A VA Inpatient Respite Program for Patients With Dementia

Kye Y. Kim, M.D.
Susan B. Hall, M.S.W.

As the number of adults older than 65 years increases, the prevalence of Alzheimer's disease, one of the most disabling conditions among this population, is expected to increase (1). Veterans in this age group accounted for 38 percent of the total veteran population in 1999 (2) and are expected to number between 7.8 and 9 million until 2020 (3). With the increase in the number of older veterans who are vulnerable to Alzheimer's disease and related disorders, clinicians of the Department of Veterans Affairs (VA) as well as clinicians elsewhere need to be aware of various services available in the VA system to assist families of older veterans with dementia. One of the services for families is a respite care program provided in inpatient settings, such as sustained treatment and rehabilitation units, nursing home care units, and extended care rehabilitation units. However, in the case of nonveterans, there is no Medicare code for respite care, and Medicare does not reimburse for inpatient respite care unless the hospitalization is directly related to a medical illness.

Respite care is generally defined as a "care-giving service that provides a planned intermittent break from the ongoing responsibility of caring for a chronically disabled individual who is being managed at home" (4). Providing care for a person with dementia can result in high levels of stress, unwanted social role changes, depression, anxiety, a lowered sense of well-being, feelings of being burdened, deterioration of physical health, and a general feeling that life is overwhelming (5). Research on the family caregivers of persons with dementia has consistently revealed that respite care ranks among urgently desired community services (6).

Inpatient respite care is a short-term out-of-home stay for the patient with dementia. In the VA system, sustained treatment and rehabilitation units, nursing home care units, and extended care rehabilitation units usually provide this care for a short period, generally one or two weeks. The service gives the caregiver—who is usually related to the person with dementia, often as a spouse or adult child—a break from the stressful task of caring for the patient at home. As well as providing temporary relief from worry and stress, this type of service gives the caregiver time to attend to his or her own needs (7).

The purpose of this column is to discuss the effects of inpatient respite care on persons with dementia and on their caregivers and the clinical implications for both patients and caregivers. We include a synopsis of an inpatient respite program at a local VA medical center as an example and make suggestions for better serving persons with dementia as well as their caregivers.

Effects of respite care on patients with dementia

Although inpatient respite care provides a break to caregivers and reduces their sense of burden (8), there is some concern that patients with dementia can undergo a further decline after relocation from one environment to another (9). In clinical practice it is not uncommon to observe exacerbated confusion, increased disruptive behavior, and accelerated deterioration of self-care abilities among older adults with dementia who are in an unfamiliar environment. When patients return home, a similar decline during a period of readjustment may impose a greater burden on caregivers than before patients were admitted for respite care.

Two studies showed that inpatient respite care for patients with advanced dementia might cause a temporary decline in both functional and behavioral status after the patients' return home (10,11). These studies also found that patients with the most severe impairment tended to deteriorate the least, whereas patients who were less impaired deteriorated the most. Homer and Gilleard (11), in their study of a mixed population of patients with and without dementia, found a notable association between the absence of dementia and a lower level of social disturbance created by patients during the respite stay.

The greatest improvement in functioning was observed among patients without dementia who were being cared for by highly stressed relatives. The patients who did have dementia did not improve in functioning as much as the patients who did not have dementia.

Effects of respite care on caregivers

Current research on the effects of inpatient respite care on caregivers is very limited. The study by Homer and Gilleard (11) indicated that although there was a small reduction in caregivers' depression during the

Dr. Kim is associate professor in clinical psychiatric medicine in the School of Medicine at the University of Virginia in Charlottesville and at the Salem Veterans Affairs Medical Center, Building 7-1, Salem, Virginia 24153 (e-mail, kye.kim@med.va.gov). Ms. Hall is with the Salem Veterans Affairs Medical Center. Marion Z. Goldstein, M.D., is editor of this column.

respite period, the emotional well-being of the caregivers as measured by the General Health Questionnaire did not improve significantly. In another study, caregivers experienced a significant reduction in psychological distress during the respite stay, but the benefits were not sustained when the patients returned home (12). Skelly and associates (13) suggested that inpatient respite care was successful in relieving caregivers' burden related to patients' memory and behavior problems.

A qualitative study that explored caregivers' perceptions about inpatient respite care concluded that the health care system must realize and acknowledge many caregivers' struggles to allow themselves a respite experience (14). The authors also suggested that the health care system must be aware that the provision of a respite service does not necessarily result in a respite experience for caregivers and that the service should be provided in such a way that caregivers feel free from the everyday problems associated with caregiving.

Respite program at the Salem VA Medical Center

The increasing number of older veterans with various dementing disorders has posed substantial challenges for the VA system. Given that resources are limited, each VA medical center attempts to deal with these challenges through the interaction and integration of clinical programs available in the individual medical centers. The VA Medical Center in Salem, Virginia, has four respite beds on the sustained treatment and rehabilitation unit (known as the dementia unit) and an undesignated number of beds in the extended care rehabilitation center. Respite patients in the dementia unit are referred primarily from the memory disorders clinic that centralizes the ambulatory care of all patients with dementing disorders, especially Alzheimer's disease.

The treatment team at the memory disorders clinic recommends a respite program to a caregiver if indicated. A respite nurse at the clinic further evaluates the caregiver and the patient and schedules an admission to the respite program if appropriate. The caregiver can also make a request to the treatment team for inpatient respite care.

Some caregivers may be reluctant to expose their family members to unfamiliar surroundings and people. They fear that their loved ones may be unable to sleep or may dislike the food served by the program and that staff will not know how to care for them. A respite nurse or team social worker may need to help caregivers with the decision-making process. Patients admitted to the respite program receive a complete intake evaluation and physical examination as well as basic laboratory tests. The patients' drug regimens are also thoroughly reviewed during the stay; typical stays range from one to two weeks. It is an ideal opportunity to review patients comprehensively while their caregivers take a break from their responsibilities. The intake evaluation—performed by a team consisting of a registered nurse, a physician's assistant, and a geriatric psychiatrist—collects extensive information, including the patients' background, habits, food preferences, daily routines, and cognitive, mood, and functional status. A wide range of concerns can be addressed on the basis of the intake evaluation.

If indicated, various consultations can be sought to minimize or alleviate problems before a patient returns home. Proposed changes may include environmental adaptations, diversional programs at home, prosthetic evaluation, adjustment of medications, and laboratory studies. The social worker can initiate discussions with the caregiver about coping skills, in-home care services, alternative living situations, adult day care programs, and advance directives. Issues that are not resolved during the respite stay can continue to be addressed in the memory disorders clinic.

Visits from the caregiver during the respite admission are generally discouraged to allow the patient to adjust to the program as soon as possible and to give the caregiver the intended rest. The treatment team helps the patient maintain routines and promotes independence according to individual ability.

An exit interview is conducted with the caregiver when the patient leaves the respite program. Useful information and observations can be shared between staff and caregivers. When the patient returns home, follow-up telephone calls are made by the respite nurse to monitor the patient's readjustment. Because most of the respite care patients are linked with the memory disorders clinic, their readjustment can be monitored on a regular basis. As the respite program accumulates more information about individual patients, the caregivers and staff can use the information to better serve both patients and caregivers.

Discussion and clinical implications

Although many studies of other services for patients with dementia and their caregivers have been conducted, research on inpatient respite care for this population is very limited. Judging from the literature on this topic, inpatient respite care appears to differentially influence the cognitive and functional status of persons with dementia. Effects that were identified included a deterioration in the functional and cognitive abilities of patients with dementia after a temporary respite stay. The deterioration during respite care was more significant among higher-functioning patients, whereas lower-functioning patients improved or remained the same during the respite stay. However, respite care does relieve caregiver burden, if only for a brief period. Many caregivers were able to continue caring for patients in the home after using an inpatient respite program, although the time in the home before placement in a nursing home may not be substantial for some individuals.

In summary, inpatient respite care seems to benefit caregivers, at least transiently, but may pose a risk for some patients with dementia. Research should be conducted to examine the relationship between the benefits derived by caregivers and the appropriateness of the inpatient respite service to determine whether inpatient respite programs can be of great

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service to caregivers of persons with dementia. The results of such research would assist practitioners in establishing more effective respite services for these patients. ♦

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