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Hidden Heroes

Caregivers to America's Ill, Injured, and Wounded Service Members and Veterans

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RAND Office of External Affairs

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The RAND Corporation

Hidden Heroes
***Caregivers to America's Ill, Injured, and Wounded Service Members and Veterans*²**

Before the Committee on Veterans' Affairs
Subcommittee on Health
House of Representatives

December 3, 2014

Chairman Benishek, Ranking Member Brownley, and members of the Subcommittee, thank you for inviting me to testify.

Earlier this year, RAND released *Hidden Heroes: America's Military Caregivers*. Funded by the Elizabeth Dole Foundation, the study shed new light on the number and needs of the men and women caring for our nation's wounded, ill, and injured service members and veterans. For the rest of my testimony today I will refer to these individuals as **military and veteran caregivers**. In addition, our study identified the services available to support these military and veteran caregivers. By collecting data on both caregivers and the organizations that serve them, we were able to identify unmet needs and make policy recommendations on areas for improvement. Today, I will share with you highlights from this research with a specific focus on the need to expand services to military and veteran caregivers, and important considerations we should keep in mind when doing so.

The Burden of Caregiving

Our study was one of the first that provided an accurate estimate of the number of military and veteran caregivers living in the United States today. We estimate that there are 22.6 million adults – or 9 percent of the adult population – currently serving as caregivers to other adults. These caregivers are taking care of aging parents, ill and injured spouses, adult children living with disabilities, or neighbors in need of help to keep them living in the community. Of this group, 5.5 million are military or veteran caregivers, providing care and assistance to someone who either

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² This testimony is available for free download at <http://www.rand.org/pubs/testimonies/CT421.html>.

currently serves or previously served in the United States military, regardless of whether that individual's injury or illness resulted directly from military service. Of these 5.5 million military and veteran caregivers, 20 percent – or 1.1 million – are caring for someone who served in Iraq or Afghanistan, a group I'll refer to as **post-9/11 caregivers**. The remaining 4.4 million I'll refer to as **pre-9/11 caregivers**.

Caregivers provide a range of support and assistance that includes helping those they are caring for to eat, bathe, and walk; assisting them with paying bills, buying groceries, and completing chores around the house; and importantly, for persons with mental health or cognitive difficulties, helping them cope with or manage stressful situations. Were the country to replace the time that caregivers spend performing these tasks with the services of home health aide attendants, the total cost would be more than \$10 billion for pre-9/11 and more than \$3 billion for post-9/11 service members and veterans.

In addition to this economic value, the critical support provided by caregivers facilitates the overall health and recovery of those service members or veterans for whom they are caring. However, caregiving duties take a significant toll on these military and veteran caregivers. Relative to the non-caregivers we surveyed, caregivers report worse overall health. They also report that their health affects their ability to perform physical tasks. Their mental health suffers as well: Our study found that the number of hours a person spends providing caregiving duties relates directly to the likelihood that they meet symptom criteria for depression. Their romantic relationships suffer, especially if the person they are caring for is their spouse. Those who are parents report that caregiving negatively affects their relationships with their children, as well. Finally, many caregivers also have waged jobs outside of their caregiving responsibilities, and these caregivers report having to take unpaid time off of work, cut back their work hours, or quit working altogether as a result of caregiving. While both civilian and military and veteran caregivers suffer these same outcomes, those most profoundly affected are post-9/11 caregivers.

Threats to Informal Caregiving

If our nation were to stop supporting military and veteran caregivers, it would leave a cadre of wounded, ill, and injured service members and veterans without the support they need to live or to live in the community in a non-institutional setting. Without caregivers, this group could suffer increased homelessness, morbidity, and even mortality. These concerns are exacerbated in light of what we identify as three critical threats to our nation's caregivers, specifically among the children, parents, and spouses serving in this role:

1. **Children as Caregivers.** In 2013, the AARP Public Policy Institute highlighted that the number of adult children able to care for their parents over age 80 is shrinking, from seven adult children to one aging parent in 2010 to a projected 4-to-1 ratio in 2030 and 3-to-1 ratio by 2050. A large portion of this aging group in need of caregiving support is the pre-9/11 veterans who currently rely on caregivers, plus an unknown additional number of veterans who will need such support as they age.
2. **Parents as Caregivers.** Of the 1.1 million post-9/11 caregivers, 25 percent are parents. As these parents age, who will be available to continue to provide caregiving support to their wounded, ill, and injured sons and daughters?
3. **Spouses as Caregivers.** Thirty-three percent of post-9/11 caregivers are spouses. Caregiving strains these marriages, many of which are quite young, and some are likely to dissolve. Without a caregiver, it is unclear who and what services will be available to provide the assistance that the wounded, ill, or injured veteran needs.

Services Available for Caregivers

We identified 120 organizations currently offering services that directly support military and veteran caregivers. One of these organizations is the Department of Veterans Affairs. The VA offers a wide array of services to caregivers, including those offered through the VA Program of Comprehensive Assistance for Family Caregivers. This program is similar to those of many other organizations that offer services to military and veteran caregivers in that it offers caregiver training and structured social support. However, it is unique in many ways as well. It is one of the few programs to offer a financial stipend to military and veteran caregivers, respite to those who need a temporary break from caregiving duties, health insurance to those who do not have access through other means, and health care to caregivers who need it. Another aspect that makes it unique from the programs of other organizations is that it serves the caregiver directly. Many organizations target most of their services to wounded, ill, and injured service members and veterans, serving caregivers only as an incidental population. For example, the Department of Defense's Special Compensation for Assistance with Activities of Daily Living, or SCAADL, provides its stipend to the service member who qualifies, whereas the VA program provides its stipend directly to the caregiver.

Aside from the VA program, we identified 13 other government-sponsored programs that serve military and veteran caregivers, most of which are in the Department of Defense and serve wounded, ill, and injured service members while offering complementary services to their caregivers. And then aside from a few private, for-profit organizations that serve caregivers directly, the vast majority of the remaining 106 programs are nonprofit organizations that either

serve military families or serve all caregivers and serve military and veteran caregivers incidentally as a subset of both.

Two-thirds of these nonprofits are less than 10 years old, and their longevity is threatened in two ways. First, there is evidence of waning public interest in supporting military and veterans' issues, which may threaten the financial resources needed to sustain these organizations. Second, there is a lack of empirical evidence and evaluation studies showing that the programs they offer actually work, which may dampen funders' enthusiasm for support. This is why research is urgently needed to identify which services being offered are reducing caregiver burden and distress, improving the caregiving support that is being provided, and ultimately improving service member and veteran well-being.

Although there are 120 organizations offering services to military caregivers, not all military and veteran caregivers can access all of them. In addition to the VA Program of Comprehensive Assistance for Family Caregivers, 12 organizations offer services exclusively to post-9/11 caregivers. Other programs may offer services only to individuals who are exclusively caring for a family member or to those caring for someone with a VA disability rating or with a specific condition, such as traumatic brain injury or Alzheimer's disease.

Caregiver Use of Services

Perhaps because there are more services available to them, post-9/11 caregivers tend to use caregiver support services more commonly than pre-9/11 caregivers. For example, nearly three-quarters of post-9/11 caregivers report accessing some form of caregiving support from the Department of Veterans Affairs, though not all are accessing the Program of Comprehensive Assistance for Family Caregivers. This compares to only 38 percent of pre-9/11 caregivers. While this may appear to be a marker of underutilization, our data suggest that most of those not using VA or any other services indicate that it is because they do not want to use them. Among the roughly 20 percent of military and veteran caregivers not using – but who would want to use – a specific service, most reported that they were not using the service because they were unaware of the resource or that it was difficult to find information about it.

A Heterogeneous Group

Caregivers are a diverse group, and differences are perhaps most pronounced between the two groups of military and veteran caregivers that I referenced earlier in my testimony.

- Post-9/11 caregivers tend to be young men and women taking care of their spouses, neighbors taking care of a friend, or parents taking care of their children. Of those service members or veterans in their care, 58 percent have a VA disability rating; most are suffering from back pain; and more than 60 percent have a mental health or substance use disorder, like posttraumatic stress disorder.
- By contrast, the pre-9/11 military and veteran caregivers look similar to non-military and veteran caregivers: They tend to be adult children or grandchildren taking care of an aging parent or grandparent. The veterans in their care commonly experience back pain and tend to suffer from chronic conditions like hypertensive vascular disease or neurological conditions like dementia.

Organizations wanting to serve all military and veteran caregivers must cater to this diversity of caregivers and care recipients. For example, training that educates caregivers regarding how to help an aging parent bathe and dress may not be relevant to post-9/11 caregivers who need to learn how to help their spouses cope with stressful situations to mitigate the risk of a panic attack. Similarly, the type of respite care required for someone with Alzheimer's or another form of dementia may be very different from respite care for someone with symptoms stemming from a traumatic brain injury. To be effective, programs must account for and offer services to a range of caregivers; it may be better to avoid offering services to certain caregiving groups if it is not possible to do so with competence.

Caregiving as a National Priority

Caregivers face unique needs that programs specifically designed for them can certainly address. Research suggests that structured support from other caregivers is beneficial and that caregivers similarly benefit from training provided specifically to them. Respite is the only service that directly reduces the hours spent caregiving, and the time spent performing caregiving duties is the primary contributor of negative outcomes among caregivers – including risk for depression – so we consider respite to be a critical service for caregivers. Accordingly, some military and veteran caregivers are unable, ineligible, or unwilling to access respite offered by the VA, so reauthorizing and fully funding the Lifespan Respite Care Act will broaden the respite services available to all types of caregivers.⁴

⁴ The Lifespan Respite Care Act (P.L. 109-442) was signed into law in 2006 and authorized Congress to spend \$288 million between FY2007 and FY2011 to provide high-quality respite at state and local levels; allocations have been approximately \$2.5 million per year since 2009.

There are other policy vehicles through which all caregivers, including military and veteran caregivers, can gain access to specific support. The Department of Health and Human Services, for instance, oversees the National Family Caregiver Support Program and Medicaid's Home and Community-Based Services (HCBS) Waiver Program, both of which offer services specific to caregivers. However, it should be noted that not all military and veteran caregivers are currently eligible to access these services. The National Family Caregiver Support Program, for example, is geared largely toward caregivers of people over age 60 and of those with Alzheimer's; thus, while many pre-9/11 caregivers will qualify for services offered under this program, most post-9/11 caregivers will not. Likewise, states interpret eligibility for Medicaid's HCBS Waiver Program differently. Some of them may restrict services to those caring for people over age 60 or to family caregivers – thus excluding neighbors and friends, who account for between 10 and 25 percent of all caregivers. This is why we recommended that eligibility for programs be determined by the tasks and duties that caregivers perform rather than the age of those they are caring for or their relationship to the caregiver.

Because between half and three-quarters of military caregivers are also employed, employers have a role to play as well. Some provisions of the American Disabilities Act prevent discrimination against individuals related to persons with a disability, which may include some – but not all – caregivers. The Family Medical Leave Act (FMLA) also protects the jobs of caregivers who have to take time off of work to attend to caregiving duties. In 2008 and 2010, the National Defense Authorization Act expanded the injuries and illnesses covered for military caregivers and the period of time that military and veteran caregivers could take leave under the FMLA.

In addition to adhering to these legal requirements, employers themselves can take proactive roles in supporting military and veteran caregivers. In 2007, the Equal Employment Opportunity Commission published for employers best practices for supporting employed caregivers. While many were related to preventing caregiver discrimination in recruiting, hiring, and promoting, other best practices encouraged work-life balance and strategies to accommodate caregivers, such as offering flexible work schedules or employer-sponsored services like Employee Assistance Programs to mitigate some of the stressors caregivers may face.

Given that the Departments of Health and Human Services, Labor, Veterans Affairs, and Defense all have a role in supporting military and veteran caregivers, it is critical that efforts to serve this population be coordinated. While there is some evidence of collaboration between departments, gaps and inconsistencies in eligibility criteria and program definitions remain. Efforts to facilitate interagency coordination, such as through interagency working groups or task forces and federal

Commissions, could enhance the alignment and quality of services to support military and veteran caregivers.

Conclusion

Honoring and serving our current and former members of the armed forces, particularly through periods of illness or when recovering from injuries and wounds, is a national priority. Our report makes it clear that honoring and serving this group requires that we attend to their family members and friends who provide the informal care that is critical to keeping them alive and thriving. We titled our report “Hidden Heroes” because this group often stands in the shadows of its disabled service members and veterans and is rarely the focus of policy attention. I commend Congress for taking it upon itself to learn more about what it can do to support these hidden heroes. This hearing will prompt an emerging and much needed national dialogue on how the nation can better support its caregivers, and I hope that our data are helpful in informing this discussion. As I have noted, understanding the diverse nature of their characteristics and needs is critical because a one-size-fits-all approach will not be effective in serving all military and veteran caregivers simultaneously.

Thank you, Chairman Benishek, Ranking Member Brownley, and members of the Subcommittee for inviting me to testify before you today to be part of this dialogue. I look forward to answering your questions.