

# Improving Caregiver Knowledge of Support Resources

LaDonna Clark Thomas, DNP, ANP-C, VHA-CM

After reading a resource manual, caregivers of veterans with disabilities reported being more knowledgeable and empowered regarding available support resources.

In 2012, 1.3 million veterans who were wounded in action had a severe service-connected disability—nearly triple the number in 2001 (482,000).<sup>1</sup> Given the increased number of wounded veterans, the need for caregivers also increased.

The act of caring for an individual with a chronic disability can be a daunting task for the caregiver. However, what is not so commonly recognized is the need for caregiver awareness of the available support resources. Caregivers who do not receive necessary support experience physical and emotional consequences that interfere with their ability to care for veterans with disabilities. Therefore, there is a significant need to provide adequate support for the caregiver to maintain optimum care of the veteran.<sup>2</sup>

Increased caregiver strain among family caregivers of veterans with long-term disabilities and their lack of knowledge of support resources is a clinical concern. A comprehensive review of the literature provided evidence that access and use of caregiver support resources improved caregiver quality of life.

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**Dr. Thomas** is a compensation and pension examiner nurse practitioner in the ambulatory care department at the Durham VA Health Care System in North Carolina.

The purpose of this project was to provide an educational intervention of caregiver resources that were available at the Durham VA Health Care System in North Carolina and in the surrounding community. The desired outcomes included (a) increasing the caregiver's knowledge of resources available at the VA and within the community to decrease caregiver burden; and (b) assisting the caregiver in determining the best resources for the caregiver and patient. This project was deemed to be a quality improvement project and did not require institutional review board (IRB) approval.

## BACKGROUND

The term *strain* is used to describe the burden, trouble, or burnout that a caregiver encounters when caring for a person with a long-term illness or disability.<sup>3</sup> Caregivers of veterans remain in their role longer and have a heavier burden of care than that of all other caregivers: 65% are in a high-burden caregiving situation compared with 31% nationally.<sup>4</sup> The consequence of providing care without assistance has all the features of chronic stress.<sup>2</sup> Moreover, the decline of the caregiver's health can significantly compromise the ability to provide care.<sup>3</sup>

Empirical observations of the

negative health effects of caregiving noted over the past 2 decades have helped convince policymakers that supporting caregivers is an important public health issue.<sup>2</sup> To this end, Congress mandated legislation that required the VA to provide a support program for veteran caregivers. In May 2010, President Obama signed the Caregivers and Veterans Omnibus Health Services Act of 2010 into law.<sup>1</sup>

## SUPPORTING LITERATURE

The VA caregiver resource program offers a variety of support resources.<sup>1</sup> A better understanding of caregiver needs is necessary to provide the right support resources, improve the health and well-being of caregivers, and make decisions regarding individual caregiving situations.<sup>5</sup> For example, respite care offers temporary or periodic relief from caregiving, allowing caregivers to attend to personal tasks, such as shopping, running errands, relaxing, and socializing. This service can increase the physical and mental well-being of the caregiver.<sup>6</sup> Studies show that early use of support services is paramount in order for caregivers to receive the greatest positive impact.<sup>5</sup>

Chen and colleagues conducted a study of 164 caregivers. The

study showed that caregivers who received assistance with accessing the correct support resource exhibited considerably higher satisfaction with the services they received.<sup>7</sup> Determining which support therapy was best for the caregiver and the patient for whom they were caring was seen as the initial step. Providing a tool that supplies all the information caregivers need as well as assisting them with accessing services more efficiently is beneficial.

The National Alliance for Caregiving conducted a study to evaluate the needs of caregivers of veterans of various conflicts.<sup>4</sup> In the study, caregivers reported that a resource guide would be beneficial. Some of the services they wanted to include in the directory were VA disability benefits, respite care, home health care, hospice services, assisted living, rehabilitation therapies, caregiver support group information, and community resources.

Based on the literature, the author believed that better knowledge of support resources was needed for caregivers. The literature included detailed descriptions of how knowledge of support resources improved caregiver's well-being by increasing his or her ability to cope with stress related to providing care. However, the literature could have provided a more elaborate discussion on this topic. That was the only weakness identified in each of the studies. Nonetheless, it was clearly noted that resource knowledge yielded a positive effect.

## METHODS

The project took place at the Durham VA Health Care System and was implemented from August 2015 to October 2015. The participants targeted were caregivers of veterans with disabilities who were consid-

ered the veteran's primary caregiver. Participation was voluntary.

During the veteran's clinic appointment, the caregiver was given an implied consent letter, pre- and postquestionnaire forms, and a caregiver resource manual. The manual included information on caregiver support resources at the Durham VA Health Care System and in the community (eg, adult day care centers; home-based primary care, hospice care, skilled care, and telehealth; homemaker and home health aide programs; respite care). Other information was provided, such as the Caregiver Support Program application process, contact names, numbers, and helpful websites. Before reading the manual, participants completed the prequestionnaire form and returned it the day of the veteran's visit. After reading the manual, the caregiver was instructed to complete the postquestionnaire form.

The project coordinator (PC) collaborated with the Veteran Health Education coordinator in developing the caregiver resource manual and questionnaires to ensure that the material met the requirements set forth by the educational program within the Durham VA Health Care System. The PC also collaborated with the Caregiver Support Program subject experts, the chief and acting assistant chief of social work when formulating the contents of the manual and questionnaires. The questionnaires were used to assess the effectiveness of the manual.

The 3 questions on the prequestionnaire and 3 questions on the postquestionnaire were geared to measure the caregiver's knowledge. There also were 4 questions on the postquestionnaire that were used to address manual revisions.

On the prequestionnaire form, the following questions were asked: (1) If you needed to find caregiver support resources, how much knowledge do you have finding the resources that fit your needs as well as the veteran's needs? (2) Rate how aware you are with knowing what caregiver support resources are available at the VA and within the community; and (3) Would knowing which caregiver support resources to choose from at the VA and within the community decrease your stress level and give you "peace of mind?"

The same questions were asked postintervention, and the participants were asked to rate their knowledge after reviewing the manual. The participant's responses on the questionnaires were measured using a 5-point Likert scale.

## PARTICIPANT DEMOGRAPHICS

Demographic information was obtained from the cover letter distributed to each participant. The demographic information included age, gender, relationship to the veteran, and number of years to date in the current caregiving role. Participants eligible for inclusion in this project were primary caregivers of veterans with disabilities from all eras of conflict, aged  $\geq 18$  years.

Fifteen caregivers participated by returning the cover letter containing the implied consent, reading the manual, and completing the pre- and postquestionnaires. There was a wide age range of caregivers who participated, from 29 to 77 years. Of those who responded, there also was a wide range in time in their current caregiving role, ranging from 1 to 41 years. The mean number of years in the current caregiving role was 7 years.

Of the 15 participants, most were

female spouses. There were no husbands who participated. The relative's category included a cousin, a son, and a daughter. The "other" category included a son-in-law and a fiancé.

## DATA ANALYSIS

Both outcomes were measured using the responses from questions 1 through 3 with the use of running a descriptive statistical analysis. In addition, a *t* test was used to determine statistical significance, set at  $\alpha$  level  $< .05$  of knowledge increase from pre- to postintervention data. Based on the facility, educational benchmarks were set at 80% with the 80% equal to 4 on the Likert scale. Therefore, 80% was the identified benchmark for this project. The goal was that  $> 70\%$  of the participants would score 80% or better on the postquestionnaire.

## RESULTS

Both outcomes were met: (1) increasing the caregiver's knowledge regarding resources available at the VA and within the community to decrease caregiver burden; and (2) assisting the caregiver in deciding which caregiver resources located in the manual were the right fit for the caregiver and the veteran for whom they were caring. The percentage of participants who scored 80% or better on the prequestionnaire was 54% ( $n = 8$ ). The postquestionnaire outcomes were considered an improvement based on caregiver's knowledge of support resources as well as whether the information in the manual decreased their stress level and gave them peace of mind. The intended outcome for the postquestionnaire was that  $> 70\%$  of the participants would score  $\geq 80\%$  after the intervention. This goal was

met as final results revealed 73% ( $n = 11$ ) of the participants scored  $> 80\%$  on the postquestionnaire.

The postresults supported that caregivers' knowledge increased, they had peace of mind, and stress levels were decreased with the use of an educational intervention, a comprehensive Caregiver Resource Manual. The postquestionnaire revealed that all of the participants found the Caregiver Resource Manual easy to navigate, and 93% of participants found the Caregiver Resource Manual useful. Out of 15 participants, 8 provided comments. Seven provided positive comments, reporting that the information in the manual was interesting, the manual was simple/easy to read, and the outside resources listed were helpful.

The participant who provided a negative comment was one of the caregivers who did not meet the benchmark of 80% on the pre- or postquestionnaire. The participant was a 33-year-old wife of a veteran with disabilities who had been in the current caregiving role for 9 years. This participant reported that the Caregiver Resource Manual was not geared to younger caregivers, so she would not benefit from using the manual. This caregiver also was the only participant who reported that the Caregiver Resource Manual neither gave her peace of mind nor decreased her stress level.

Comments or suggestions would have been helpful from the other 8 individuals. Because it was not written in the IRB proposal to contact the participants other than to follow-up with telephone calls regarding unreturned questionnaires, no further contact was made with the participants.

## DISCUSSION

The preliminary success of this

project suggests that there is a significant need for an educational conduit to ensure sufficient caregiver knowledge. Interprofessional collaborative efforts along with using information systems/technology to deliver the Caregiver Resource Manual electronically are important future consideration for improvement of the overall outcomes for a wide range of caregivers, veterans, and health care providers. Health care policy changes on the organizational level, systems level, and national level could further support caregivers of disabled veterans by enabling easy access to caregiver resources as a mandated practice.

## Limitations

Limitations centered on the recruitment process. There were a total of 15 caregivers who participated. Although the participation did not meet the PC's expectation, the final number of participants was adequate in obtaining data regarding evaluating the impact of this project.

## CONCLUSION

The results of this project provided evidence that the Caregiver Resource Manual was effective. Caregivers gained a sense of knowledge and empowerment regarding available resources within the VA and the community. Providing the caregiver with peace of mind and improving the overall health and well-being of the caregiver and veteran were essential.

Moreover, just as the veterans who fought for freedom were equipped with full body armor to help protect them from the potential negative consequences of combat, caregivers who care for these brave soldiers are now equipped with a resource tool and a "full armor of knowledge" to care for their loved

ones...our nation's heroes...our veterans. ●

### **Author disclosures**

*The author reports no actual or potential conflicts of interest with regard to this article.*

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