, and caregivers. We attended multiple presentations and conducted a free-listing exercise that involved inviting attendees to generate research questions and priorities. In addition, we administered a survey to attendees to assess perceptions about specific priorities.

We integrated information from these sources to develop a list of caregiver-related research objectives. We then reviewed studies evaluating these objectives, looking at both military and veteran caregivers and informal caregivers more broadly. Finally, we used ExpertLens™ — a RAND-developed, web-based tool that assesses stakeholder consensus—to elicit ratings of each research objective from panels of stakeholders. We included three panels: one comprising military and veteran caregivers; one comprising caregiving researchers, government officials, and funders; and one comprising program leaders.

Where to focus research on military and veteran caregivers?

Diagramming the Research Process

**Collect Data**
- Observation and documentation
- Free-listing
- Survey

**Review Information**
- ExpertLens
- Research objectives
- Research inventory

**Identify Gaps in Research**
- Research topics
- Research priorities
- Rationalizations
Based on our data collection efforts at the summit, our literature review, and our ExpertLens panels, we evaluated ten research objectives and grouped them within the three components of the research blueprint (site plan, floor plan, and elevation). In this section, we describe each objective as a specific research question and summarize observations about the objective's importance, cultural acceptability, implementation cost, and learning potential, as well as the effectiveness of current research in that area. The ratings across each of these dimensions are also summarized on p. 12.
Who are the nation’s military and veteran caregivers? Existing studies have described the unique attributes of the nation’s military and veteran caregivers, highlighting the important ways in which they differ from the broader population of caregivers in the United States. Stakeholder participants pointed to gaps in the existing knowledge about certain groups of military and veteran caregivers, as well as caregivers more broadly—for example, children, 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 of those who served in the military before the terrorist attacks of September 11, 2001 (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 to ensure that programs and policies are better designed to support them.

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 growing participation of women in the workforce are among the trends that will change not only who assumes the role of a caregiver but also the landscape of cost savings attributed to caregiving. Our stakeholder participants noted that research in this area should also include the expenses that military and veteran caregivers must bear—that is, the trade-offs of informal caregiving. Estimates of the cost savings attributed to caregivers may vary depending on the methodology that studies employ, but calculating these cost savings, balanced with the costs of caregiving on society, is an important way of understanding the contributions and sacrifices caregivers make.
How does caregiving affect caregivers? While several studies have documented the short-term impact of caregiving for those supporting individuals with specific age-related health conditions (such as dementia), little is known about the longer-term impact of caregiving on military and veteran caregivers in particular. Some stakeholder participants noted that understanding how caregiving affects caregivers could help inform programs and policies designed to mitigate any adverse effects. In addition, caregiver participants felt that more public education and public awareness about the role of caregivers are needed to increase the demand for research. Many panelists mentioned the importance of focusing on health, employment, and family well-being outcomes in research studies—for example, mental health, loss of income or a much-valued position, divorce, and abuse, as well as the positive outcomes.

How does caregiving affect the children of caregivers? We did not identify any published studies about the impact of caregiving on the children of caregivers. However, all of our stakeholder participants felt it was a vital topic, making this a high priority for future research. Topics meriting attention among our panels included 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 and long-term effects of caregiving on children. There was no agreement among stakeholders about the cultural acceptability to conduct research on the impact of caregiving on children. While some found the research objective too important to overlook, others thought that some parents might be unwilling to share insights about their children for fear of being criticized.
How does caregiving affect care recipients? Caregivers play an essential role in supporting the recovery and reintegration of wounded, ill, and injured veterans by helping coordinate medical care, administer medications, and provide supportive environments. Some research has been done to examine the impact of caregiving on care recipient outcomes. However, the majority of that research has focused on short-term outcomes among civilian care recipients, and there is a limited understanding of the long-term outcomes; therefore, more studies are needed, particularly for military and veteran care recipients. ExpertLens participants saw this question as critical for justifying continued support for programs and services for caregivers. Program leaders in particular emphasized the importance of showing the need and impact on care recipients of resources targeted to caregivers. One program leader commented, “If resources are to be increased that are targeted to caregivers, there must be strong evidence of need and impact on care recipients.” Stakeholders noted that much can be learned about how to improve the mental health and quality of life of military and veteran care recipients, and some highlighted the need for longitudinal research. It is important to note that some panelists felt that this topic might be sensitive because of the potential stigma associated with being a care recipient.

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 of and strain on the caregiver. However, only two studies published to date have examined how care recipients’ needs change over time. This topic was widely viewed as extremely important among our stakeholders; research in this area could, for example, ensure that caregiver skills and knowledge keep pace with the changes in care recipient needs over time. Several program leaders felt that the focus should be on the long-term needs of different populations because “these needs might vary greatly by type of injury, type of care, and myriad other factors.” Along these lines, one caregiver thought that society is more accepting of a Vietnam-era veteran needing care than a post-9/11 veteran, which is likely tied to a perception that older individuals require such support. The idea of a veteran in his or her 20s or 30s needing a caregiver seemed overwhelming and potentially expensive in the long run, but given the age of most post-9/11 veterans, more research on this topic is needed.

What factors are associated with caregiver and care recipient harm? Fraud, harm, and abuse are often unpopular topics of discussion, but research with civilian caregivers indicates that this area deserves serious attention. Understanding the extent to which these issues occur and why they occur is important for safeguarding caregivers and care recipients and minimizing adverse consequences. But the effort is complicated by the stigma associated with admitting that a caregiver or care recipient is abusive in some way. Because of the sensitive nature of this topic, some panelists felt that original, potentially expensive studies would be needed. A subtopic of this research objective is medical fraud among caregivers and recipients, and panelists did not agree about whether to study this topic. Stakeholders acknowledged that if a care recipient’s health improves, a family could lose its benefits, which could be very disruptive. Caregivers acknowledged that losing benefits could lead to fraud or abuse. Thus, to ensure a full understanding of the risks and consequences associated with these issues, further research is necessary.
What are strategies for making effective programs more accessible to more caregivers? Few studies have focused on the accessibility of caregiver programs that provide training, peer support, or health services, and no research has been done to understand the efficacy or effectiveness of workplace policies to support caregivers. Caregivers noted that even if a program were accessible, it might not always be available (for example, if there is a waiting list). They also expressed concerns that caregivers might be reluctant to use support programs because doing so may suggest that the caregiver could not handle his or her responsibilities. However, there was general agreement that this was an important topic for future research.

How effective are programs and policies for ensuring caregiver well-being? 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. Our research inventory identified more than 80 articles examining caregiving interventions. The vast majority of research was 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 caregivers with caregiving tasks. About one-third of the literature on program effectiveness focused on care recipients with dementia. Thus, studying 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 for military and veteran caregivers.

How effective are programs and policies for supporting caregivers’ ability to provide care? Although this question has been fairly well studied in the past, caregivers 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. Thus, future research may be needed to examine how well research findings are translated into policy.
Considering Cross-Cutting Issues

In crafting this blueprint, several issues were raised that cut across the research objectives. Many stemmed from the lack of studies on specific subpopulations of caregivers, especially children and men. Research on these populations should consider how caregiving affects them in ways that may be unique or different from the impact experienced by adults (in the case of children) and by women or spouses (in the case of men, some of whom may be providing care for friends). Studies should also specifically address the efficacy and effectiveness of programs or policies for these groups.

A second cross-cutting concern was the lack of research focused on those caring for a particular type of care recipient—for example, those with a brain injury. A large longitudinal study currently being conducted by the U.S. Department of Defense to examine the caregivers of service members who experienced a traumatic brain injury during the post-9/11 era will provide valuable insights, but additional research will be needed to ensure that all health issues affecting care recipients and caregivers are studied.

Using the Blueprint

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. 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. We suggest the following three strategies for gaining support for, adopting, and implementing the blueprint.

Establish partnerships. The military and veteran caregiver stakeholder community can partner with some of the many organizations that are interested in research on various aspects of caregiving. Partnerships and consortia could call for increased research investment, encourage the research community to focus on caregiving, and demand more evidence-based decisionmaking for future caregiver support programs and policies.

Convene a military and veteran caregiver research summit. A research summit could be convened to focus on cultivating new research studies designed around elements identified in this research blueprint. Participants could include researchers from multiple disciplines, as well as caregiver representatives.

Create a research center of excellence. A research center of excellence within the military and veteran caregiving community could foster the strategic pursuit of the research blueprint and begin to address the knowledge gaps outlined in this report, thus promoting better support for military and veteran caregivers in the future.
### Summary of Stakeholder Ratings

The table aggregates what we learned from all panels of our stakeholder consensus process about the importance of a specific research objective, the effectiveness of previous research on that topic, the cultural acceptability of conducting research in that area, the implementation cost of performing new research, and the learning potential of new research in this area over the next five years. For this summary table, we present the median rating of each dimension as either high (that is, important, effective, acceptable, inexpensive, or potentially informative) or uncertain; no objective had a low median rating for any dimension. This table also highlights the number of published articles identified for each of the objectives, enabling a view of potential gaps and areas for future investment.

#### Focus (Blueprint Component) | Research Objective | Importance | Effectiveness | Cultural Acceptability | Implementation Cost | Learning Potential | Number of Articles Identified
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Caregivers as members of society (site plan) | Describe caregivers. | * | * | * | | | 34 (5)
 | Quantify the societal cost savings attributed to caregiving. | | | * | | | 5 (1)
Impacts of caregiving on caregivers, care recipients, and their families (floor plan) | Document the effects of caregiving on caregiver outcomes. | * | | | | | 72 (6)
 | Assess the consequences of caregiving on the children of caregivers. | | | * | | | 0 (0)
 | Document the effects of caregiving on care recipient outcomes. | * | * | 36 (0)
 | Assess how the needs of care recipients change over time. | * | | | | 2 (1)
 | Examine factors associated with caregiver and care recipient harm. | | | | | | 3 (0)
External factors that influence caregiving (elevation) | Identify strategies for making effective programs available to more caregivers. | * | | | | | 10 (1)
 | Evaluate the effectiveness of programs and policies for ensuring caregiver well-being. | | | * | | | 24 (3)
 | Identify effective programs and policies to support caregivers' ability to provide care. | * | | | | | 50 (10)

* One panel rated this as high.
** One panel rated this as uncertain.
+ The number in parentheses represents the number of articles that specifically focused on military or veteran caregivers.

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The importance and the learning potential of nearly all research objectives were rated highly important.

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The research described here is fully documented in Terri Tanielian, Kathryn E. Bouskill, Rajeev Ramchand, Esther M. Friedman, Thomas E. Trail, and Angela Clague, Improving Support for America's Hidden Heroes: A Research Blueprint, RR-1873-TEDF, 2017 (available at www.rand.org/t/RR1873). To view this brief online, visit www.rand.org/t/RB9950.

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