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Military Caregivers

Cornerstones of Support for Our Nation's Wounded, Ill, and Injured Veterans

Terri Tanielian, Rajeev Ramchand, Michael P. Fisher, Carra S. Sims, Racine Harris, and Margaret C. Harrell

Key findings

- **Unique Caregiver Population:** Military caregivers tend to be younger women with dependent-age children, dealing with a different set of patient variables than the general caregiver population.
- **Unique Challenges:** Along with typical caregiver responsibilities, military caregivers also act as case managers navigating multiple health systems, advocates for new treatment, and financial and legal representatives. Many are also raising children and holding jobs outside the home.
- **Self-Sacrifice:** Studies indicate that caregivers in general suffer from physical strain and overall worse health and tend to put their own concerns behind those of the individuals for whom they are caring. Military caregivers suffer disproportionately from mental health problems and emotional distress.
- **Available Resources, Limited Help:** Many government programs are still in their infancy, and community resources are scattered and uncoordinated. Difficulties are presented by differing eligibility criteria, lack of access, and the way caregivers' needs change over time.

SUMMARY ■ The United States has been at war longer than any time in its history. While thousands have been wounded in this long-running conflict, advances in battlefield medicine mean many of our troops survive catastrophic wounds. The nature of many of their wounds, however, means some require long-term caregiving support.

Those caregivers often toil in relative obscurity, and they are challenging to count or describe. They are spouses, parents, children, and relatives of the wounded veteran, but many coworkers, neighbors, and friends also take on responsibilities. They provide care and assistance, promoting faster recovery for their loved ones and thus saving our nation millions of dollars in health care costs. However, the personal impact of providing this care is enormous. The time required can result in lost jobs, lost wages, and a possible loss of health insurance; in addition, the physical and emotional toll can be substantial.

The Elizabeth Dole Foundation commissioned the RAND Corporation to assess the needs of military caregivers, scan the services available to them, and identify how their needs are—and are not—being met. This report reviews existing research on the needs of caregivers in general, and assesses how lessons learned can be

applied to military caregivers. This knowledge will inform policy and program development in the short term. We also present information gleaned from military caregivers themselves and from policymakers and program officials who either directly support, or advocate on behalf of, military

caregivers. We provide a snapshot of the number and characteristics of military caregivers, the roles they serve, the physical and emotional impact caregiving has on their lives, and the resources available to them.

We estimate that there are between 275,000 and one million men and women who are caring or have previously cared for wounded, ill, or injured service members and veterans—but the actual number may be even more. Caregivers perform a wide variety of roles and functions in support of their wounded warriors—assisting with the normal activities of daily life, serving as mental health counselors, advocating for new and better treatment, even serving as the family’s legal and financial representative. Taken together, these responsibilities can amount to more than a full-time job. And yet, military caregivers may also be parenting young children and providing an income for their family.

The appeal of military service to future generations is based upon our nation’s commitment to support our service members, veterans, and military families. Ensuring adequate care for wounded, ill, and injured veterans is a critical aspect of this commitment, and a large portion of this care rests on the shoulders of America’s military caregivers. Many of them prioritize their veterans’ well-being over and above their own. In addition to general physical strain, caregivers may experience a greater incidence of disease or other negative health outcomes. Specifically, they are at high risk for coronary heart disease, hypertension, compromised immune function, and reduced sleep. They suffer disproportionately from mental health problems and experience emotional distress associated with caregiving.

Despite the need, no national strategy for supporting military caregivers exists. Government agencies and other organizations are trying to help, but most programs are in their infancy and inadequate to meet the needs of this growing population.

Future research conducted by RAND and the Elizabeth Dole Foundation will provide a clearer understanding of the number and composition of military caregivers, as well as their needs, the resources available to them, and the gaps that exist. RAND will develop actionable recommendations that policymakers, the private sector, and nonprofit organizations can implement so that, as a country, we rise to support those who are fundamental to the care of our military service members and veterans.

The needs of returning wounded warriors have been the subject of significant inquiry and national policy solutions, as well as the focus of much private philanthropy. But the needs of their caregivers remain largely overlooked.

INTRODUCTION

Throughout the nation's history, many Americans have borne the wounds of war, dealing with the lingering effects of war-related injuries and illnesses long after leaving military service. Since 2001, the United States has been engaged in the longest continuous period of combat operations in our history, fought by just 1 percent of Americans—all of them volunteers. Advances in battlefield medicine have led to much higher survival rates among those wounded in combat operations, but the result is many more wounded left to live with injuries that require significant care and support for months, years, or decades. The ultimate recovery of these wounded warriors hinges on many factors, including treatment from health care providers, the opportunities afforded by their current and future employers, and the support they receive from society. However, the most vital factor in ensuring their well-being is perhaps the care and support they receive from spouses, parents, children, colleagues, and friends. These caregivers assist wounded service members and veterans with the traditional activities of daily living, such as bathing, dressing, and eating—as well as help them relearn basic skills, take them to medical appointments, manage their finances, and care for their children.

Military caregivers stem the short- and long-term public health consequences of war and mitigate some of the cost consequences as well. By providing care and assistance, they not only promote faster recovery for their loved ones but also save our nation millions of dollars in health care costs. The Department of Veterans Affairs (VA) recognizes that “Caregivers provide crucial support in caring for Veterans.”¹ Not only does the home environment enabled by a caregiver provide a “significant psychological benefit for the veteran...,” it can also defer or delay institutionalization and thus reduce medical costs.²

Along with a growing recognition of the value of informal caregivers' contribution to the physical and psychological well-being of care recipients, projections have also been made of the

financial savings they pass on to society.³ Military caregivers, much like family caregivers more generally, provide critical long-term care and support in an era of rising health care costs, and at a time when many in society face obstacles in accessing care.

However, these public savings often come at significant personal cost to the caregivers who shoulder the burden of facilitating the recovery of returning veterans or who provide long-term care for those veterans who will live long lives but never fully recover from their wounds, illnesses, or injuries. Caregivers absorb many social, legal, and economic costs,⁴ which in turn lead to under-recognition of the total costs of war. In many ways, our nation relies on caregivers to fulfill its responsibility to care for veterans and mitigate those costs. The burdens borne by military caregivers may create additional public health problems, however—for example, six in ten caregivers report their own health has worsened because of caregiving.⁵

While much has been written about the role of caregiving for the elderly and chronically ill, we lack an understanding of who *military* caregivers are, the scope of their roles, how their

Who Are Military Caregivers?

A *military caregiver* is a family member, friend, or other acquaintance who provides a broad range of care and assistance for, or manages the care of, a current or former military service member with a disabling injury or illness (physical or mental) that was incurred during military service. Advocates and policymakers have all proposed different definitions and eligibility criteria for military caregivers, but we use the term generically throughout this report to include anyone who serves in this capacity for any current service member or veteran regardless of whether they are related to the individual, live with the individual, or are caring for a person with injuries or physical or mental illnesses.

lives are affected upon assuming these roles, and the resources available to them. (See “Who Are Military Caregivers?” for further explanation.) In short, we need improved knowledge to better address and overcome their unmet challenges.

The needs of returning wounded warriors have been the subject of significant inquiry and national policy solutions, as well as the focus of much private philanthropy. But the needs of their caregivers remain largely overlooked. Military caregivers tend to the bedside and long-term rehabilitation needs of their loved ones, devoting significant time and effort to support our wounded. While it is a noble job, it can exact a significant toll. In order to ensure that our nation’s military veterans are supported fully, we also must attend to the needs of their caregivers.

This report presents the findings from the first, exploratory phase of a larger research effort and collaboration between the RAND Corporation and the Elizabeth Dole Foundation. In conceptualizing a broad research agenda on military caregivers, it quickly became clear that they differ from civilian informal caregivers in several important ways: Military caregivers are younger, tend to live with the individual to whom they provide care, and have to navigate multiple systems of health care and benefit provision for individuals with complex injuries and multiple comorbidities (see “Why Is Military Caregiving Unique?” for further discussion of these differences).

Thus, the Elizabeth Dole Foundation asked RAND to synthesize the existing research on caregivers’ needs—looking specifically at military situations but also drawing from appropriate, applicable research on civilian caregivers that can help inform policy and program development in the short term. Looking farther ahead, research is needed to understand what policies and services will best support military caregivers specifically. In this report, we review and consolidate the available literature most applicable to military caregivers, and we present information gleaned from both military caregivers themselves and from policymakers and program officials who directly support or advocate for these caregivers. We provide a snapshot of the number and characteristics of military caregivers and describe the roles they serve, the effect that caregiving has had on their lives, and the resources available to them.

The effort documented here also lays out the framework for the next phases of the collaboration, which will kick off critically needed, evidence-based research on military caregivers. In those phases, RAND and the Elizabeth Dole Foundation will conduct a comprehensive and objective needs assessment, a formal

environmental scan of the support services available, and a gap analysis to identify how caregivers’ needs are (and are not) being met. These efforts will provide a comprehensive understanding of military caregivers’ needs and the landscape of resources available to support them, forming the basis from which policymakers and program officials can develop sound policies and programs.

Population Estimates

While the exact number of military caregivers is unknown, RAND estimates there may be anywhere from 275,000 to more than one million Americans who are currently serving or have served in this role for Iraq and Afghanistan veterans. No study has yet quantified the exact number of individuals serving as caregivers, but one can derive an estimate using existing data on the incidence and prevalence rates of injuries and illnesses among recent veterans from Iraq and Afghanistan. This approximation, however, rests on a series of assumptions that limit the precision with which we can quantify the size of this population.

Between October 2001 and December 2011, the United States deployed just over 2.4 million service members. Over a roughly comparable period, more than 63,000 service members were medically evacuated from Iraq and Afghanistan—suggesting that roughly 3 percent of those deployed were medically evacuated. This number is only part of the picture, however, because some injuries that require caregiver support do not call for medical evacuation. For instance, some health-related problems may present or worsen post-deployment, including mental health conditions and traumatic brain injury (TBI). Estimates of the number of previously deployed personnel who meet the criteria for these conditions vary,⁶ and the variance is particularly large for estimates relating to posttraumatic stress disorder (PTSD) and screening rates for the incidence of TBI among troops.⁷ Based upon prior studies, we estimate that up to 30 percent of those who deployed in support of Operation Iraqi Freedom or Operation Enduring Freedom—roughly 725,000 service members—may have experienced a TBI or meet criteria for PTSD or depression.⁸

These “invisible” wounds can be just as debilitating as physical injuries. Additionally, service members and veterans with physical wounds, particularly those with severe poly-traumatic injuries, may experience these cognitive or mental injuries as well. There is currently no data on which to base a sound estimate of the proportion of these individuals that required or will require the assistance and support of a caregiver for at least some period of time during their recovery. As such,

Beyond an approximate magnitude of the number of people who have supported or are supporting Iraq and Afghanistan veterans, we simply do not know exactly how many caregivers are ensuring the care of our nation's veterans.

employing a few reasonable assumptions is necessary to further the construction of our estimate. Assuming that 25 percent of these individuals require or required some caregiving yields an estimate of nearly 200,000 with caregiving support. Assuming 100 percent need caregiving results in an estimate of nearly 800,000 Iraq and Afghanistan veterans requiring caregivers. Any overlap between those medically evacuated from theater and those with post-deployment mental health problems would reduce these estimates. However, our estimates omit service members and veterans with other types of post-deployment health problems, such as musculoskeletal problems or other physical health illnesses, that may require caregiving; including this group would raise our estimates.

Using these figures, we can also estimate the types of individuals who are caregivers to these wounded, ill, and injured service members. Of the 2.4 million who deployed, 59 percent are married, 45 percent have children, and 36 percent have never been married nor had children. Using these demographics, we assume that the deployment-related wounded, ill, and injured who are married rely on the caregiving support of a spouse, that those with children require some caregiving support from those youth, and that those who were neither married nor parents require the support of their own

parents. Using the 25 percent and 100 percent assumptions presented earlier, we estimate that there are between 115,000 and 465,000 military spouses, between 90,000 and 355,000 military children, and between 70,000 and 285,000 military parents—for a total of between 275,000 and more than 1.1 million Americans—who may have served or are currently serving as military caregivers.⁹

These numbers provide only a rough magnitude of the military caregiver population serving veterans of the operations in Iraq and Afghanistan and may be inaccurate. For example, some parents, spouses, and children (particularly younger children) may not be serving as caregivers in a substantial capacity.¹⁰ Our method assumes two caregivers—one spouse and one child—for those individuals who are married and have children, which may also lead to an overestimate. On the other hand, we may be underestimating the number of caregivers by assuming only one parent fills a caregiving role for those service members without spouses or children or by assuming only one child serves as a caregiver.

Due to a lack of data, we also exclude siblings, extended family, friends, and coworkers who can assume a caregiving role. In addition, we are likely underestimating the number of individuals with injuries who require caregiving support because our estimates are based only on deployment-related injuries among Iraq and Afghanistan veterans. While these are likely the most severe and most common injuries, service members and veterans may also suffer other sorts of injuries or experience illnesses outside of the deployment context that require caregiving. Our estimate is also restricted to Iraq and Afghanistan veterans; if we were to include veterans from prior eras, the number of caregivers would necessarily be higher. Beyond an approximate magnitude of the number of people who have supported or are supporting Iraq and Afghanistan veterans, we simply do not know exactly how many caregivers are ensuring the care of our nation's veterans.

Demographic Characteristics

Military caregivers are young and old; they may be spouses or neighbors. Most feel obliged to care for their loved ones, who often suffer from comorbid conditions, including specifically TBI. Although we can roughly estimate the number of military caregivers, we do not know for certain the composition or makeup of this caregiver population. The most specific data available comes from a 2010 study conducted by the National Alliance for Caregiving (NAC), which surveyed a convenience

Research on military caregivers is critically important to inform policy and to aid in the development of programs and services geared specifically to this population.

sample of military caregivers through veteran service organizations. Although their sample was concentrated among an older population of military caregivers (i.e., only one-third of respondents were providing care to a veteran from Iraq or Afghanistan), the characteristics of the responding caregivers yield important insight. The overwhelming majority of respondents (96 percent) were women; most were caring for their husbands, although roughly one-fourth of veterans from Vietnam or later conflicts relied on caregiving support from their parents.¹¹ Eighty percent of caregivers in that sample lived with their veteran, which may be explained by the prevalence of spouse caregivers. Forty-one percent of caregivers in the sample were between 18 and 54 years of age.

Although the NAC survey is not representative of all military caregivers in the United States, it does highlight some important aspects of the population, including its needs and how it differs from the broader caregiving population. To date, research on caregivers in the general population has focused on those who are, most typically, 50-year-old women caring for elderly individuals with dementia, chronic illnesses such as cancer or heart disease, stroke, or general frailty in old age. Many such elderly patients require the support of their middle-aged children, and only one-quarter of those caregivers report living with the person for whom they are caring.¹² This differs from the characteristics and experiences of military caregivers, especially the caregivers of those who served in more recent conflicts in Iraq and Afghanistan. This group is younger and caring for very different types of injuries (see “Why Is Military Caregiving Unique?”). Thus, while past research may be helpful in framing the needs and experiences of military caregivers, there are important differences between civilian and military caregivers that suggest the circumstances are quite different. For this reason, research on military caregivers is critically important to inform policy and to aid in the development of programs and services geared specifically to this population.

RAND conducted initial research in this area by completing two focus groups with military caregivers in October 2012.¹³ Although not specifically designed to do so, the focus group participants mirrored the characteristics of the NAC survey sample described earlier: Most were women caring for their spouse or partner, and the average age was 38. Many of the wounded veterans cared for by the focus group participants had experienced a TBI, the “signature wound” of the current conflicts.¹⁴ However, these service members and veterans suffered from multiple conditions. Of the 20 military caregivers, 17 were caring for an individual with current PTSD. Some were caring for an individual with partial or total hearing or vision loss, respiratory problems, a spinal cord injury, and/or paralysis. Some caregivers were tending to an individual recovering from surgery. These experiences are consistent with those reported by the NAC survey, which found that Iraq and Afghanistan veterans were more likely to require caregiving related to TBI than were veterans from other war eras.¹⁵

These caregivers reported that while they generally served as the primary caregivers, they relied heavily upon other family members and friends who assumed a caregiving role. For example, one caregiver stated, “*My in-laws have moved in with us to help. . . . [and] with my in-laws there, I can spend time with the kids.*” Another important, although often ignored, caregiving contingent is the children of wounded service members. Another caregiver said, “*If I do ever step away, the only people that he’ll trust are our own children. . . . My children have had to take on the caregiver role when I cannot.*” Unfortunately, most research on caregivers has focused on persons at least 18 years old, and little is known about the impact caregiving has on younger children.

Military caregivers do share one important characteristic with caregivers of the elderly: They feel obliged to assume such a role. Almost half of all caregivers feel that they do not have a choice of whether to take on the responsibility of care-

Caregivers shoulder multiple responsibilities, from providing direct care to managing financial and legal responsibilities.

Case Management

Military caregivers often identify and coordinate professional care and services for their loved one. An estimated 85 percent of military caregivers perform some facet of this role.²⁶ Care coordination may include communicating with health professionals, communicating health and treatment status between providers, implementing care plans, organizing in-home care (e.g., nursing care), coordinating transitions from one care setting to another (e.g., from hospital to home), and executing other tasks related to navigating care delivery systems.²⁷

The role of care coordinator may be particularly important given that military caregivers navigate multiple government systems to facilitate care, services, and benefits for the veterans they support. These include the Military Health System, the Veterans Health Administration, the Veterans Benefit Administration, and often private health care providers operating in their communities. Coordinating through these different systems requires understanding the distinctions among the systems, such as differences in eligibility criteria and benefits offered, and the means by which to ensure

Why Is Military Caregiving Unique?

Multiple and Severe Injuries or Illnesses

Military caregivers often care for service members or veterans with multiple injuries or illnesses, many of which are severe or require substantial or unique assistance.^a Caring for persons with TBI was common among the caregivers in the NAC study and among those to whom we spoke. These different injuries often necessitate numerous types of care and assistance from caregivers.

Complex Systems of Care

Military caregivers are navigating complicated health systems necessary to treat the multiple illnesses and injuries from which their loved ones are suffering. In addition, this care may be provided in various locations and by various providers, including the Department of Defense (DoD), the Veterans Health Administration, and private providers.

Invisible Wounds

Military caregivers can face a daunting task even when service members return home without visible wounds. For example, researchers have found that caregivers of veterans with PTSD experience a burden of care on par with caregivers of individuals with dementia and chronic schizophrenia.^b

Around-the-Clock Care

Military caregivers often provide care continuously, day and night. Care may be labor-intensive, and caregivers are sometimes the only available, knowledgeable, or trusted person to provide care. The amount of time that military caregivers spend providing care appears to vary greatly, with some providing upward of 80 hours per week.^c

A Lifetime of Care

Given the relatively young age at which service members are often wounded, their need for caregiving may extend several decades. As a result, military caregivers tend to provide care for long periods of time—upward of 10 years of care at twice the rate of other caregiving populations.^d

Sources: ^a NAC and AARP, 2004; NAC, 2010; L. J. Resnik and S. M. Allen, "Using International Classification of Functioning, Disability and Health to Understand Challenges in Community Reintegration of Injured Veterans," *Journal of Rehabilitation Research and Development*, Vol. 44, No. 7, 2007, pp. 991–1006.

^b G. Manguno-Mire, F. Sautter, J. Lyons, L. Myers, D. Perry, M. Sherman, S. Glynn, and G. Sullivan, "Psychological Distress and Burden Among Female Partners of Combat Veterans with PTSD," *Journal of Nervous Mental Disorders*, Vol. 195, No. 2, 2007, pp. 144–151.

^c NAC, 2010.

^d NAC and AARP, 2004; NAC, 2010; E. Pinkus, 2011 *Survey of Nebraska Members on Long-Term Care and Caregiving Issues*, Washington, D.C., AARP, 2012.



Caregivers are pulled in all directions all the time and rarely have time for themselves.

continuity of care across multiple providers who work under different structures.

In our focus groups, some caregivers reported receiving formal assistance with care coordination, such as through the Federal Recovery Coordinator program. However, it appears that in some cases this did not negate or reduce the caregiver's need or desire to be involved in care coordination directly. One focus group participant stated, *"Someone gets paid to [coordinate care] but I am his case manager. She has the title, but she doesn't help alleviate the load at all. It frustrates me. It sometimes makes it worse. I am the one that keeps it all together."* Caregivers of service members and veterans with multiple injuries and ailments are often negotiating multiple systems and have more than one case manager; said one caregiver, *"I'm also a manager of case managers."*

Mental and Emotional Support

Military caregivers are mental health counselors, providing emotional support and helping their loved ones manage mental health symptoms. They provide emotional support to their loved ones ranging from everyday companionship (akin to a "buddy" or "cheerleader") to more in-depth emotional support that caregivers describe as "therapy." Military caregivers in particular may be tasked with providing high levels of emotional support due, in part, to the nature of their loved one's injuries

or illnesses. For example, caregivers for veterans with TBI, PTSD, depression, or anxiety appear to play a significant role in balancing their loved one's emotions.²⁸ One focus group participant stated, *"You have to anticipate every aspect of the day, every aspect of a social interaction before it happens, and watch him for his cues so that he does not react in a negative way so that it will stir him up too much."* In one study, nearly all military caregivers reported helping their loved one cope with stressful situations, avoid "triggers" of anxiety, or thwart anti-social behavior.²⁹

Legal, Financial, Advocacy Roles

Legal and financial planning issues are seldom discussed in the literature on caregivers, yet it appears that many military caregivers handle their family's legal and financial issues, including those associated with their loved ones' injuries.³⁰ One focus group participant stated the need to apply for legal guardianship over her severely injured veteran: *"When all the [service members] deploy, they have to sign their living will, power of attorney, all that stuff. . . . When they come back, that power of attorney expires. And when it does, you have no legal right to make decisions for them. . . ."* These decisions are complicated and difficult. For example, other participants in the same group described the emotional and legal downsides to guardianship and the reasons they had been counseled not to seek guardianship of their veteran. Military caregivers also reported navigating other legal and financial planning issues, such as drafting a will or living will, setting up a trust, or arranging an advance directive.³¹ For some, this means contemplating what arrangements are needed on their service members' behalf, should they themselves be incapacitated and unable to continue in their caregiving roles.

Military caregivers are advocates for their loved ones, researching the latest treatment options and pushing for high-quality care. Many military caregivers reported that they occupy the role of advocate, serving as a "buffer" between their loved one and systems of care or mediating between different providers. Several in our focus group noted that this becomes one of their most important roles. Moreover, some reported that they find themselves advocating for specific treatments or therapies or relaying clinical information. One focus group participant stated, *"Sometimes we have to educate the medical staff. You are the expert. . . . They doubt your ability because you're not a physician or a nurse or whatever. . . . But, we are the ones educating the medical staff about our veteran's medical conditions and treatment needs."*

Some caregivers reported experiencing a sense of guilt when taking needed time for themselves; some reported simply not taking this time in order to avoid negative repercussions.

HOW DOES CAREGIVING AFFECT MILITARY CAREGIVERS?

The roles and responsibilities of military caregivers often take more time than holding a typical full- or part-time job. In the NAC survey of veteran caregivers, approximately one-fifth provided more than 80 hours a week of care, and more than two-thirds (69 percent) provided more than 20 hours of care per week, leading some caregivers to experience a decline in their own health and well-being. As a result, some military caregivers have extensive needs, independent of the needs of their loved ones. Although some research has examined the sacrifices and needs of military caregivers,³² relatively little is known about this population. Needs assessment activities for caregivers, in general, are lacking, and even less attention has been given to military caregivers.³³ We next discuss what is known about the sacrifices and needs of military caregivers, building off the limited information about this population, as well as information about caregivers more generally.

Health Deterioration

Although research on health outcomes among military caregivers is limited,³⁴ general studies on caregivers indicate that many experience high levels of physical health problems. The most commonly measured health outcomes among caregivers are “physical strain” and a “general decline in physical health.” In some studies, roughly 16 to 18 percent of caregivers reported that their health had declined as a result of their caregiving

activities, and roughly the same proportion reported their health as fair or poor.³⁵ Military caregivers, in particular, experience a high level of physical strain that appears to be greater than among caregivers generally (40 percent versus 14 percent in the general caregiving population).³⁶

In addition to general physical strain, caregivers also experience a greater incidence of disease or negative health outcomes associated with disease.³⁷ Specific conditions for which caregivers are at high risk include coronary heart disease,³⁸ hypertension,³⁹ compromised immune function,⁴⁰ and reduced sleep.⁴¹ Caregivers in one study reported chronic conditions at nearly twice the rate of non-caregivers (45 percent versus 24 percent among non-caregivers). Even after accounting for differences in health status, caregivers have higher mortality rates than non-caregivers.⁴²

Those who become military caregivers tend to reduce their own health-promoting behaviors, such as exercising, eating well, and even attending medical or dental appointments.⁴³ For example, one focus group participant stated, *“I’ve been told I have symptoms of [a serious illness]. I haven’t been to a doctor to follow up. Logistically I can’t figure out when to see the doctor. . . . My calendar is booked every single day with responsibilities for my veteran.”* Another said, *“I have a crown that’s needed fixing for 3 years. . . . It is just not a priority for me, he is.”* In fact, caregivers told us that their own health problems had to generally reach a “critical point” before they sought care for themselves.

Mental and Emotional Distress

Military caregivers may experience a decline in their mental health as well. The most commonly reported mental health outcome among caregivers, generally, is depression.⁴⁴ Studies report that the prevalence of depression among certain caregiving populations is between 40 and 70 percent, substantially higher than among non-caregivers.⁴⁵ Although depression and secondary traumatic stress have received the most attention in research studies, anxiety and substance use have also been documented among caregivers.⁴⁶

Military caregivers in particular suffer from mental health issues at rates greater than the non-caregiving population,⁴⁷ with one study showing about two-thirds suffering some type of emotional stress.⁴⁸ Those performing multiple caregiving tasks appear to be most likely to suffer,⁴⁹ and emotional stress was found to be especially high among those caring for veterans of the National Guard or Reserve, veterans under 65 years of age, or veterans suffering from PTSD, depression, anxiety, or a TBI.⁵⁰

Even beyond formal mental health disorders, the emotional needs of military caregivers are complex, multidimensional, and often include a profound sense of grief and guilt. Caregivers may be faced with a period of grieving the loss of the “*person [they] used to know*,” while at the same time adapting to their new role as a caregiver. Some caregivers reported experiencing a sense of guilt when taking needed time for themselves; some reported simply not taking this time in order to avoid negative repercussions. For example, a focus group participant spoke about leaving her husband with a mental health problem alone: “*I was only gone an hour. I felt guilty because I left him. I wasn’t there for him. I could have prevented this [outburst].*” Another stated: “*The issue is not that we don’t want to find time [for ourselves], but the repercussions of [taking time away from caregiving] are far worse.*”

Isolation

Many caregivers find themselves socially isolated, which is a detriment to maintaining good mental health.⁵¹ Research on caregivers, generally, has found that more than two-thirds spent less time with their family and friends after becoming caregivers.⁵² This may be a result of the time military caregivers devote to caring for their loved ones, but there can be other reasons as well. For example, they may intentionally evade awkward conversations with individuals they feel “*do not understand their situation*,” or avoid constant reminders of how their lives have changed. One focus group participant stated, “*We moved [to a different state] to isolate ourselves because we didn’t want to be around people who used to know my husband. . . . [Family members] will say things [to him] like, ‘you used to like [to do this], why don’t you anymore?’*”

Military caregivers may also experience challenges within their families. Some caregivers, particularly spouses, no longer have the same relationship with their loved one or may experience decreased intimacy or sexual satisfaction.⁵³ In our focus groups, military caregivers with children reported facing additional challenges related to not having sufficient time or energy to devote to parenting and feared negative consequences for their children.

Loss of Income

Like their counterparts in the general population, military caregivers may also be affected at their job or be unable to maintain a job.⁵⁴ Studies have found that roughly one-third to

just over one-half of caregivers, generally, maintain jobs they held before they assumed a caregiving role.⁵⁵ Studies have also found that roughly two-thirds of caregivers with jobs reported missing work and about one-third reported cutting back their work hours because of their caregiving responsibilities.⁵⁶ Caregivers also appear more likely than non-caregivers to leave the workforce.⁵⁷ Although data describing the work-related issues of military caregivers are limited, one study reported that nearly half were forced to quit work or take early retirement because of their caregiving roles.⁵⁸

A reduction in work hours for caregivers is likely to result in lost wages.⁵⁹ High rates of financial hardship have been found among military caregivers, and caring for veterans with certain conditions, notably mental illnesses and TBIs, has been shown to be associated with particularly high rates of financial hardship.⁶⁰

In the general population, caregivers struggle with the significant costs associated with their own and their family members’ medical care. For these families, out-of-pocket medical expenses are 2.5 times greater (11.2 percent versus 4.1 percent of total family income) than among non-caregiving families, and more than half of all caregivers report having problems paying household medical bills incurred by themselves or their family members.⁶¹ Many of these challenges may result from a lack of health insurance: Caregivers overall in the United States are less likely than the non-caregiving population to have health insurance.⁶² The extent to which a lack of insurance or the burden imposed by health care costs are an issue for military caregivers is unclear because many of those who are injured and ill—and their families—are insured through the DoD’s TRICARE program or are eligible to receive care through the VA. Nevertheless, service members and families who are not accessing TRICARE insurance (specifically, those in the National Guard or Reserves) may be subject to a significant health care burden, as are those who have not qualified for, or are in the process of qualifying for, benefits offered by the VA.

WHAT RESOURCES ARE AVAILABLE FOR CAREGIVERS?

Military caregivers cope with the ongoing challenge of caregiving itself while sorting through a maze of policy structures, program opportunities, and well-wishers to meet both their own needs and the needs of their veteran. These efforts are

not always successful. Our findings, as well as other literature, highlight the complexity and individuality of each caregiver's situation.⁶³ Even when specific resources are available for military caregivers, the effectiveness of these resources in meeting caregivers' needs may not be well-established.

There exists a bewildering maze of potential services and support that caregivers can or must navigate.⁶⁴ The "maze" results from government programs still in their infancy offering unique services with different eligibility requirements. Though well-intentioned, community-based efforts to serve this population are scattered and largely uncoordinated. Nonetheless, these resources can generally be categorized into those that provide

- information on medical conditions
- training to more effectively serve as caregivers
- administrative support to help track appointments or medication schedules
- assistance to enable caregivers to focus on their own health and well-being
- financial support to caregivers
- networking and social support.

In this section, we briefly describe the types of services available across all of these resources. However, before doing so, it is important to recognize that caregivers' needs are unique and ever-changing, and that each caregiver brings to his or her situation a unique set of skills, capabilities, and resources.

Military caregivers must navigate a maze of policies, systems, eligibility requirements, information, and resources to care for their loved ones.



These differences across caregivers and their experiences can make it inherently challenging for universal approaches to policymaking and program development. At the same time, the benefits and services available across these different types of resources often depend upon specific criteria used by the organization to define eligibility for services. Thus, caregivers need to understand not only what is available but also what they may be eligible for based upon their own situation.

Changing Needs

Several factors determine the needs of military caregivers, and one-size programs or policy options never fit the needs of all. The service member's own injuries may be multiple and have different symptoms and severities, which in turn affect what activities of daily living, instrumental activities of daily living, and other services the caregiver provides.⁶⁵ Over time, through the process of recovery and rehabilitation, the service member's need for care and services should naturally change, and this, in turn, should affect the nature of the care provided. Ideally, the trajectory is positive, and caregiving becomes less necessary as the service member's condition improves. However, it is possible that the injuries incurred may ultimately warrant more intense caregiving or that the injured service member may require additional care sooner. For example, service members with TBIs may be at increased risk for Alzheimer's as they age.⁶⁶

The caregiver and service member's family situation and social support system also affect the dynamic. For instance, dependent children may be both an additional demand on the caregiver and a source of support. The child's role may also change as he or she ages, as may the roles of others. For example, with the passage of time, a spouse caring for his or her service member may also face the challenge of providing support to ailing parents.⁶⁷ As we heard in the focus groups, the experience of caregiving is so life-altering that caregivers and veterans may find it difficult to interact or socialize with friends or relatives, much less depend on them for assistance. At the same time, the benefits and support systems available to military caregivers may shift over their transition from the DoD to the VA. Due to the differences in the definitions of eligibility for caregiver support programs between the two departments, the transition to veteran status may create a gap in caregiver support services for families.

The resourcefulness, perseverance, and other personal characteristics of individual caregivers also affect the resources

they are able to apply to the demands of caregiving. Just as the needs of the injured service member or veteran vary, so do the resources individual caregivers bring to the situation. The resources personally available to the caregiver may change as policy changes institute new initiatives that support them in their endeavors. Similarly, as caregivers' own health, well-being, or resources deplete, caregiving tasks that were once manageable may become increasingly burdensome.

Types of Resources Available to Caregivers

Information on medical conditions. Myriad informational websites offering both general and specific information, brochures, and links to other resources are available. Our web search unearthed 93 different organizations providing these low-intensity resources. Such information, often regarding specific ailments and how to care for them, is a recognized caregiver need.⁶⁸ However, the variance in the quality of online health information can be problematic, and sorting through the options to determine which resources are of high quality and provide relevant information is complicated and suggests a time investment that many caregivers are inherently unable to make.⁶⁹

Training to more effectively serve as caregivers. Training caregivers to fulfill their multiple roles may be helpful. We heard this in the focus groups, although some caregivers specified that the training provided was really most relevant for those at the early stages of assuming their caregiving responsibilities. The VA's Program of Comprehensive Assistance for Family Caregivers (described later) imposes training for caregivers as an eligibility requirement for caregivers of veterans or service members undergoing medical discharge.⁷⁰ Presumably, this program would catch some caregivers near the beginning of their caregiver tenure. Nevertheless, focus group participants indicated that the basic level of information offered is less relevant for those who are already engaged in providing care. A handful of other trainings are offered via workshops for the general caregiving population. Training is also available online, which may be more accessible to persons who face difficulties finding child care or transportation to classes that may be located far from their homes. For all of these resources, both "schoolhouse" and online, the efficacy, applicability to a given situation, and ease of access may vary based on the caregiver's individual situation, which may affect how helpful he or she finds the offered material.

As caregivers' own health, well-being, or resources deplete, caregiving tasks that were once manageable may become increasingly burdensome.

Administrative support to help track appointments or medication schedules. Resources are available to help caregivers organize the help of relatives and friends. The resources include scheduling and coordination tools, as well as some interactive online tools through which caregiver communities can be created and help can be arranged. In addition, a few websites provide toolkits for caregivers, which include medication lists and schedules, appointment logs, and other useful documents that can be shared among caregivers and providers. How well these serve to implement the assistance of the support network and how well they work to meet needs that change over time is unknown.

Assistance and encouragement for caregivers' self-care. There are only a few programs and resources that help caregivers take care of their personal needs, many of which derive from new public policies or changes to existing ones. For example, Section 1672 of the National Defense Authorization Act of 2008 introduced an expansion of medical care available to family members accompanying recovering wounded, ill, and injured. The 2010 Caregivers and Veterans Omnibus Health Act provided for a greatly increased range of services for caregivers of veterans injured in the line of duty, primarily veterans injured post-9/11; the expansion included increases in health care coverage and mental health services. In addition, some resources are available to provide aspects of medical care to those otherwise unable to afford or qualify for them. Other organizations offer assistance, such as online mental health self-assessments that may or may not be geared specifically to caregivers.

Respite care, defined as short-term, temporary relief during which a trained individual tends to the individual for whom

Respite care and day centers where such care is offered are relatively sparse, and caregivers may encounter eligibility hurdles.

the caregiver is caring, permits caregivers to dedicate some time to themselves. The VA is one example of an organization providing this type of assistance; as specified in the Omnibus Act referenced above, it offers resources for caregivers of those seriously injured after 9/11. However, respite care and day centers where such care is offered are relatively sparse, and caregivers may encounter eligibility hurdles. Caregivers may also face difficulties identifying services that service members and veterans can trust and depend on. Moreover, such resources may only be located near large population centers (although some resources do try to alleviate the transportation needs of rural service members and veterans). The evidence basis for many of these programs is undetermined. In the 2010 NAC study, which was conducted prior to the passage of the Omnibus Act, only 15 percent of veteran caregivers reported using respite care services from the VA or from other organizations in the past year, and approximately 40 percent reported not having a care or case manager for their loved one, let alone such a service for their own needs as a caregiver. Studies of caregivers of individuals over 50, including those with dementia, found that roughly 10 percent of these caregiving populations use respite services.⁷¹ Caregivers who tend to use respite services are likely to have a high burden in their caregiving role, care for an older veteran, and not be caregivers of those with PTSD.⁷²

Financial and job support to caregivers. The policy landscape is undergoing changes in this domain. However, these changes are still relatively new, and whether they effectively address needs is unclear. In recent years, lawmakers have amended the Family Medical Leave Act (FMLA) to permit

family members of “covered” service members up to 26 workweeks of leave to care for their service member;⁷³ in 2010, this was extended to include family members of veterans. These amendments do not provide direct financial remediation for the long-term needs of caregivers.

In 2012, a report from the Quadrennial Review of Military Compensation (QRMC) addressed this issue specifically.⁷⁴ It highlighted two programs currently in their infancy that attempt to alleviate potential negative financial consequences associated with caregiving: the DoD Special Compensation for Assistance with Activities of Daily Living (SCAADL) program and the VA Program of Comprehensive Assistance for Family Caregivers. These new programs are slated for caregivers who assist their service members or veterans with activities of daily living, such as bathing, dressing, and feeding. While important, these programs are in the early stages of implementation and serve only a small fraction of military caregivers, a population which may number as many as one million. In addition, as noted in the QRMC report, the programs are already disjointed. For example, each program imposes different eligibility criteria: The DoD definition covers injuries and illnesses, but the VA definition only covers injuries, including physical injury, traumatic brain injury, psychological trauma, or other mental disorders. The VA also requires that the caregiver be a family member or live with the care recipient and that the caregiver have provided at least six months of continuous assistance already; SCADDL imposes neither of these requirements.

Networking and social support. Some nonprofit organizations offer retreats intended to engage both caregivers and their veterans or service members. Military-specific online support communities and forums are also available. It is not clear how well these networking programs reach their targeted populations, and evidence is lacking regarding the efficacy of the various programs. In addition, some caregivers noted that taking time away from their service members to attend a retreat or group meeting was almost impossible and would generate negative consequences for their loved ones. On the other hand, some caregivers emphasized that interacting with other caregivers was critically important to them. One caregiver said, “*There has to be more of caregivers coming together to have wine, or have a cry or have whatever.*” Another stressed the importance of online networking: “*The only ‘me time’ I get is late at night when I can sit on my computer to talk to other caregivers online.*” When we asked caregivers what advice they would give newer caregivers, several emphasized the need to “*find other caregivers.*”

HOW DO WE MOVE FORWARD?

The viability of the all-volunteer force depends, in no small part, on that force's understanding that the nation is committed to supporting veterans and military families. Should this commitment come in to question, it could lessen the appeal of military service to future generations. Ensuring adequate care for wounded, ill, and injured veterans is a critical aspect of society's commitment to its military services, and in the United States, a large portion of this care rests on the shoulders of those serving as military caregivers.

While many service members and veterans will recover from their wound, illness, and/or injury, many others will need years, possibly a lifetime, of care. To ensure that the nation can support those who care for these veterans and service members, be it in the short term or for the rest of their lives, policymakers need objective, concrete research and findings to provide a firm foundation for policy decisions. That research must address the following questions:

- How, as they age, will the caregiving needs of veterans and wounded service members change?
- How will these changes in demand for caregiving support (time and type) be met in the long term?
- How will decades of serving as caregivers affect military spouses?
- For men and women who rely on their parents as caregivers, what will happen when the parents can no longer meet their child's caregiving demands—and perhaps need caregivers themselves?
- For those children serving as caregivers to a veteran parent, how will it affect their own health and well-being or future relationships in the long term?

Significant attention has been called to the crises facing family caregiving more broadly in the United States. Citing an aging population, the growing burden of chronic illnesses, and an overburdened health care system, the Rosalyn Carter Institute for Caregiving (RCI) called for a fundamental shift in how our nation values and recognizes caregivers. The RCI's recommended strategy called for more research and development, system redesign, and better public and tax policy for caregivers.⁷⁵ Additional attention and national strategy is needed to ensure that military caregivers' needs are fully understood and addressed. It will not be enough to make programs available to military caregivers; efforts will be required to ensure that the programs are accessible and tailored to their specific needs.⁷⁶

The RAND Corporation and the Elizabeth Dole Foundation are poised to address these and other questions critical to informing the policies and programs that support military caregivers. The research we propose to conduct is substantial and includes a comprehensive needs assessment of military caregivers, a formal environmental scan of resources available to military caregivers, and a gap analysis to identify where there are sufficient resources and where there is opportunity for improvement.

In the meantime, as the nation honors the contributions and sacrifices of the men and women who serve in the Armed Forces on its behalf, the people of the United States should not overlook the contributions and sacrifices of the caregivers who support those who return with war-related wounds, illnesses, and injuries. The lives of these men and women—spouses, parents, children, siblings—are often forever changed when their loved ones return from deployment with injuries, disabilities, wounds, or mental illness. Military caregivers are an important cornerstone of the nation's ability to support its wounded warriors. Future research will be needed to ensure that their needs are recognized and addressed effectively.

Notes

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⁶ This variability is associated with the populations studied and the methods of assessment. Studies that have assessed the prevalence of PTSD using validated scales among samples that are representative of the entire previously deployed population find rates of PTSD between 13 and 20 percent and screening rates for the incidence of TBI to range from 12 to 23 percent. While important, estimates from studies that have limited their analysis to incident PTSD, such as the Millennium Cohort Study, or produced from samples not representative of the entire deployed population were not used in the current calculations.

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¹⁰ The National Alliance for Caregiving and the AARP defined five levels of caregiving based upon the amount of hours spent each week providing care and the burden of care associated with helping with activities of daily living. "Level 1" caregivers devote relatively few hours each week and provide no assistance with activities of daily living, whereas Level 5 caregivers provide help with at least two activities of daily living and spend more than 40 hours providing care each week. NAC and AARP, 2004.

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About This Report

This report was prepared as part of Phase I of a research study funded by Caring for Military Families: The Elizabeth Dole Foundation. The report should be of interest to policy officials and program leaders who work with military caregivers, as well as to individuals interested in supporting military caregivers more broadly.

The research was conducted within the Forces and Resources Policy Center of the RAND National Security Research Division (NSRD). NSRD conducts research and analysis on defense and national security topics for the U.S. and allied defense, foreign policy, homeland security, and intelligence communities and foundations and other nongovernmental organizations that support defense and national security analysis. For more information on the Forces and Resources Policy Center, see <http://www.rand.org/nsrd/ndri/centers/frp.html> or contact the director (contact information is provided on the web page).

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