

Advances in Geriatrics

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Reaching Out to Caregivers of Veterans With Dementia

The VA provides ambulatory services to nearly 4 million veterans over the age of 65.¹ Planning for the care needs of these veterans began in the 1970s when the VA developed 20 Geriatric Research Education and Clinical Centers (GRECCs) nationwide. The VISN 19 GRECC, established in 1987, is stationed at the VA Salt Lake City Health Care System (VASLCHCS) and serves veterans throughout Utah, Wyoming, Idaho, Nevada, Colorado, and Montana. Because much of the VISN 19 catchment area consists of underserved rural and frontier regions with limited health care resources, a primary focus of the VASLCHCS GRECC is to improve access to health care among older veterans residing in these areas.

One method to improve access to services for veterans with dementia is to support their caregivers.² The caregiver is an important member of the health care team for veterans with dementia,³ and historically, GRECCs have addressed caregiving issues as part of their mission. More recently, the VA system's emphasis on family caregivers of Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) veterans⁴ has increased public interest in caregiving. Unfortunately, although all VA medical centers have established na-

tional caregiver support points of contact,⁵ caregivers of aging World War II, Korea, and Vietnam veterans can be easily overlooked.

Family caregivers of aging veterans manage a range of issues from basic activities of daily living to agitation and aggressive behavior. Given these diverse and challenging caregiving activities, it's not surprising that caregivers experience higher levels of depressive symptoms and other mental health problems, as well as increased rates of hypertension, cardiovascular disease, and premature mortality compared with non-caregiving peers.⁶ In some instances, poor health may impair a caregiver's ability to address the needs of the frail veteran, potentially increasing the risk of institutionalization.

IDENTIFYING CAREGIVERS

The VASLCHCS GRECC is committed to providing services to these caregivers to improve caregiver health and thereby better assist aging veterans. However, identifying and recruiting caregivers for clinical services research is difficult. The stigma associated with dementia leads many caregivers to isolate themselves from family, friends, and even support services. Caregivers

also face many practical barriers, such as time constraints, limited transportation, or arranging for supervision of the veteran with dementia. In addition, cohort characteristics, such as limited familiarity with psychologically-oriented support services,⁷ may hinder the caregiver's willingness or attempts to seek additional support.

The purpose of this article is to introduce strategies for the identification and recruitment of caregivers of veterans with dementia. These strategies were developed as part of the Supporting Caregivers of Rural Veterans Electronically (SCORE) project, funded through the Office of Geriatrics and Extended Care (GEC) and the Office of Rural Health (ORH). We will describe how we reached out to family caregivers of veterans and how we addressed the challenges inherent in this effort.

SCORE PROJECT

Rather than the traditional focus on the veteran as a patient, the objective of the 26-week intervention was to provide direct caregiver support through clinical services embedded within an applied research framework. This goal was accomplished in 2 ways: (1) licensed clinical social workers

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The VHA's Geriatric Research, Education and Clinical Centers (GRECCs) are designed for the advancement and integration of research, education, and clinical achievements in geriatrics and gerontology throughout the VA health care system. Each GRECC focuses on particular aspects of the care of aging veterans and is at the forefront of geriatric research and clinical care. For more information on the GRECC program, visit the Web site (<http://www1.va.gov/grecc/>). This column, which is contributed monthly by GRECC staff members, is coordinated and edited by Kenneth Shay, DDS, MS, director of geriatric programs for the VA Office of Geriatrics and Extended Care, VA Central Office, Washington, DC.



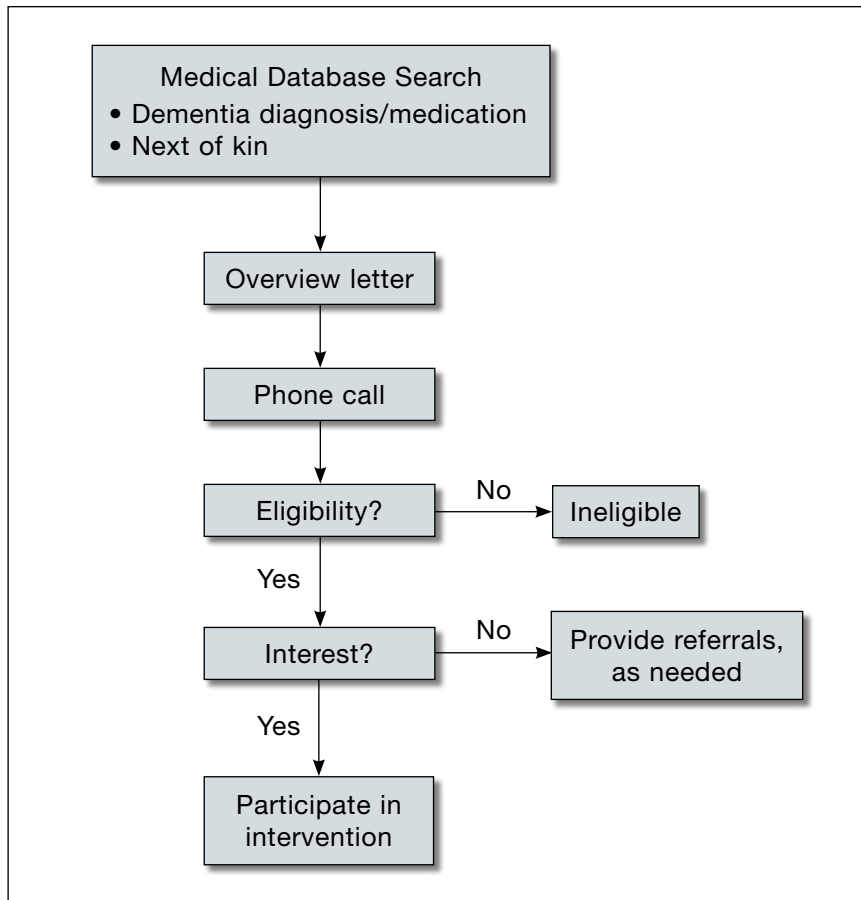


Figure. Recruitment model.

provided education, brief intervention and psychosocial support via the telephone; and (2) educational information was disseminated using the Internet or a home telehealth device.

The educational curriculum addresses topics presented as progressive learning modules that focus on skill training, mood management, and resource access for the caregiver. For example, initial modules focus on information about dementia and potential problems associated with informal dementia care. The goal was to provide the caregiver with sufficient knowledge about dementia and its progression to educate the caregiver that symptom worsening can be due to disease progression rather than poor informal care. The module-based educational information was intended to improve

the caregiver's coping resources and address skill deficits.

A key component of evaluating the efficacy of this program was to document not only the efficacy of SCORE, but our experiences identifying, recruiting, and interacting with caregivers of older veterans. It is our hope to inform the research and clinical care of this population.

WHO ARE THE CAREGIVERS?

The step-by-step process to identify and enroll caregivers in the SCORE project is summarized in the Figure. We initially queried electronic medical records to identify veterans who were diagnosed with dementia-related disorders or prescribed an antedementia medication. For this population, medical records identified veteran's next

of kin who might be a care provider of the veteran. Potential participants were sent a letter, via the veteran, providing an overview of the study.

Licensed clinical social workers contacted the next of kin to determine interest and screen for eligibility. Initially, 1,457 veterans were identified as potential participants. Of those, 385 individuals were screened for eligibility; 140 were uninterested, and 194 were deemed ineligible. Caregivers were ineligible if: (1) the veteran was bedbound, had a life expectancy less than the length of the study, or were receiving cancer treatment, such as chemotherapy or radiation therapy; (2) the veteran had a serious and persistent mental illness diagnosed before age 45; (3) the caregiver was cognitively impaired and unable to provide informed consent; or (4) the caregiver was illiterate or sufficiently visually impaired to prevent understanding SCORE material. To date, 47 caregivers have enrolled in the study.

IDENTIFYING BARRIERS

We encountered 3 challenges, or "barriers," when identifying and recruiting caregivers. These barriers underscore the process caregivers personally experience when adopting the caregiving role: (1) minimizing the meaning of progressive symptoms; (2) recognizing that the veteran has dementia, though the caregiver may not be fully aware of his or her caregiving role; and (3) recognizing dementia and caregiving role but lack of time to participate (Table).

Barrier 1: Caregiver framing of the veteran's symptoms. Many caregivers attributed progressive cognitive decline to aging, even though a dementia diagnosis had been made and many of these caregivers were already performing traditional "caregiving duties," such as managing the veteran's medications and finances. These caregivers described their spouse as being in the earlier stages of dementia when

functional impairment was less noticeable. Many caregivers also reported stigma and misperceptions about dementia and Alzheimer disease, highlighting the importance of including basic educational information about the nature and course of dementing illnesses. For this group, it was helpful to focus on specific symptoms, such as wandering and safety issues. For example, one participant expressed uncertainty about whether her husband really had dementia, though she had recently taken over medication and financial management for him due to repeated mistakes in these areas. However, she was eager to enroll because she was interested in receiving specific intervention components from the SCORE modules.

Barrier 2: Caregiver framing of his or her role. Many caregivers who declined to participate reported that the care recipient was “doing fine.” These caregivers recognized that the veteran had dementia, but they did not perceive themselves as “caregivers,” per se. Research staff informed these potential participants that, though their spouse or parent is doing well now, SCORE information could be useful in the future (for example, early intervention). Many potential participants continued to perceive that the information would be useful only if the veteran was already experiencing late-stage dementia-related problems. We recommend providing resource information for future use so that caregivers who do not perceive an immediate need will know how to take advantage of services in the future. This barrier highlighted the need for consumer-based support to allow caregivers to get help when and how they need it.

Barrier 3: Limited time. Caregivers have limited time, and any new activity, even a caregiver-specific intervention, could be perceived as burdensome. We anticipated this barrier and designed SCORE to be time-limited. Participants were informed up

Caregiving role	Intervention strategies
Interpretation of progressive symptoms	Focus on symptom management and offer support for specific symptoms
Caregiver doesn't recognize his or her role	Provide contact information for contact at a future date
Limited time	Offer flexible phone or online support, available at the caregiver's convenience

front that modules would require participating 10 to 15 minutes per day, 3 times a week. The intervention is completed at home at the caregivers' convenience. Completion of the intervention at home eliminates time away from the care recipient, something that many caregivers worry about. Furthermore, caregivers living in rural locations can access the intervention without the additional travel barrier.

WHAT DID WE LEARN?

We found 3 strategies that increased the likelihood of caregiver participation: **Strategy 1: Flexible responding.** Flexibility was necessary to successfully reach caregivers. This included adjusting telephone support based on the caregiver's differential time constraints. For example, many caregivers preferred to spend time on the telephone with the social worker discussing several caregiving issues, while others focused specifically on the task at hand, keeping the telephone support brief. Social workers providing the telephone support were able to identify the caregiver's needs and adjust as needed. Though many caregivers are retired, they continue to have many demands on their time. We recommend contacting the caregiver at a time of their preference and increasing staff availability, such as providing contact information for multiple staff members who are accessible by telephone.

Strategy 2: Strategic contact. Initially meeting with the caregiver in

person provides caregivers with a face-to-face VA contact. We recommend meeting at the caregiver's convenience, such as before or after a veteran's scheduled medical appointments, to eliminate potential travel and scheduling barriers. In addition, establishing a relationship with the caregiver recognizes that the caregiver is a member of the health care team. This contact consisted of periodic telephone “check-ins” to address care issues. During these check-ins it was important to support caregiver needs guided by empathic and normalizing statements.

Strategy 3: Relationship building. Most important, providing a verbal and understandable explanation of the consent form allowed for an in-depth discussion not only of the issues related to research participation, but also concerns about dementia and caregiving. During this discussion, many caregivers disclosed how little support they had and described feeling isolated and alone. One of the major benefits of employing licensed clinical social workers in this role was that they were able to provide support to these isolated caregivers and assist them with receiving additional support services, as needed.

CONCLUSIONS AND FUTURE DIRECTIONS

With the VA's recent shift in focus among OIF and OEF veterans to include family members of veterans as part of the care services team, clearly

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support for caregivers of aging veterans is also much needed. Caregivers of older veterans with dementia exist in very large numbers and also experience substantial need. Providing services to caregivers of veterans with dementia increases the health care access of aging veterans, a primary VAS-LCHCS GRECC focus.

Unfortunately, many caregivers of veterans with dementia in our project appeared to struggle with their role as “caregiver.” It is clear that caregivers have limited time due to the multiple demands on their time, though they can feel isolated. To overcome these barriers, we highlight strategies we have found helpful, such as including the caregiver as a member of the health care team and flexibly responding to the caregiver’s needs. Finally, developing a relationship using face-to-face meetings and regular

check-ins alleviates common feelings of isolation. Interventions aimed at the caregiver, such as SCORE, will not only improve their personal situation, but increase health care access for our older veterans. ●

Author disclosures

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