Developing a VA Palliative Care Program

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As the veteran population ages, the need for VA palliative care services increases. These providers describe how their institution developed a comprehensive and multifaceted palliative care program—and offer tips for others interested in emulating their success.

he World Health Organization defines palliative care as the active total care of patients whose disease is not responsive to curative treatment. Symptom control and psychosocial and spiritual care are paramount. The primary goal of palliative care is to achieve the best possible quality of life for patients and their families.¹

The VA provides health care for patients who are, on average, a decade older, more seriously and chronically ill, and dying in greater numbers than the general population. It is estimated that 1,600 veterans die each day in the United States and 27,000

veterans die annually as inpatients in VA facilities.² As such, palliative care has become a major priority for the VA over the past decade. Hospice and palliative care have been covered benefits for enrolled veterans since 2003. By policy, every VA medical center is required to have a palliative care team comprised of a physician, a social worker, a nurse, a chaplain, and a program coordinator. In addition, VA facilities are encouraged to establish palliative care beds to meet the needs of dying veterans who cannot stay in the community.² Beyond clinical services, the VA also has prioritized interprofessional education, research, and community partnerships relating to palliative care.

Recognizing the increasing palliative care needs of the veteran population, the Clement J. Zablocki VA Medical Center (ZVAMC) in Milwaukee, WI has established a comprehensive, interdisciplinary program for its patients. Since inception, this program has developed steadily and has been recognized nationally for its excellence in palliative care.

In this article, we describe this program and its components, the palliative care database that is used for program evaluation and other research purposes, and policies that have been established to address palliative care practices. In addition, we highlight strategies that have facilitated program development, challenges encountered during program establishment, and future directions for continued growth. We hope that this article will serve as a tool for professionals interested in developing or expanding existing palliative care programs at their institutions.

HISTORY OF THE PROGRAM

The ZVAMC is a highly affiliated, academic medical center that offers a comprehensive continuum of care. including primary and specialty care clinics, home care programs, community-based outpatient clinics, and tertiary inpatient care. The veteran population it serves extends throughout the northern tier of the Great Lakes Health Care System (VISN 12), including the state of Wisconsin, the upper peninsula of Michigan, and part of northern Illinois. The ZVAMC has 170 hospital beds, 113 extended care beds, and 365 domiciliary beds. Each year, it admits more than 6,500 patients and has over 540,000 outpatient visits. Approximately 240 patients die at the medical center each year.

Palliative care initiatives at the ZVAMC began in 1996. At that point, leadership in the division of rehabilitation and extended care recognized a strong need to provide better endof-life care not only to extended care residents but also to other veterans served by the medical center. In order to begin preparing staff to provide specialized end-of-life care, the medical center brought in end-of-life care

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experts from the community for a two-day orientation to the principles of hospice and palliative care. Weekly rounds also were initiated with the pain clinic, radiation oncology service, hematology-oncology service, and pharmacy to review specific patient needs.

In 1999, the palliative care program was officially created to provide comprehensive, interdisciplinary, palliative and end-of-life care to patients throughout the medical center. The mission of the palliative care program is to maximize the quality of life of the veteran by promoting independence, providing pain and symptom relief until the moment of death, and supporting the veteran's family during the dying process and after the veteran's death. In order to convey the program's holistic approach to patient care, it has adopted the "tree of life" as its symbol, with five branches each representing the physical, social, emotional, intellectual, and spiritual aspects of the patient's life. This image is used on the program's brochures and other printed materials.

PROGRAM COMPONENTS

Currently, the ZVAMC palliative care program encompasses an inpatient palliative care unit (PCU), a palliative care consultation team (PCCT), a palliative care outpatient clinic, a grief and bereavement program, spiritual care services, a volunteer program, an educational program, and a developing research program. The sections that follow describe each of these components in detail.

The PCU

The PCU is a 31-bed inpatient unit, located within the ZVAMC's Extended Care Center, that specializes in the care of veterans with end-stage diseases—82% of which are cancer. The unit also cares for veterans who are undergoing palliative radiation therapy and chemotherapy but expect to return to the community after completion of treatment.

The PCU uses an interdisciplinary approach to care. Its staff consists of a medical director, who is an academic geriatrician with board certification in palliative medicine; an internist and a geriatrician with training in palliative care; a geriatric nurse practitioner (NP) with certification in palliative care; a nurse manager; 10 registered nurses (RNs); nine licensed practical nurses (LPNs); five certified nursing assistants (CNAs); a social worker who is also the palliative care program coordinator; a psychologist; a physical therapist; an occupational therapist; a chaplain; a dietitian; a pharmacist; and a recreation therapist. Members of this staff meet weekly as a team to discuss care plans, review documentation, and discuss current issues and needs of the PCU.

The PCU admits approximately 200 patients per year. Patient referrals are made primarily by the following services: acute medicine and intensive care unit (ICU) (44%), hematology-oncology (20%), radiation therapy (11%), and primary care (7%). Another 7% of referrals come from community hospitals.

The PCCT

Established in September 1999, the interdisciplinary PCCT provides consultation for both inpatients and outpatients throughout the medical center. The PCCT addresses issues such as admissions and transfers to the PCU, pain management and symptom control, prognosis assessment, goal setting, psychosocial and spiritual care, discharge planning, and referrals to the community for palliative and hospice care. Another important function of the team is to coordinate care and improve communication among health care providers, patients, and their families. The team frequently uses family meetings to establish goals of care and to facilitate the transition to palliative care.

Any clinician in the medical center can request a palliative care consultation through the computerized patient record system using the palliative care consultation template. Referrals are assessed within 24 hours. Since its inception, the PCCT has gained significant visibility in the medical center, and it currently receives approximately 380 requests for consultations per year. In fiscal year 2006, the PCCT was involved in the care of approximately 60% of patients who died in the medical center.

The outpatient clinic

The palliative care outpatient clinic began to operate in 2001. It is staffed by an interdisciplinary team comprised of a physician, an RN, and a social worker. A psychologist and a chaplain also are available during patient visits if needed. The clinic's main function is to offer continuity of care to palliative care patients after discharge from the hospital. It also provides consultative and coordiinated care to veterans with advanced diseases who do not meet criteria for enrollment in the Medicare hospice benefit.

Grief and bereavement services

Grief may be understood as the multifaceted psychological and physical response experienced by individuals in a state of bereavement due to the loss—or anticipated loss—of a loved one.³ The ZVAMC's VA palliative care program seeks to address the grief and bereavement needs of veterans, staff, and families through the provision of a variety of services.

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Veterans admitted to the PCU are assessed by the psychology service for anticipatory grief reactions and the presence of more severe psychological symptoms, such as depression and anxiety. Based on this assessment, an individualized treatment plan is developed. Therapeutic interventions include supportive psychotherapy, cognitive-behavioral strategies, nonpharmacologic methods for managing symptoms (such as anxiety or pain), existential exploration, and life review. Patients who require pharmacotherapy are referred to the psychiatry services. In addition to individual psychotherapy, a weekly support group for veterans is facilitated jointly by the psychology postdoctoral fellow (an individual who works primarily with the palliative care program as part of the Interprofessional Fellowship in Palliative Care, which is discussed later as part of the educational program) and a psychiatric clinical nurse specialist. Topics discussed include coping with a terminal diagnosis and in one's life and death, finding meaning in the diagnosis, communicating with staff and family members, and symptom relief.

Grief support is provided to nursing staff in the palliative care program through twice monthly meetings facilitated by the PCU psychologist and the psychology postdoctoral fellow. These meetings provide staff with an opportunity to express their emotional reactions to veterans' deaths, validate their important contribution to the quality of veterans' lives in the terminal stages, discuss team communication and interpersonal conflicts, and receive information about psychological factors affecting palliative care patients and their families. The psychologist also is available to conduct supportive debriefing sessions with palliative care staff members on an individual basis as needed. Staff members who require more formal and ongoing grief and bereavement counseling are referred to the medical center's Employee Assistance Program.

In order to address the needs of the bereaved families, a grief and bereavement program was implemented on the PCU in 2003. Consistent with research suggesting that family members benefit from contact with medical center staff following a patient's death,⁴ the grief and bereavement program provides opportunity for ongoing communication through mail, telephone, and in-person remembrances. Specifically, the current program consists of a sympathy letter mailed to the bereaved family members within two weeks of the veteran's death; telephone calls by trained nursing staff one month and six months after the death; and mailings focused on grief during the second, fourth, and ninth months following the death. Mailings also are sent out around the holiday season and on the first anniversary of the death. Contact information for the bereaved family members is tracked by the palliative care secretary, as are the mailings.

The initial mailing invites the family members to contact the palliative care social worker should they desire a referral for additional grief support. During the one- and six-month telephone calls, bereaved family members are asked about their coping resources. If they express a desire for follow-up, referrals for specialized care in the community are provided. In addition, psychological support in the form of grief and bereavement counseling may be offered to surviving family members on a time-limited basis by the PCU psychologist and psychology trainees.

Memorial services are another component of the grief and bereave-

ment program. These are organized by the chaplain service and held every six months. Family members, friends, and staff are invited to attend.

Based on a review of the medical literature and on input from the palliative care program at the Bay Pines VA Healthcare System in Bay Pines, FL, the ZVAMC palliative care program developed and implemented a bereavement risk assessment tool in 2005. (Copies of the tool are available upon request; please e-mail trisha.o'leary@va.gov.) The goal of this tool is to identify individuals who may be at risk for complicated grief, which may be understood as a deviation from the expected grief experience with respect to duration or intensity of symptoms.5 The tool addresses the caregiver's understanding of the patient's disease and prognosis and perceptions of his or her relationship with the patient. It also includes the assessor's clinical impression of the caregiver based on observations and collateral information from other staff and family members.

The bereavement risk assessment tool is now included as part of each patient's psychosocial assessment in the computerized medical record. While research is needed to evaluate the reliability and validity of the tool, anecdotal experience thus far suggests its usefulness in helping palliative care staff to identify individuals at risk for complicated grief, thus enabling staff to offer specialized grief support and more intense follow-up after the patient's death.

Spiritual care

Promoting spiritual care is an important function of the palliative care program. Chaplains from several denominations are available throughout the medical center to meet the spiritual or pastoral needs of veterans and their families.

To address the specific needs of patients in the palliative care program, a spiritual assessment tool was developed, and it serves as a guideline for the chaplain's care plan. Reliability and validity data on this tool are not yet available because the tool is currently being revised and updated based on the VHA's Spiritual and Pastoral Care Procedures Handbook. In its current form, the tool assesses the patient's religious preference, faith, life values, faith group participation, life changes, established support systems, religious history, and life history.

A pastoral care plan is formulated based on the patient's needs and religious preference. Chaplains approach spiritual care according to each patient's belief system. Spiritual interventions commonly used include communion; religious services; Bible reading; and use of rituals, prayers, and sacraments that relate directly to healing, dying, and helping the patient to cope with the end of life.

The volunteer program

The ZVAMC's palliative care program uses volunteers from the community to enhance veterans' quality of life. Some veterans are admitted to the PCU to receive medical treatment that is unavailable near their homes or because their loved ones can no longer care for them at home. These veterans often are hours away from their families and friends. PCU volunteers visit with patients to promote meaningful social interactions. Volunteers also perform such activities as reading to patients, playing musical instruments, accompanying patients to appointments or to the outside patio, sitting vigil with patients who are close to death, and participating in functions and events to improve patients' quality of life (such as holiday celebrations).

Volunteers are recruited from area churches and county retirement programs and by word-of-mouth. Individuals who expresses an interest in volunteering on the PCU are referred to the ZVAMC's volunteer coordinator for review of polices, privacy acts, and other needs. The palliative care coordinator then meets with the volunteer to provide a two-hour training session on death and dying. Training focuses on the general aspects of palliative care, as well as emotional and physical signs of pain. The palliative care coordinator meets regularly with each volunteer to review his or her activities and work experience and to identify any ongoing training needs. If additional educational needs are identified, appropriate literature is provided. Volunteers are encouraged to notify the palliative care coordinator if they are feeling overwhelmed or need additional support.

The educational program

Interprofessional education has been a priority of the ZVAMC palliative care program since its inception. The palliative care education program provides continuing education and training to physicians, residents, fellows and medical students of the Medical College of Wisconsin, nurses, nurse practitioners, social workers, psychologists, and pharmacists. The paragraphs that follow describe several educational initiatives.

In 1998, the ZVAMC was selected as one of the sites for the VA Faculty Leaders Project for Improved Care at the End of Life, which was funded by a grant from the Robert Wood Johnson Foundation. The objective of this project was to establish palliative care training curricula within VAMC-based internal medicine residency programs.⁶ A multifaceted palliative care curriculum was developed at the ZVAMC and integrated into the Medical College of Wisconsin's medicine residency curriculum.⁷ Multiple teaching methods were used, including morning report to discuss palliative care topics, case discussions on ethical issues, and six core curriculum lectures based on the American Medical Association Education for Physicians on End-of-Life Care (EPEC) project.⁸ One of the highlights of this project was the development of a palliative care educational experience for internal medicine residents, which was integrated into an existing geriatrics rotation.⁹

In 1999, several ZVAMC faculty, nursing staff, NPs, and fellows attended a 12-week faculty development course in palliative care.¹⁰ The intent of this course was to improve VA faculty and staff knowledge of, attitudes about, and skills in palliative care and to prepare these staff members to teach other trainees in the medical center. Also in 1999. an eight-session nursing education program in palliative care was developed by the palliative care team to provide basic knowledge to nurses who work directly with palliative care patients.¹¹ In May 2000, this program was expanded to a day-long nursing symposium, which was attended by approximately 70 members of the medical center's nursing staff and was videotaped and used for orientation of new PCU staff.

In 2001, the ZVAMC's palliative care program was recognized for its excellence in education and clinical care and was chosen as one of six sites nationwide for the VA Interprofessional Fellowship in Palliative Care.² The fellowship offers interdisciplinary training in a broad end-of-life care curriculum. The ZVAMC offers training positions for physicians, nurses, psychologists, pharmacists, and social workers. The fellowship provides training experiences in several areas,

including inpatient, outpatient, and consultative palliative care; home hospice; home-based primary care; pain management; oncology; radiation oncology; community-based palliative and hospice care; and several other rotations tailored to the fellows' individual career goals. To date, 15 palliative care fellows have received training at the ZVAMC, and several have assumed palliative and hospice care leadership positions after graduation. The palliative care fellowship has organized a variety of educational opportunities for VA staff and the community to disseminate palliative care knowledge. In 2003, a large symposium offered education in the basic domains of palliative care to VA employees and community hospice workers.

Other educational initiatives include regular teleconferences addressing a range of topics related to interprofessional education in palliative care. The conferences are based at the ZVAMC and are offered to other VA medical centers and community hospices. In addition, the palliative care program promotes medical center grand rounds and facilitates a monthly palliative care journal club that is open to all VA staff.

At the unit level, continuing education efforts in palliative care have concentrated not only on maintaining end-of-life care skills but also on gaining additional expertise in the field. The PCU's NP and several of the RNs have attained certification through the Hospice and Palliative Nurses Association (HPNA). During 2005 and 2006, review courses based upon core curricula developed by HPNA were presented to the PCU CNAs and the LPNs, resulting in successful certification of five CNAs and six LPNs.^{12,13} Standards of nursing care, clinical guidelines, end-of-life teaching guidelines, and a progress note template that uses a modified version of the Edmonton Symptom Assessment System¹⁴ have been completed and are in use to guide and document nursing care. Palliative care nurses have served as faculty for a course on end-of-life care in the nursing home and as resources for end-of-life symptom management throughout the long-term and acute care areas of the medical center.

Palliative care research

Developing research in palliative care is another focus of the ZVAMC's palliative care program. Projects that have been completed successfully by palliative care faculty and fellows include the study of rehabilitation interventions in palliative care patients,15,16 assessment of spiritual beliefs and practices among palliative care physicians and nurses,17,18 the use of mindfulness meditation as a psychotherapeutic tool with palliative care patients, and the assessment of grief and coping among palliative care providers. Currently, a study on the knowledge, attitudes, and behaviors related to end-of-life practices among ICU providers is underway.

COLLECTING AND ANALYZING DATA

The palliative care program uses an electronic database to enhance patient care follow-up, program management, and data reporting. This database includes clinical data on the PCU and PCCT, including:

- patient demographics (such as age and gender);
- diagnosis;
- number of admissions, dates, and lengths of stay on the PCU;
- reasons for admission to the PCU (such as pain and symptom control, palliative radiation therapy, or palliative radiation and chemotherapy);

- services that referred patients to the PCU;
- number of deaths on the PCU;
- discharge site (such as the home, home hospice, long-term care, or other VA facility);
- number of palliative care consultations and the services that referred patients for consultations;
- number of palliative care clinic referrals and the services that referred patients to the clinic;
- number of deaths in the medical center and the percentage of these deaths for which the PCCT was consulted; and
- average number of days between initial palliative care consultation and the patient's death.

Data on patient and family member satisfaction have been collected to assess the quality of care provided through the palliative care program. In 2002, 104 PCU patients (100% of those who were surveyed) reported a high level of satisfaction with the care received in the following areas: information received from staff regarding illness, wishes being respected by staff, information regarding daily activities, pain management, timeliness in receiving pain medication, staff timeliness in responding to call lights, and degree to which spiritual needs were met. In a separate survey, family members of 46 deceased patients who were treated on the PCU (100% of those who were surveyed) reported high levels of satisfaction with the quality of care provided to the patient, pain control, degree of involvement in decision making, amount of information from medical providers regarding the patient's illness, and perception of their needs being met as a spouse or caregiver.

PALLIATIVE CARE POLICIES

To aid in formalizing the development of the palliative care program,

Table. Steps for successful palliative care program development¹⁹

- · Justification of the need for a palliative care program
- Securing institutional support
- Implementation and program operation:
 - -Establishment of the program mission
 - -Development of short- and long-term program goals
 - -Recruitment and development of a palliative care team
 - --Selection of a palliative care service model (inpatient, outpatient, consultative, or some combination thereof)
 - -Development of policies and procedures
 - -Development of marketing strategies
 - -Development of a method for evaluating program performance
 - Development of a palliative care database, including clinical and financial data
 - -Development of a quality improvement process
 - -Development of a grief and bereavement program
- Development of educational and research initiatives

several policies and procedures were established to address specific care needs of the palliative patient. The first of these was a professional services memorandum that describes the mission, goals, functions, and components of the palliative care program.

A policy addressing admission to the PCU defines palliative care, the criteria for admission (namely, patients with a life expectancy of six months or less, patients needing symptom control with the desire to return home afterward, and patients requiring close observation during active radiation therapy or chemotherapy), and the hours during which admissions are accepted. The admissions policy also identifies patients who cannot be accommodated on the unit, specifically those who are dependent upon a ventilator, those receiving heparin drips or restorative total parenteral nutrition, and those with a psychiatric diagnosis whose behavior requires a locked unit. An admission packet also was developed, which contains a description of the PCU and the services provided, as well as teaching materials for patients and families. These teaching materials include booklets entitled "Preparing for Your Loved One's Death" and "Living through Your Grief."

The palliative care program has established additional policies with regard to symptom control approaches and definitions of patients' wishes, including:

- continuous intravenous infusion of opioid drugs,
- subcutaneous infusions,
- palliative sedation,
- comfort measures only,
- aromatherapy,
- nebulized morphine delivery,
- deactivation of implanted cardioverter-defibrillator devices, and
- pronouncement of death. Institutional policies that were

already in place for other aspects of care—such as skin care, medication delivery, blood transfusions, do not resuscitate orders, and use of restraints—also are used on the PCU.

KEYS TO SUCCESS

Several factors contributed to the successful development and implementation of the ZVAMC palliative care program. First, having effective leadership and a well developed team were essential. During initial recruitment of staff to the palliative care program, VA staff were invited—not required—to join the team. This laid the foundation for a committed, caring, passionate, and highly skilled palliative care team. Team members are very dedicated to all three aspects of the palliative care program: patient care, teaching, and research. In fact, several of them serve on local, regional, and national palliative care committees and organizations.

Roles and responsibilities of each team member are clearly specified to avoid role confusion and to strengthen the team, and great efforts are made to maintain open and consistent communication among the team members. Regular team meetings to review goals and develop strategies for continued growth also have been essential for program development.

Support from the medical center administrators has been another integral part of the program's success. Administrative support was obtained through several meetings with medical center leaders to address the need to improve end-of-life care for veterans. Additionally, the palliative care database has proven valuable in capturing program growth and reinforcing the need for the palliative care program. The survey data on patient and family satisfaction also have been shared with medical center administrators to reinforce the need for and mission of the program.

Strategizing program development is key to continued growth. We use a step-by-step process for program development that focuses on the needs of the medical center, patients, family members, and staff (Table).¹⁹ The team has established clear goals, priorities, specific timeframes, and individuals and resources required to meet

each goal. This process allows for continued and successful growth, as well as ongoing program evaluation.

The VA Faculty Leaders Project and the Interprofessional Palliative Care Fellowship have enhanced program recognition and accelerated further development, as several educational and research projects were accomplished as part of these initiatives. The strong academic affiliations of the medical center and effective networking with several medical schools, nursing programs, schools of social work, other VA medical centers, and community-based programs also were extremely important for program expansion.

Overcoming obstacles

Recognizing and addressing challenges also is crucial to successful program development. The most significant challenges we've encountered have been fiscal limitations, gaps in the palliative care team staff, and cultural barriers within the institution.

The medical center provides salary support for palliative care program staff and funds for a range of program initiatives, such as environmental improvements on the PCU, purchases of educational and program materials, and participation of team members and fellows in professional meetings and conferences. The palliative care program was able to secure additional funding to support other initiatives through grants, donations, and income generated from educational programs.

For some time, the PCCT was lacking an RN. This problem was solved by hiring a nurse who will serve both in this role and as a case manager on the PCU.

Finally, the ZVAMC, historically, has been no exception to prevailing culture in U.S. health care, which focuses primarily on curative treatment.

With palliative care education and outreach efforts, however, referrals to palliative care at the medical center have increased exponentially. Furthermore, an increasing percentage of these referrals include requests for symptom management and assistance with family meetings and goal setting, in addition to PCU admission. Even so, referrals often are placed late in the care continuum, which hinders the palliative care team's ability to enhance patients' quality of life. The team continues to work on increasing the awareness of palliative care and reinforcing the importance of timely referral within the institution through educational programs targeted at hospital staff and trainees.

FUTURE DIRECTIONS

Ongoing evaluation of the palliative care program's effectiveness and anticipation of future enhancement to endof-life care are essential for continued program growth.²⁰ The interdisciplinary palliative care team will need to develop methods for assessing quality of care beyond the patient and family satisfaction surveys that have been used thus far. Utilization of the National Consensus Project Guidelines for Quality Palliative Care²¹ to assess the effectiveness of care planning is an example of one such effort that is underway on the PCU.

The establishment of an intensive care unit–palliative care task force has allowed for the strengthening of relationships between the two areas, and the results of a recent end-of-life needs assessment of ICU personnel will lay the foundation for future educational presentations and collaboration. Similar collaborative efforts are targeted for the medical-surgical and primary care areas of the ZVAMC. Other future goals for the program include progressive certification of all staff in palliative care, development of a complementary therapy program, environmental improvements for the PCU, expansion of volunteer services, and further development of palliative care research and education.

IN CONCLUSION

The need for VA palliative care services is expected to increase over the next several years. The ZVAMC has successfully established a multifaceted palliative care program to address the needs of dying veterans. Keys to program success have included effective leadership, the interdisciplinary team's commitment to the mission of the program, institutional support, programmatic initiatives that focus on patients' needs, educational initiatives, and research. Several elements of this program may be adapted and utilized by other VA medical centers that identify a need to develop and expand their palliative care programs to meet rising demand.

Author disclosures

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