Palliative Excellence in Alzheimer Care Efforts (PEACE): A Program Description

JOSEPH W. SHEGA, M.D., AMY LEVIN, R.N., B.S.N., GAVIN W. HOUGHAM, M.A., Ph.D., DEON COX-HAYLEY, D.O., DANIEL LUCHINS, M.D., PATRICIA HANRAHAN, Ph.D., CAROL STOCKING, Ph.D., and GREG A. SACHS, M.D.

ABSTRACT

Hospice is the standard method for providing quality end-of-life care in the United States. However, studies reveal that persons with dementia are infrequently referred to hospice, that barriers exist to increasing hospice utilization in this population, and that patients with dementia would benefit from hospice or hospice-like services earlier in the disease course. The Palliative Excellence in Alzheimer Care Efforts (PEACE) program responds to these deficiencies, striving to improve end-of-life care of persons with dementia and to integrate palliative care into the primary care of patients with dementia throughout the course of the illness. The PEACE program is a disease management model for dementia that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages. PEACE is coordinated through the primary care geriatrics practice of the University of Chicago. Patients and caregivers are interviewed every 6 months for 2 years, and a postdeath interview is conducted with caregivers. These interviews assess care domains important for the optimal care of persons with dementia and their caregivers. A nurse coordinator reviews interviews and provides feedback to physicians, facilitating enhanced individual care and continuous quality improvement for the practice. Initial feedback suggests patients have adequate pain control, satisfaction with quality of care, appropriate attention to prior stated wishes, and death occurring in the patient’s location of choice. Families voiced similar high marks regarding quality of care. This program demonstrates an innovative model of providing quality palliative care for dementia patients and their caregivers.

BACKGROUND

Studies such as SUPPORT1 that documented serious deficiencies in the care of people at the end of life, and that motivated the Promoting Excellence in End-of-Life Care initiative, are well known to readers of the palliative care literature. What is probably less well known is that patients with dementia are at particular risk for receiving poor end-of-life care for a variety of reasons. A primary factor is that few patients with dementia are ever enrolled in hospice care, the dominant model of providing superb end-of-life care in this country.2 Fewer than 2% of patients enrolled in hospice have a primary diagnosis of dementia.3 Underutilization of referral to hospice for these patients may be related to a lack of recognition of dementia as a terminal disease, and the difficulty in quantifying a prognosis of 6 months or less. At the same time, hospice pro-
grams may be unfamiliar or uncomfortable with caring for patients with dementia. The need for effective models of end-of-life care for patients with dementia is critical given the expected increase in the number of people with dementia in the United States from approximately 4 million today to an estimated 14 million by the year 2050.4

The collaborators in the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program at The University of Chicago and the Hospice of Michigan (HOM) developed two different models of care in an effort to improve care at the end-of-life for people with dementia and their families. The HOM group implemented a palliative care consultation program for patients with dementia who were residing in long-term care institutions. The HOM portion of PEACE attempts to bring hospice-like care to patients who are severely demented but who may not be eligible for formal enrollment in hospice under Medicare. The University of Chicago portion of the PEACE program attempts to integrate palliative care into the primary care of patients with dementia throughout the course of the illness. This program essentially demonstrates a disease management model for dementia, consistent with proposals for MediCareing,5 that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages. The two PEACE sites share similar goals and philosophies of care, as well as a common set of evaluation tools. The Chicago portion of PEACE is described in the remainder of this paper.

**POPULATION/SETTING**

The Chicago portion of PEACE is coordinated through the primary care geriatrics practice of the Section of Geriatrics of The University of Chicago. At the time of subject recruitment and enrollment, the outpatient practice in geriatrics was confined to one clinic, the Windermere Senior Health Center (WSHC). (In July 2000, after PEACE enrollment had closed, a second geriatrics clinic was opened—the Outpatient Senior Health Center at South Shore. Figures describing the geriatrics practice are those of the WSHC that applied at the outset of PEACE.) This geriatrics practice, located in the community a mile from the University campus, provides primary care to approximately 2200 older adults in a comprehensive, multidisciplinary fashion. The average age of patients at this site is 80, two thirds of the patients are women, and approximately two thirds are African-American. Recognizing that African-Americans historically have lower rates of utilization of advance directives, do-not-resuscitate (DNR) orders, and hospice, there were concerns that the high proportion of African-Americans at the WSHC would represent an additional challenge.6 The clinic provides primary care to approximately 500 patients with dementia. None of the patients are enrolled in Medicare health maintenance organizations (HMOs) or other capitated systems. Thus, coordination of care across different providers and sites, including hospitals, home care agencies, and nursing homes, presented another challenge for the PEACE program.

The staff at the Windermere Senior Health Center includes nine geriatric fellowship-trained physicians, one social worker, and two clinical nurse specialists. Other services available onsite include consultation in neurology, geriatric psychiatry, neuropsychology, ophthalmology, and dentistry, as well as nutrition counseling, audiology evaluation, a low vision clinic, and physical and occupational therapy. Phlebotomy, electrocardiography, and limited diagnostic radiology tests are all available on site, as well. The PEACE program utilizes several community-based services including hospice, home health, adult daycare, and homemaker services. For low-income patients, the Illinois Department on Aging offers financial assistance for adult daycare and homemaker services. In addition, the geriatricians who participate in the program are also affiliated with two nearby community nursing homes, and two WSHC physicians serve as the medical directors at these sites.

**PROGRAM DESIGN**

This innovative program integrates palliative care into ongoing comprehensive primary care of persons with dementia over the disease course, from initial diagnosis to death. Focus areas include advance care planning, symptom manage-
ment, education on disease process, caregiver support, optimal utilization of community resources, and improved coordination of care. In addition, in the advanced stages of the disease, the PEACE program strives to ensure that all patients and families are offered hospice care, that patients die in their desired location (usually at home), and that they do not undergo undesired invasive procedures or hospitalizations. Research assistants interview patients and family members at enrollment and every 6 months thereafter. These interviews collect data that contribute to evaluating PEACE as a pilot project. In addition, the information collected is clinically relevant and is shared with the care team. All PEACE subjects are informed that the interviews are in part, designed to uncover unmet needs and that this information will be used in improving care.

The linchpins in this process are the two clinical nurse specialists who help coordinate care, review all interview records, and provide feedback and follow-up to physicians and families based on the information gathered. As the PEACE program evolved, the nurse specialists became more proactive and involved in addressing the unmet needs of patients and caregivers. For example, if caregiver stress was elicited during the research interview, the nurse specialist would notify the physician and make appropriate social work referrals. Similarly, caregiver concerns about difficult behaviors lead the nurse specialist to perform educational interventions to assist caregivers in identifying the possible triggers of the behavior as well as provide suggestions on how to manage the behavior. In addition, the nurse care coordinators foster continuous quality improvement by providing the research team and the clinical practice with feedback on systemic issues or recurring concerns that surface in the interviews.

The PEACE project study includes patients at all stages of disease and with all types of dementia (notwithstanding the “Alzheimer” in the acronym). Patients and family members who serve as proxies are recruited into the program either by direct physician referral or review of the WSHC practice patient registry. Verbal consent is obtained from the patient and the proxy, or if the patient lacks decision-making capacity, proxy consent and patient assent suffices. Participants are interviewed at study entry, and 6, 12, 18, and 24 months thereafter. First interviews take place in the clinic; subsequent interviews are conducted either in the clinic or home, whichever is preferred by the patient and caregiver. The program also includes interviews with family members after the death of the patient. In addition, we try to interview family members of non-PEACE patients with dementia who received primary care at the clinic and died during the study period. The non-PEACE families serve as a comparison group to attempt to examine differences in care provided at the end of life between PEACE and non-PEACE patients. Postdeath interviews address satisfaction with care and symptom management during the last two weeks of life, as well as the location of death.

The interviews of patients and proxies occur separately, and each encounter takes between 15 and 30 minutes to complete. Patient interviews include the Folstein Mini-Mental State Examination (MMSE),7 the Geriatric Depression Scale (GDS),8 questions regarding pain, any other bothersome symptoms, and questions concerning quality of care. Interviewers complete a Checklist of Nonverbal Pain Indicators8 as well as the patient section of the Clinical Dementia Rating Scale (CDR). Proxy interviews include the Beck Depression Scale, the Caregiver Strain Index (CSI),9 psychoactive medications of the caregiver, two patient behavior scales (Cohen Mansfield Agitation Index [CMAI]10 and Revised Memory and Behavioral Problem Checklist [RMBPC],11 the Katz Index of Activities of Daily Living,12 Instrumental Activities of Daily Living, questions on perceived pain, and other bothersome patient symptoms, and questions concerning quality of care. Upon completion of the encounter, the interviewer completes the caregiver portion of the CDR, a patient medication list, a weighted index of co-morbidity,13 a medical complications checklist, the Functional Assessment Staging (FAST),14 and abstracts patient demographics from the chart.

PROGRAM EVOLUTION

Challenges

As this project progressed from conception to implementation, several challenges arose. The integration of research into a well-established and
busy primary care clinic posed several barriers in scheduling logistics. The prescheduled clinic visit eased patient enrollment, yet it sometimes proved difficult to have patients and families stay for both a clinic visit and the research interviews. Clinician-researchers experienced challenges because of caregiver constraints that included: poor access to a telephone; frequently disconnected or changed telephone numbers; limited caregiver availability because of employment or other familial obligations. While some family members have found it comforting to be able to talk to PEACE interviewers, others cited caregiver stress or other burdens as a reason to defer interviews. Occasionally, a patient’s designated proxy withdrew as a result of stress, illness, or relocation, and another individual was designated as proxy. Infrequently, patients became frustrated, agitated, or fatigued while waiting in the clinic. Rarely, it was difficult to locate the necessary space to conduct the interviews in this busy geriatrics clinic.

To cope with time pressures, patient frustration, and limited space, several changes to the protocol were necessary. The list of instruments administered was shortened and the CDR administration was modified. Flexibility in scheduling subsequent interviews and the use of phone interviews as well as home visits enabled us to retain high levels of program participation.

Clinical indicators

In keeping with the goal of improving care of persons with dementia throughout the course of their disease, several clinical indicators were identified as especially important to monitor. These include pain, behavior problems, and depression. Unfortunately, some of these domains lacked measurement instruments that had been validated in a population with dementia. For instance, we were unable to find a well-validated instrument for assessing pain in patients with dementia. Some instruments had to be adapted for use in dementia and for proxy reports. Once the research team agreed on which symptoms to monitor and which assessment tools to utilize, attention turned to developing an appropriate mechanism for feedback to the primary care physician. We wanted the feedback to be received by our colleagues in a spirit of continuous quality improvement and not as personal criticism.

As with other diagnoses with uncertain prognosis and a fluctuating course, difficulties have sometimes arisen in families’ understanding and acceptance of the diagnosis of dementia. Some caregivers misinterpret a loved one’s preserved social skills—such as greetings and courtesies—as indicators of intact cognition. This misperception may lead families to inappropriately forgo community resources or other interventions, sometimes resulting in less assistance with care than their clinicians recommended. At times, acute clinical events that occur in the course of dementia challenged previously outlined patient preferences and plans of care which led to revisions in the palliative care plan. In some cases, despite comprehensive family involvement in advance care planning, large investments in clinicians time and energy were required when complications or acute deterioration occurred. For instance, the daughter of one enrolled patient with advanced dementia expressed anxiety over not providing antibiotics or intravenous fluid with each acute event, such as a urinary tract infection, even though in prior discussions the daughter had communicated a desire to limit therapy to symptom management. With each clinical complication, she expressed concern that lack of aggressive care was sub-optimal care. All physicians caring for PEACE patients were supportive of the program and committed to its goals. However, one can see that the time and energy spent discussing palliative care options might be a challenge to replicate in other settings. Busy clinical practices may make it impractical to spend the necessary amount of time with a family to ensure complete understanding and appropriateness of a palliative care approach. Unfortunately, this challenge may lead to the path of least resistance: hospitalization.

The PEACE program was integrated into a primary care setting without a formal comparison or control group. The program’s evaluation was designed to assess the feasibility of offering primary care with a palliative approach to persons with dementia and to collect information on the effectiveness of this approach. Future analysis of the PEACE data will compare baseline PEACE evaluations to follow-up interviews as well as to historical controls in the literature. Also, comparisons of PEACE and non-PEACE patient after-death interviews will help delineate any differences in care between these patient groups.
DISCUSSION

Results

The 150 patients recruited for the PEACE program at the University of Chicago were an average age of 82.1 years, 75% were female, and 82% were African American. Detailed results will be published in forthcoming papers. Initial feedback by patients and families suggest high rates of satisfaction with the quality of care, adequate pain control, appropriate attention to prior stated wishes, and patients dying in desired locations. Families were receptive to hospice referral which was offered to approximately two thirds of the patients who have died to date, and approximately half of the patients had been enrolled in hospice at the time of death. Approximately two thirds of patient deaths occurred at home (the desired site of death for most patients known to have a preference). Caregivers continue to experience significant stress despite the other accomplishments of the PEACE program. Further analyses will examine how caregivers experience stress over time in the PEACE program, and explore which factors associated with high caregiver stress are likely to be modifiable by adding available services.

Given the positive feedback provided by patients, families, and health care providers at our institution, we are now transitioning the PEACE program from a research initiative to a fully integrated component of our geriatrics practice. We are trying to abbreviate the data collection process to see if it is possible to rely on more caregiver report measures and instruments administered by telephone, rather than by in-person interviewing. Some of the instruments used, such as those measuring agitation and behavioral symptoms, were of particular interest to our research team, but may not be necessary for a clinical replication of the PEACE program.

FUTURE DIRECTIONS

We are looking at ways to integrate the data collection process into other places where data are collected on patients in our geriatrics clinics and the University of Chicago’s Memory Center. We are planning to offer our service as palliative care consultants in dementia care as another means of sustaining our efforts. We plan to offer individual consultations to individuals, families, and physicians, as well as institutional consultations for nursing homes, provider groups, and payers that are interested in incorporating a PEACE-like approach into their programs. We hope to evaluate these dissemination efforts, as well.

In future publications on the PEACE program, we will show in more detail that it is possible to provide high-quality end-of-life care to patients with dementia and to set benchmarks for this kind of care. The costs of implementing the PEACE program are not large, but the addition of a nurse coordinator working in conjunction with physicians is a critical component for a managed care organization, integrated health system, or other payer. These costs should be more than offset by savings in other areas. Although a detailed cost-effectiveness study was not part of the initial PEACE grant, we believe that decreased emergency room trips and hospital admissions near the end of life, along with decreased use of certain technologies such as feeding tubes, would yield cost savings that would exceed the expenses involved in the program. For instance, the nurse coordinator’s familiarity with one patient with advanced dementia and an acute illness facilitated communication with the patient’s primary physician, which resulted in the family declining hospitalization and choosing hospice. Future research on the PEACE model should include both a comparison to usual or routine care and an accounting of costs in each model.

We hope to interest other groups involved in dementia research and care, such as Alzheimer Disease Centers (ADCs) and the Alzheimer’s Association in the PEACE program. ADCs see a number of patients with dementia and collect large amounts of data, especially relating to the accurate diagnosis of dementing illnesses. It would be a major advance in dementia care for ADCs to promote excellent care at the end of life as within their purview. The PEACE program might even be more easily adopted in an ADC than in other busy clinical practices. The Alzheimer’s Association currently plays a critical role in educating family members and advocating for affected patients and families. We think that the Association could expand its educational efforts to encompass end-of-life care and inform families that high quality palliative care, such as that pro-
vided in PEACE, is possible for people with dementia. Educated and empowered families might, in turn, contribute to advancing clinical practice by demanding this kind of care. The Alzheimer’s Association and other groups would then be able to help advocate for changes in regulations and reimbursement that would greatly facilitate replicating PEACE.

REFERENCES


Address reprint requests to:
Joseph W. Shega, M.D.
The University of Chicago
Section of Geriatrics
5841 South Maryland Avenue
W-700 (MC 6098)
Chicago, IL 60637

E-mail: jshega@medicine.bsd.uchicago.edu