Engaging, Supporting, and Sustaining the Invisible Partners in Care:
Young Caregivers of Veterans From the Post-9/11 Era

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Few studies have explored the health effects of caregiving for post-9/11 veterans who have been traumatically injured, have traumatic brain injuries, or have post-traumatic stress disorder. Post-9/11 veterans and their caregivers tend to be younger than veterans who served exclusively prior to 9/11. In response to the needs of caregivers, Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, was passed, providing unprecedented support for informal caregivers of veterans. This support includes a monthly stipend and health insurance for caregivers who meet eligibility criteria. The uptake in these support services, and the resulting cost of services, has far surpassed expectations. As the Department of Veterans Affairs continues to provide caregiver support services, it is essential to determine the value and direct impact of the services provided to caregivers and veterans.

"One day it could be residual effects of surgery, and the other days it's the PTSD coming through...There's a lot of days that I just really have to sit beside him and basically hold his hand throughout the day and do every single thing. So on those days, obviously I can't go to work. I can't do anything."

Caregiver

An estimated 5.5 million informal caregivers provide medical care, emotional support, and physical assistance to veterans. Of those, an estimated 1.1 million provide care for veterans who served after September 11, 2001. An informal caregiver is "a relative, partner, friend, or neighbor who has a significant personal relationship with and provides a broad range of assistance to an older person or adult with a chronic or disabling condition" [1]. This article discusses only these informal caregivers, not agency-based staff.

In 2014, the RAND Corporation released a report entitled "Hidden Heroes: America's Military Caregivers," which reported significant demographic differences between caregivers of post-9/11 veterans, pre-9/11 veterans, and civilians, as well as differences in utilization of caregiving services, social support, and the nature of caregiving tasks [2]. Post-9/11 veterans tend to be younger than veterans who served exclusively prior to 9/11, with 46% aged 18–30 years and an overwhelming 94% aged 55 years or younger [2]. Post-9/11 caregivers of veterans differ from traditional informal caregivers (typically older females or daughters) as 40% of caregivers of post-9/11 veterans are aged 18–30 years. Moreover, caregivers of post-9/11 veterans are more likely to be male [2].

Caregivers of post-9/11 veterans provide assistance with fewer activities of daily living (ADLs) and instrumental activities of daily living (IADLs) than civilian caregivers, but they provide greater assistance in helping "care recipients cope with stressful situations or avoid triggers of anxiety or antisocial behavior" [2]. Given that the signature injuries of recent conflicts are traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD), the need for this type of assistance is prevalent and may be challenging for caregivers due to the unpredictability of care needs. Due to the unpredictability of day-to-day caregiving, many of these caregivers say they are struggling. Fifty-three percent of caregivers of post-9/11 veterans reported having no support system [2]. Moreover, caregivers indicated high levels of work strain, financial strain, depression, and difficulty planning for the future.

We know that caregiving can have adverse health impacts and can create persistent economic strain for traditional older caregivers [3, 4]. Yet few studies have explored the health effects of caregiving for veterans who have been traumatically injured (polytrauma) or who have TBI and/or PTSD. Thus, understanding the long-term impact of caregiving on caregivers is crucial, as caregivers of veterans not only include traditional caregivers but also a large portion of relatively young caregivers providing care for young veterans.

In response to the needs of caregivers, Public Law 111-163, the Caregivers and Veterans Omnibus Health Services Act of 2010, was passed, providing unprecedented support for informal caregivers of veterans. The legislation established

Electronically published November 13, 2015.

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N C Med J. 2015;76(5):320-322.
0029-2559/2015/76511

education and training, services, and assistance for informal caregivers of veterans in need; these services were provided through 2 landmark programs: the Program of Comprehensive Assistance for Family Caregivers (hereafter the Comprehensive Program) and the Program of General Caregiver Support Services (hereafter the General Program).

The Comprehensive Program aims to reduce strain for caregivers by supporting those who care for severely injured post-9/11 veterans who need assistance with ADLs or who require supervision or protection because of the residual effects of their injuries. The additional services for the caregiver include a monthly stipend; access to health care services through the Civilian Health and Medical Program of the Department of Veteran Affairs (CHAMPVA), if not already covered under a health insurance plan; education and training; travel reimbursement (lodging and subsistence); respite care; and mental health services.

The General Program aims to enhance support and services for caregivers of veterans of all eras, including education, training, and respite. Education and training for the programs is delivered through several mechanisms, including Easter Seals.

The Veterans Health Administration (VHA) responded to and met the requirements of the law rapidly. Initial estimates predicted that about 4,000 caregivers would be approved for the Comprehensive Program by September 30, 2014. However, uptake in the Comprehensive Program far surpassed expectations, with over 37,000 applications received and more than $720 million spent. From the inception of the program, in May 2011, through May 2015, more than 25,000 caregivers qualified to receive a monthly stipend and support services, and over 5,000 caregivers qualified for health care services through CHAMPVA. The Fayetteville Veterans Affairs Medical Center has one of the highest enrollments in the Comprehensive Program nationally, reflecting the important role military bases play in North Carolina and the high numbers of veterans who remain in the state after discharge from the military.

How to Best Support Young Caregivers

Training for older caregivers of elderly individuals reduces caregiver strain [5, 6] and increases coping [7, 8], self-efficacy, self-reported skill [9, 10], and self-care [10], but there is a gap in evidence about how training impacts younger caregivers and care recipients. Younger caregivers for veterans with TBI and PTSD have very diverse care needs, with physical assistance as only part of the story. There is little evidence about how to best train and support caregivers of veterans with TBI, PTSD, and co-occurring physical and mental health conditions, whose needs differ from those of the traditional geriatric care recipient. It is critical to understand if training focused on the needs of traditional caregivers is still applicable and meaningful for caregivers of younger veterans.

The principal challenge currently facing VHA is how to provide both prolonged and successful caregiver support catered to the needs of nontraditional caregivers and care recipients. First, as veterans live longer with traumatic injuries, caregivers provide care for longer periods of time. Moreover, as 33% of caregivers of younger, post-9/11 veterans are spouses [2], they are adopting the role of caregiver at a younger age. It is unclear whether programs are needed for the initial period when caregivers are adjusting to their role, or indefinitely, as they change the way they use their time—often towards caregiving and away from gainful employment. Secondly, it is difficult to define what a successful program looks like. What outcomes should we expect to improve when a support program is successful? Moreover, what is the appropriate metric to measure these outcomes?

Caregiver Support Program Perspective and Policy Implications

Currently, benefits provided to caregivers of veterans of all eras through the General and Comprehensive Programs include at least 1 full-time caregiver support coordinator at every Veterans Affairs (VA) medical center. These professionals, who each serve between 6 and 251 caregivers [11], serve as clinical experts in caregiving issues and also work to sensitize health care providers to the important role that caregivers play in supporting veterans' health care. Given the impact of the signature wounds of the post-9/11 era, such as TBI and PTSD, the role of caregivers is crucial to veterans' integrated care, and care coordination is imperative. Sensitizing health professionals to the needs and roles of caregivers in veterans' medical care cannot be overstated.

VA has also implemented a series of support services for caregivers of veterans of all eras, including a toll-free Caregiver Support Line and website. The Caregiver Support Line is staffed by licensed social workers who provide support, resources, and referrals, and it has responded to 190,000 calls. VA also hosts an active website to provide veterans, caregivers, and the general public with helpful information and resources concerning caregiver supports; this website currently has more than 40,000 subscribers. Finally, VA has partnered with the Fisher House Foundation to provide frequent flier miles, known as Hero Miles, to caregivers in need of respite care.

VA will continue to provide services and supports to caregivers; thus, it is essential to determine not only the value of these services, but also the direct impact of the services provided. Caregivers are not necessarily VA patients, so their unique health care needs, utilization of health care services, and outcomes are difficult to identify and track using existing VA data. Therefore, previous program evaluations have centered on the impact of program participation on the health of the veteran, which does not capture the full impact of the program's benefits. For example, VA has provided education and training to nearly 30,000 caregivers nationwide. Caregivers' response to this training through formal satis-

faction surveys has been overwhelmingly positive. However, distal outcomes of the training, such as whether training can reduce symptoms of depression or caregiver burden, have not yet been rigorously examined. Additionally, no information exists about which services are most useful. The need for caregiver supports and services is evident, but the lack of evidence about the effectiveness of these interventions impacts the scalability of comprehensive support and the provision of prolonged support for young caregivers, who may require these supports and services for the rest of their lives.

Evaluation Plan

In response to this gap in knowledge, the Caregiver Support Program and the Quality Enhancement Research Initiative have partnered with a team at the VA Center for Health Services Research in Primary Care in Durham to evaluate the Caregiver Support Program. This evaluation is being conducted in collaboration with the leaders of the Caregiver Support Program in the Central Office.

The Partnered Evaluation Center is evaluating the impacts of the Comprehensive Program and the General Program on veterans and caregivers. The evaluation uses a multiple and mixed-methods approach, as well as rich data sources to provide a full evaluation of the programs' short-term impacts. First, the evaluation will use VA medical records data to assess the impact of the Comprehensive Program on the health and well-being of veterans, by examining health care encounters expected to be sensitive to caregiver support (potentially avoidable utilization). Second, data from a national survey will describe caregivers in the Comprehensive Program and assess how training, the stipend, and other benefits have affected their health and well-being (for example, perceived financial strain). Third, we will describe the experiences of caregivers participating in the Comprehensive Program and the General Program, using survey and semi-structured interview data, to gain a contextual understanding of their perspectives on the usefulness of the programs, challenges, and/or unmet needs. Finally, we will generate a detailed profile of the costs and services provided in the Comprehensive Program and the General Program, in order to assess the value of the programs to veterans, caregivers, and VHA.

The rigorous evaluation of the Caregiver Support Program will produce recommendations for adjustments to the programs and will contribute evidence to a growing body of literature about the impact of interventions for caregivers on veteran and caregiver outcomes. This evaluation will address a critical gap in the literature about the value of these programs as well as opportunities for improvement. Caregivers matter because they often prevent veterans from facing abject poverty, long-term institutionalization, homelessness, and continuingly decreasing health status. Given the high cost of these programs, however, we need to understand how caregivers use and value the services provided and the programs' impact on caregivers' and veterans' health care use, overall health, and well-being. This will illuminate how to optimize services for caregivers of veterans. NCMJ

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Acknowledgments

Financial support. This evaluation is funded by the Caregiver Support Program and Quality Enhancement Research Initiative, PEC 14-272. The VA Caregiver Support Program Partnered Evaluation team at the Durham VA Medical Center includes the following individuals: Courtney Van Houtven, PhD, MSc; S. Nicole Hastings, MD, MHS; Eugene Oddone, MD, MHS; Matthew Maciejewski, PhD; Nina Sperber, PhD; Karen Steinhauser, PhD; Corrine Voils, PhD; G. Darryl Wieland, PhD; Cristina Hendrix, RN, DNS, GNP-BC, FNP; Maren Olsen, PhD; Valerie Smith, DrPH; Karen Stechuchak, MS; Jennifer Lindquist, MS; Merritt Schnell, MPH, MS; Lesa Powell, MS; Sara Morris, MPH, RD; Katherine Ramos, PhD; Megan Shepherd-Banigan, PhD, MPH; Katherine Miller, MSPH; and Margaret Campbell-Kotler MPH, RN, at the Caregiver Support Program.

Potential conflicts of interest. All authors have no relevant conflicts of interest.

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