HOME CARE FOR PATIENTS WITH DEMENTIA

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While patients with dementia often do best in a familiar setting, providing home care to such patients presents many challenges. This article describes how teams from VA sites across the country put their heads together to work out some of these issues.

Dementia, particularly that associated with Alzheimer's disease, has become a major public health problem in the United States. Dementia of the Alzheimer type (DAT), which is neither curable nor reversible,[1] is a progressive condition that causes substantial disability. As it advances, DAT increases patients' vulnerability to accidents and injury,[2] ultimately making them completely dependent on caregivers for all aspects of daily living.[3] Other types of progressive dementia—including dementia with Lewy bodies, vascular dementia, and frontotemporal degenerations[4]—have similarly destructive courses.

DAT is common among elders, with an estimated prevalence of 10% in people aged 65 or older and 47% in those aged 85 or older.[5] These age groups, which comprise the population at highest risk for developing DAT,[6] also represent the fastest growing segments of both the general U.S. and U.S. veteran populations. In fact, the VA estimates that by the year 2010, there will be 8.5 million veterans aged 65 or older (representing 43% of the total veteran population) and 1.3 million aged 85 or older (triple the number from 2000).

All these factors, combined with the high cost of treatment,[7,8] have made finding the best, most cost-effective ways of managing dementia a high priority for the VA. In recent years, there has been a heightened interest in community-based alternatives to institutional care for veterans with dementia. First and foremost, outpatient, community-based care offers the family the opportunity to tend to quality-of-life issues for the patient in the familiar and comfortable home environment.[9] Hospice concepts can be implemented in any care setting,[10] and interventions to

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manage the challenging behavioral symptoms that occur across the progressive stages of dementia also can be carried out in the home or in a community-based program (such as adult day care).[11] Family caregivers can be taught to assess the patient's capacity to carry out activities of daily living,[12] thus ensuring that they provide the appropriate amount of assistance to neither overtax ability (creating stress[13]) nor cause deconditioning.

The BTS approach relies on small but continual process changes that add up, eventually, to a significant improvement in care.

In the VHA, most home care is provided by Home Based Primary Care (HBPC) teams. Traditionally, these teams cared for veterans discharged from a hospital after an acute episode of a medical illness. As the VHA provides more outpatient dementia care to its veteran patients, however, it will have to offer HBPC teams trained in dementia care and change practice patterns to improve care for veterans with this condition who remain at home.

Recognizing this need, the VA Office of Geriatrics and Extended Care organized a collaborative quality improvement project that used rapid cycle improvement methodology and involved 20 HBPC teams from 15 Veterans Integrated Service Networks (VISNs). In this article, we describe the model upon which this project was based, summarize the structure of the project, and highlight outcomes and lessons learned from the experience.

THE COLLABORATIVE BREAKTHROUGH SERIES MODEL

The project, called Advances in Home Based Primary Care for End of Life in Advancing Dementia (AHEAD), was structured based on the Breakthrough Series (BTS) model, which was developed by the Institute for Healthcare Improvement as a method for implementing rapid changes in health care systems (Table 1).[14,15] The basic idea is that interdisciplinary teams from multiple sites that want to achieve higher levels of performance work together over six to nine months on a common aim under the guidance of faculty members who have expertise in the topic area or in health care quality improvement.

Teams come together for three two-day learning sessions that are conducted by the faculty and involve education, sharing, and planning. Between the sessions, teams implement suggested changes, measure the results of these changes, and report back to the larger group. Teams are supported through monthly educational and troubleshooting conference calls, individual coaching by faculty members, and an e-mail discussion forum designed to stimulate interaction among teams. Monthly progress reports help identify which teams need additional faculty assistance or motivation to stay on track.

The BTS approach relies on small but continual process changes that add up, eventually, to a significant improvement in care. The changes are implemented using a "plan-do-study-act" (PDSA) cycle.[15] The initial "plan" phase generally involves a review of existing knowledge from practice settings and medical literature to help formulate a plan of action, which is implemented in the "do" phase. During the "study" phase, the effects of implemented changes are measured, a crucial component in the process. Review of these measurements leads to acceptance or modification of the changes in the "act" phase, and the cycle begins again.

APPLYING THE MODEL

In accordance with the BTS model, the AHEAD project involved a planning phase with faculty and VA leadership, a competitive application process, and three two-day learning sessions over a period of nine months attended by one to five representatives from the participating teams. During the planning phase, a faculty group was organized and applications solicited from all 72 VHA HBPC teams. Applications had to be endorsed by senior leaders at each site and by the local management, promising support for staff to attend the learning sessions (including local travel funding). A total of 20 teams were selected to participate in the project.

The first learning session (LS 1) included local senior leaders in order to promote administrative support. It described the model for rapid cycle improvement and reviewed principles of dementia care. The teams then engaged in a series of group activities in which they set one or more goals and designed

Continued on page 17

Continued from page 14

Table 1. The Breakthrough Series (BTS) model

Time	BTS faculty	BTS teams
Three months before learning session (LS) 1	• Identify experts and faculty • Develop change concepts and packages • Develop topic materials • Solicit teams • Identify space • Ensure support technology	• Engage senior leader • Select teams • Sign up team members • Obtain tuition
One month before LS 1	• Distribute materials • Hold initial conference calls • Prepare LS 1	• Identify focus area • Collect baseline data • Make travel arrangements
LS 1	• Conduct two-day seminar • Determine faculty-to-team assignments	• Develop aims • Generate plan for first tests of change • Consolidate team
Months one to two	• Perform group coaching through scheduled conference calls • Perform individual coaching as needed • Participate in e-mail discussion group • Review reports • Prepare LS 2	• Perform “plan-do-study-act” (PDSA) testing • Participate in e-mail discussion group and conference calls • Prepare reports for senior leader • Prepare posters for LS 2 • Plan to move to other areas of focus
LS 2	• Conduct two-day seminar • Determine faculty-to-team assignments	• Comingle with other teams • Learn about others’ successes and failures • Plan to move beyond initial aims
Months two to seven	• Perform group coaching through scheduled conference calls • Perform individual coaching as needed • Participate in e-mail discussion group • Review reports • Prepare LS 3 (final session)	• Perform PDSA testing • Participate in e-mail discussion group and conference calls • Prepare reports for senior leader • Prepare posters for LS 3 • Plan for extended spread of effort
LS 3	• Conduct two-day seminar • Stimulate learning from other teams	• Plan to spread changes beyond local environment • Plan to sustain gains

their initial PDSA cycles with the help of faculty experts. Throughout the process, the teams’ progress was monitored by monthly reports e-mailed to the project coordinator and by visual displays (storyboards) presented at the second and third learning sessions (LS 2 and 3). These subsequent sessions served to reinforce the rapid cycle improvement methodology; provide additional information about dementia care; facilitate communication among the teams; and showcase creative ideas, lessons learned, and best practices.

Initially, four aspects of dementia care were suggested as areas for improvement: early patient identification, staff education, caregiver support, and symptom management. The focus was on end-of-life care because there was a desire to promote the continuation of home dementia care until the death of the patient. During LS 1, however, we recognized that the teams had many patients in earlier stages of dementia. Therefore, we decided to combine the patient identification and symptom management topics. In the following sections, we describe outcomes and lessons

Table 2. Resources used for staff education on dementia care

- Mahoney EK, Volicer L, Hurley AC. *Management of Challenging Behaviors in Dementia*. Baltimore, MD: Health Professions Press; 2000.
- Mittelman MS, Bergman H, Shulman E, Steinberg G, Epstein C. *Guiding the Alzheimer's Caregiver*. New York, NY: New York University School of Medicine, ADRDA board; 2000.
- Volicer L, Bloom-Charette L, eds. *Enhancing the Quality of Life in Advanced Dementia*. Philadelphia, PA: Taylor & Francis; 1999.
- Volicer L, Hurley A, eds. *Hospice Care for Patients with Advanced Progressive Dementia*. New York, NY: Springer Publishing Company; 1998.
- Burns T, Hepburn K, Maddox M, Smith S. *Alzheimer's Caregiving Strategies* [CD-ROM]. Minneapolis, MN: HealthCare Interactive; 1998.

learned in these three main aspects of care.

STAFF EDUCATION

Staff education programs developed by the teams used a variety of resources (Table 2) and covered a comprehensive list of topics, including:

- general information about Alzheimer's disease and other dementias, the stages of dementia, and the 10 warning signs of dementia;
- VA dementia algorithms and clinical guidelines;
- the basics of the AHEAD project (this information was disseminated to others in addition to HBPC staff—such as memory disorder clinic staff, advanced illness care coordinators, members of the chronic care network for patients with Alzheimer's disease, geriatricians, quality management personnel, and neuropsychiatric service staff—for the purposes of cross training, consultation, and collaboration);
- dementia screening and assessment tools;
- caregiver stress and support issues;
- end-of-life care;
- VA and community resources available;
- communication with the patient and family;
- pain management, including the use of opioid and nonopioid medications;
- stress management for staff; and
- driving and safety.

Teams evaluated the effectiveness of their staff education using attendance records and surveys of dementia care knowledge conducted before and after the education. For example, one team developed a survey that asked HBPC staff members to score their level of confidence (self-efficacy) on 15 tasks organized into three areas: arranging services to help care for patients with dementia, handling problems for patients with dementia, and managing medications for patients with dementia (K. O'Neill, written communication, April 2002).

A comparison of the mean preeducation and posteducation scores revealed an overall increase in self-efficacy in all three major areas—especially in arranging services and handling problems (Table 3). Improvement was smaller in the managing medications area, in which scores already were quite high before the education. The only item for which the posteducation score was lower than the preeducation score was "Care for your patient without help from outside organizations or agencies that provide services." This may well have been due to staff members' increased understanding of the needs of veterans with dementia.

PATIENT IDENTIFICATION AND SYMPTOM MANAGEMENT

The topics addressed in this aspect of care included:

- diagnostic workup,
- inclusion of dementia in the care plan,
- discussion and completion of advance directives,
- management of behavioral symptoms of dementia,
- education to help caregivers accept the diagnosis of dementing illness, and
- follow-up of suspected dementia (in patients with such problems as minimal cognitive impairment, late onset depression, and delirium during acute hospitalization).

Continued on page 21

Continued from page 18

Table 3. Survey conducted by one team during the Advances in Home Based Primary Care for End of Life in Advancing Dementia project before and after staff education (n = 13)

Parameter	Score*		Difference
	Before	After	
Arranging services to help care for patients with dementia			
Care for your patient without help from outside organizations or agencies that provide services	6.1	5.1	–1.0
Find organizations or agencies in the community that provide services to help you care for your patient	6.0	8.5	2.5
Get answers to all of your questions about these services	6.4	8.8	2.4
Arrange for these services yourself	5.3	7.2	1.9
Find ways to pay for these services	4.8	6.2	1.4
Mean score for arranging services	**5.6**	**7.1**	**1.5**
Handling problems for patients with dementia			
Handle any problems your patient has, such as memory loss, wandering, or behavior problems	5.9	8.1	2.2
Handle any problems that might come up in the future with your patient's care	6.1	7.8	1.7
Deal with the frustrations of caring for your patient	6.4	8.4	2.0
Do something to keep your patient as independent as possible	6.2	8.8	2.6
Get answers to all of your questions about your patient's problems	6.8	8.9	2.1
Mean score for handling problems	**6.3**	**8.4**	**2.1**
Managing medications for patients with dementia			
Understand possible adverse effects from medications your patient is taking	7.2	8.1	0.9
Know how many different medications your patient is taking	7.7	7.9	0.2
Understand how your patient should take his or her medications	8.0	8.1	0.1
Understand why a new medication is prescribed for your patient	7.9	7.9	0.0
Get answers to all of your questions about medications your patient is taking	8.1	8.6	0.5
Mean score for managing medications	**7.8**	**8.1**	**0.3**
Overall mean score	**7.6**	**9.1**	**1.5**

*Items scored on a scale from 0 to 10, with 0 indicating not confident at all and 10 indicating highly confident.

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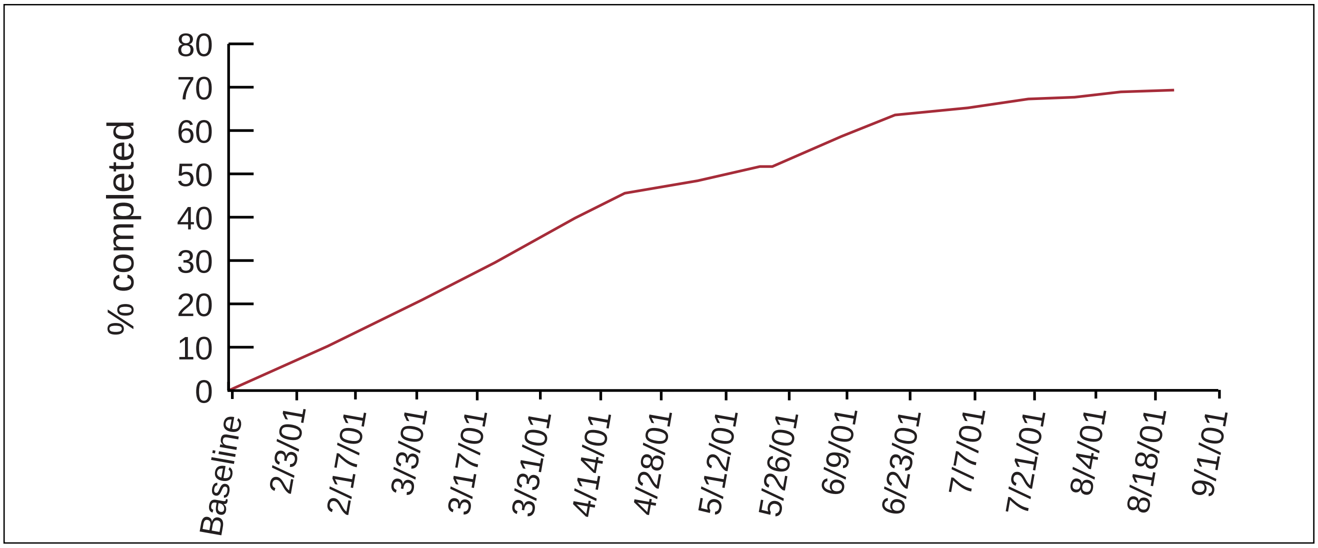

Figure 1. Percentage of Home Based Primary Care clients with completed Mini-Mental State Examinations at the VA New York Harbor Health Care System, New York, NY.

Teams used a variety of instruments to detect cognitive impairment in their veteran patients—most commonly, the Mini-Mental State Examination (MMSE)[16] (Figure 1). Shorter or otherwise modified versions of the MMSE were used when there were concerns about patients' education level or physical impairments (such as blindness or deafness) that precluded answering some questions.[17] When a short version was used, staff calculated the ratio of correctly answered questions to those for which the patient had the physical capacity to answer, considering 0.8 as a cutoff score. Other assessment tools included the Clock Drawing Test (often used if the MMSE score was questionable),[18] the Clinical Dementia Rating,[19] the Geriatric Depression Scale,[20] subjective reports from family and staff, a specially designed symptom questionnaire (A. Doubek, written communication, April 2002), and laboratory tests (such as the rapid plasma reagin test and folate, vitamin B12, and thyroid stimulating hormone levels). One team facilitated improvement of early patient identification by developing an initial assessment form that summarized the results of all evaluations (J. Andrus, written communication, April 2002).

Although some teams already were aware of the prevalence of dementia in their patient populations prior to participation in the project, others found, after improving their screening and referral processes, that their previous estimates had been low. For example, one team saw the percentage of patients in whom cognitive impairment was identified jump from 5.8% to 40% (G. Dickerson, written communication, April 2002). In some cases, the identification of cognitive impairment helped explain previous problems with patient adherence to prescribed medical treatments. Recognition of these issues led to more complete diagnostic workups and inclusion of dementia as a problem in the treatment plan (Figure 2).

Identification of cognitive impairment also resulted in discussion and completion of advance directives. Among the various forms used by the teams was the Physician Orders for Life-Sustaining Treatment form, developed by the Oregon Center for Ethics in Health Care[21]; an original form delineating four specific levels of care, developed by the HBPC team from Charleston, SC; VA-authorized advance directive forms (for individuals with decision making capacity); and a newly available proxy planning form (completed by caregivers of patients who have lost decision making capacity).[22] Teams made sure that advance directives were listed in the VA's computerized patient record system and that each 90-day review of the care plan checked for completion of an advanced directive. Some teams discussed advance directives during teleconferences with the family and other recorded informal discussions about treatment options, even when the patient or proxy didn't want to

Continued on page 25

Continued from page 22

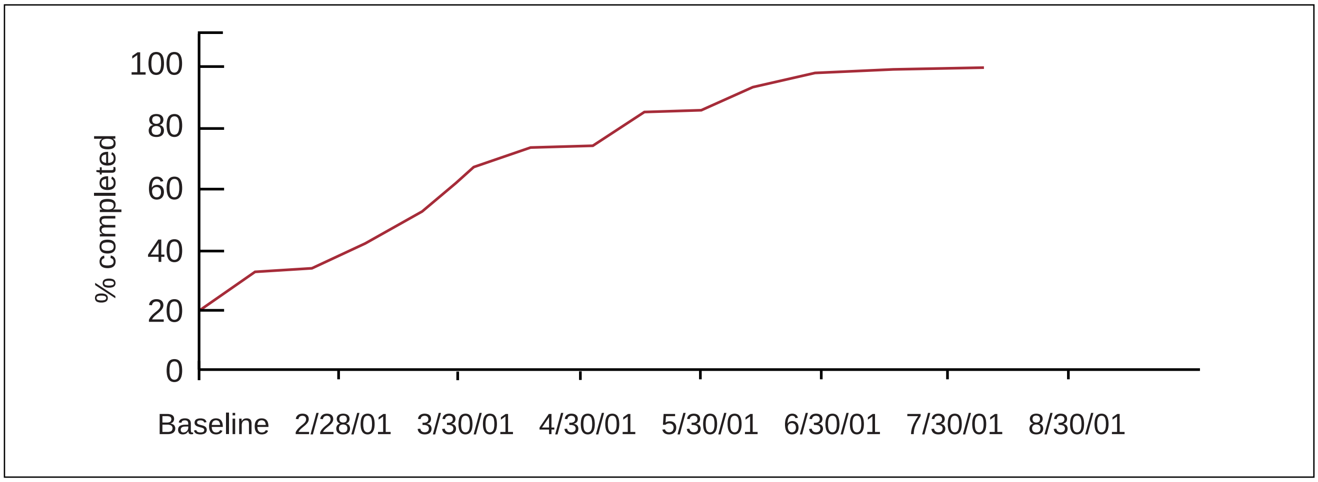

Figure 2. Percentage of care plans of clients with dementia completed to reflect the diagnosis at the VA North Texas Health Care System, Dallas, TX.

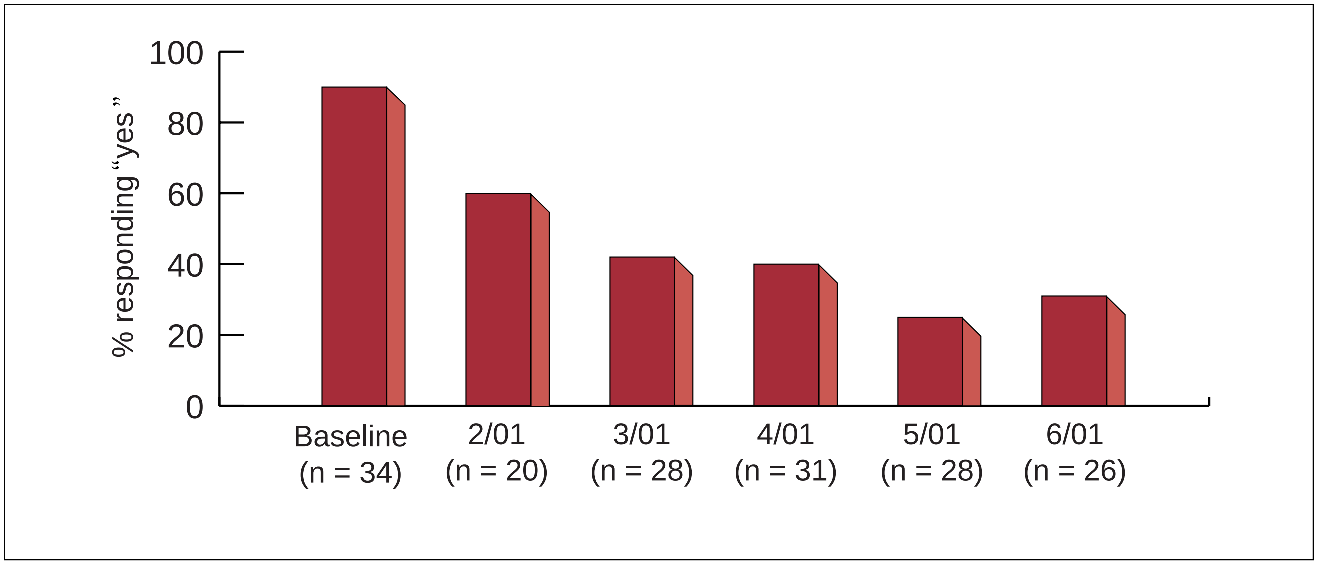

Figure 3. Percentage of caregivers responding "yes" to the question "Do you find behaviors exhibited by the client upsetting?" at the Southern Arizona VA Health Care System, Tucson, AZ.

complete a formal advance directive.

In most cases, patients with dementia had some behavioral symptoms that were distressing to the caregiver. These symptoms, which include sleep disturbances and resistance to care, are the most common reason family caregivers decide to admit patients to a nursing home.[23] Teams initiated a review of all patients by a mental health nurse practitioner or some other member of the psychiatry staff, which resulted in a significant decrease in the number of caregivers upset by patients' behavior (Figure 3). They also initiated staff education about behavioral symptoms of dementia, as well as the pharmacologic and nonpharmacologic strategies for managing these symptoms, and provided caregiver education in the form of workshops, short instructional sheets, or lists of "dos and don'ts."

CAREGIVER SUPPORT

In this aspect of care, teams addressed the following topics:

- identification of primary and alternate caregivers,
- review of care plans for inclusion of caregivers in the record,
- creation of caregiver screening and assessment tools,

- use of community resources, and
- creation of a database template to record caregiver burden.

The teams used several tools to prioritize caregivers' overall needs, identify specific educational needs, individualize care plans, and increase or decrease frequency of visits. One of the tools was taken from medical literature (the Zarit Burden Scale[24]); others were developed by the teams themselves. Original tools included: a visual analog thermometer scale, a written survey, a 10-item questionnaire, a challenging behavior scale, and a 21-item questionnaire. (Readers who wish to learn more about these tools may send e-mail to Dr. Volicer at: ladislav.volicer@med.va.gov.)

Interventions included referral to respite care programs, referral to other community resources, more frequent contact with caregivers, and caregiver education. At-home respite was made available through the use of home mental health aids and staff from local chapters of the Alzheimer's Association. Community resources included senior companion programs, home volunteer programs utilizing VA volunteers, New York City volunteer services, the Alzheimer's Association's Safe Return program, and medical alert services. Teams also provided caregivers with lists of state or county income service providers that have prorated services, lists of community resources, information about adult day health care, and information about local hospice agencies' community outreach programs.

Increased frequency of contact with patients and their caregivers was achieved by using telephone support groups, holding more caregiver and family conferences, and organizing luncheon support and learning groups. Caregiver education was provided through a newly created newsletter and a community resource list or caregiver package.

All these activities resulted in increased referrals to community resources and reduced caregiver stress. Use of caregiver burden tools allowed the teams to focus on each patient and caregiver's particular needs, resulting in individual attention that helped make patients and caregivers feel special, and on decreasing "panic" phone calls. Furthermore, enhanced understanding of dementia from caregiver education improved quality of life for the family, decreased caregiver guilt and stress, and increased caregivers' ability to understand and cope with challenging situations.

KEY FACTORS AND PITFALLS

Several factors were identified by the teams as having contributed substantially to improved dementia care for veterans. First, ongoing communication between team members and management was essential. Examples of such positive communication include: using presentations (which include practical information and employ case-based educational methods) to obtain "buy-in" from the team, planning and advertising educational activities well in advance, holding weekly team meetings, including AHEAD activities in the HBPC strategic plan, and identifying advantages of AHEAD activities for the management.

The teams' ability to secure resources for the AHEAD project was aided by a number of strategies. Offering continuing education credits for staff education related to AHEAD and having it satisfy VA continuing education and safety training requirements helped ensure staff time for these activities. Timing of staff education was modified based on local needs—from one-hour "brown bag" lunch meetings to full-day conferences. In addition to HBPC resources, successful teams involved all service lines (geriatrics and extended care, medicine, primary care, and mental health) in their activities, enlisted help from other disciplines (such as librarians, hospital education service staff, and psychiatric liaisons), and employed knowledgeable outside speakers. It was also beneficial to obtain VA funding for home health aids and both at-home and community-based respite; document senior management's commitment to AHEAD activities in writing, for use as a reminder when necessary; and utilize such outside resources as community agencies, Alzheimer's Association chapters, and drug company representatives.

Care for veterans with dementia was further improved by establishing protocols, such as clinical pathways and flow charts; documenting the caregiver burden scale in the care plan; increasing referrals to mental health care providers; and including the performance improvement staff member on the team.

Several factors were identified that impaired the ability of teams to reach their goals. Some of these related to a lack of preliminary planning—for example, the failure to check technology before the start of the project, the assumption that staff already had appropriate education, or rushing into the project before the team was ready. A lack of needed tools (such as Spanish language materials) and poor tool design (such as overly long assessments and nonstructured follow-up telephone calls) were also detrimental.

Some teams had unrealistic goals, such as a target population that was too wide to reach. Others had problems with communication, including assumptions about the roles various team members would play. Time was often a factor: Teams struggled with competing demands for staff and resources, tried to use overcommitted staff members as speakers, and found that some team members could not make a nine-month commitment to the project. When AHEAD activities were postponed, teams suffered from interrupted momentum.

There were problems with team structure and function, such as the absence of a designated team leader, lack of an alternate or backup leader, and insufficient delegation of tasks among the team members. The failure to obtain support from administration (by "selling" the program up front) and from other disciplines (by involving them in activities and education) proved to be a significant barrier. Geographical distribution of staff and programs also complicated the process.

Finally, success was impeded by such human factors as poor staff attitudes, resistance to a new task (lack of "buy-in"), unwillingness of some physicians to recognize dementia officially (such as by performing a diagnostic workup or including dementia diagnosis on the problem list), and turf battles.

IMPLICATIONS FOR THE FUTURE

The results described here indicate that the use of the BTS model improved the process of providing home care to veterans with dementia. The short duration of this project (nine months), however, didn't allow for collection of meaningful longitudinal data that would document an impact on patient outcomes. Improved identification of patients with dementia and inclusion of this diagnosis on the treatment plan are just the first steps in addressing the needs of this patient population. It will be important to measure the impact of this initiative on such parameters as hospital admissions, rate of institutionalization, and use of palliative end-of-life care. Some of this data may be difficult to interpret, though, because AHEAD wasn't designed specifically as a research project and the use of historical controls has severe limitations.

It also must be recognized that not all patients with dementia can be cared for on an outpatient basis. Limited family resources and severe behavioral symptoms may make it impossible to provide safe care at home.

The BTS model allows for flexibility in selecting goals and developing strategies for achieving those goals. The crucial element of this approach is the collection of data that are used to evaluate consequences of each change and that provide the basis for further activity. Because each of the teams participating in our project proceeded independently, it's impossible to provide a simple, uniform guide for a new team that would like to adopt this process. Nevertheless, by reviewing a compilation of the most common timetables and activities used by the AHEAD teams (Table 4), interested parties could obtain some rough guidance—keeping in mind that modifications may be needed based on local conditions. Additionally, the AHEAD web site (www.qualityscholar.com/ahead.htm) shares documents and presentations made during LS 1 through 3.

Collaborative methodology as described here allows for a flexibility and immediacy of implementation to improve patient care that isn't afforded in research projects. Research is critical for developing new knowledge that ultimately can be applied to practice. Quality improvement activities are essential for making tomorrow's care better for veterans and their families in specific VA settings. As a result of this collaborative project, changes have been made and sustained in VA HBPC programs that may lead to improvement in patient care. ●

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Table 4. Typical timeline used by teams participating in the Advances in Home Based Primary Care for End of Life in Advancing Dementia project

	Activity		
Duration	**Staff education**	**Patient identification and symptom control**	**Caregiver support**
Two weeks	Share learning session information with all team members; identify content for education survey	Perform review of patient population with team	
Two weeks	Conduct survey; identify educational priority areas	Perform needs assessment; hold staff workshop; determine current practices	
One month	Provide educational program; evaluate educational program	Identify tools: part 1 (review, pilot test, determine usefulness and practicality)	Review and choose a caregiver assessment tool for use by Home Based Primary Care staff
One month	Modify educational program to assure more staff participation	Identify tools: part 2 (test larger numbers, decide on consequences of positive testing)	Develop other measures
One to two months	Continue ongoing education of new staff		Set up and begin caregiver surveys
One month		Establish procedure for consequences of positive testing (referrals, advance directives)	Modify/develop caregiver support according to survey results

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