

A Palliative Care Coordination Program for Veterans With Advanced Cancer

Judith R. Knudson, MPAS, PA-C, BSN; Stephanie Borchardt, PhD, MPH; Tracy Pedersen, BS, RHIT, CTR; and Marcos Montagnini, MD

Consisting of an interdisciplinary team that places a strong emphasis on communication with patients and their families, the palliative care coordination program instituted in 2005 at Fargo VA Health Care System has been successful in improving the end-of-life care of its veterans with advanced and end-stage cancer.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment.¹ Pain management and symptom control as well as psychosocial and spiritual care are paramount. The primary goal of palliative care is to achieve the best possible quality of life (QOL) for patients and their families.

Over the last decade, the number of palliative care programs in U.S. hospitals has grown substantially, according to an analysis by the Center to Advance Palliative Care.² Between 2000 and 2009, the number of palliative care programs in hospitals with ≥ 50 beds increased from 658 to 1,568, representing an increase of 138%.²

Providing hospice and palliative care to veteran patients has been a major priority in the VA for

more than a decade. The VA provides health care for patients who, on average, are more seriously and chronically ill, facing challenging social and supportive limitations, and dying in greater numbers than patients in the general population. About 1,600 veterans die each day, whereas only 4% receive hospice care in a VA facility.³ The VA has funded several initiatives to promote palliative care program development, staff education, and quality improvement. Since 2003, VA facilities have been directed to have hospice and palliative care consultation teams. All enrolled veterans are eligible to receive free hospice care, regardless of age, living arrangement, service-related status, or financial status. More recently, the VA began the Comprehensive End-of-Life Care initiative to ensure reliable access to quality end-of-life (EOL) care across the VA health care systems.⁴ These efforts have significantly improved the access and delivery of EOL care to veterans nationwide. Data provided by the U.S. Department of Veterans Affairs show that the number of palliative care consults rose from 17,000 in 2005 to 41,085 in 2009, and the percentage of inpatient deaths with a palliative care consult increased from 38% in 2005 to 69% in 2010.

Parallel to the nationwide increase in the number of palliative care programs, health care models focusing on quality improvement, such as care coordination programs, have been integrated with palliative care to improve the quality of care provided to patients and families.⁵⁻⁸ Care coordination encompasses numerous aspects of health service provision, including appropriate care that is timely and provided by an interdisciplinary team comprising medical, nursing, and allied health professionals.⁵ Key elements intrinsic to care coordination include psychosocial assessment, suitable and timely referrals, information provision, and individualized treatment that considers each patient's needs and preferences.⁵

The Advanced Illness Care Coordination Program (AICCP) is a care coordination model designed to improve the quality of care for patients with serious illness.⁶ The AICCP is designed to promote communication and understanding between patients and providers about advanced illness and EOL issues to promote health literacy, achieve coordination of care, provide emotional and social support, and reduce the barriers to the use of palliative and hospice services.⁷ The AICCP has been shown to improve satisfaction with care, ad-

Ms. Knudson is a physician assistant and **Ms. Pedersen** is a cancer registrar, both at the Fargo VA Health Care System in Fargo, North Dakota. Ms. Knudson is a clinical instructor in the Department of Internal Medicine at the University of North Dakota in Fargo, North Dakota. **Dr. Borchardt** is an epidemiologist at the Wisconsin Division of Public Health in Madison, Wisconsin. **Dr. Montagnini** is staff physician and director of the palliative care program at the VA Ann Arbor Healthcare System, Geriatric Research, Education and Clinical Center in Ann Arbor, Michigan, and associate professor of medicine in the Division of Geriatrics and Palliative Medicine, Department of Internal Medicine at the University of Michigan in Ann Arbor, Michigan.

Table 1. Provider, themes, and sample questions asked at each Advanced Illness Coordinated Care-Palliative Care (AICC-PC) Program visit

Visit	Provider	Themes	Sample Questions
1	Physician assistant	Individuality Building a relationship with the veteran and family Education on definition and goals of palliative care Quality of life	“Where did you grow up?” “What was your family like?” “Can you tell me about your illness?” “How did you know something was wrong?” “Do you understand your treatment options?”
2	Physician assistant	Coping mechanisms Fears and concerns	“What are some of your concerns at this time?” “What, if anything, are you concerned or worried about?” “How is your spouse (or significant other) seeming to handle what is going on?”
3	Social worker	Practical issues (completing advanced, directives, review of veteran benefits, financial concerns)	“What practical issues is your illness creating for you?”
4	Dietician	Nutritional concerns (weight loss, anorexia, cachexia, artificial nutrition at end of life) Diet education	Questions about dietary history, with opportunity to discuss problematic issues related to feeding, as well as removing previous dietary barriers that occurred.
5	Occupational therapist	Function/safety in the living environment Home modifications to promote function and safety	Questions about the structure of the bathroom Barriers, steps, risks in bathing, toileting, and activities of daily living
6	Chaplain	Spirituality Faith Suffering	“Does spirituality have a role in your life?” “Does your faith impact how you are dealing with your disease?” “Do you find meaning in suffering?”
7	Physician assistant	Goal setting Achieving peace at the end of life Hospice referral if not already made	“As the disease progresses, where would you want to be when things slow down?” “What do you want to do with your remaining time?” “Have you found peace?” “Are you afraid of death?”

vanced care planning, communication, and care delivery to patients with advanced illnesses.^{7,8}

In 2005, Fargo VA Health Care System (FVHCS) piloted a care coordination model, based on the AICCP, to improve the quality of care to veterans with advanced cancer followed by the oncology outpatient clinic. The authors hypothesized that

this model, referred to as the AICC-Palliative Care (AICC-PC) Program, would improve the care for veterans with advanced cancer by allowing earlier recognition and treatment of the physical, social, emotional, and spiritual domains of care. The authors compared the characteristics and interventions received by veterans with advanced cancer who died

having had AICC-PC services with veterans with advanced cancer who received usual care (UC) and died before the availability of these services.

DEVELOPMENT AND STRUCTURE OF THE AICC-PC PROGRAM

FVHCS is a 70-bed tertiary care medical center with subspecialty

Table 2. Characteristics of the Advanced Illness Coordinated Care-Palliative Care (AICC-PC) Program and usual care (UC) patients

Characteristics	AICC-PC No. of patients (%)	UC No. of patients (%)	P value
Male	40 (100)	37 (93)	= .08
Median age (range)	64 (46 to 91)	69 (42 to 84)	= .13
Principal cancer diagnosis			= .07
Lung	17 (43)	30 (75)	
Colon	5 (13)	1 (3)	
Kidney	4 (10)	1 (3)	
Pancreas	3 (8)	2 (5)	
Esophagus	3 (8)	0	
Rectum	2 (5)	1 (3)	
Blood	1 (3)	0	
Prostate	1 (3)	1 (3)	
Stomach	1 (3)	1 (3)	
Bladder	1 (3)	2 (5)	
Liver	0	1 (3)	
Unknown	3 (8)	0	
Location of death outside the VA	22 (55)	25 (63)	= .50

services and outpatient clinics. Being the only VA tertiary care medical center in North Dakota in the southeast corner of the state, some veterans travel more than 6 hours for inpatient and outpatient specialty care.

Among a full complement of specialties, FVHCS provides inpatient and outpatient oncology and palliative care services. Before the implementation of the AICC-PC Program at FVHCS, veterans with advanced cancer received follow-up care from the time of completion of disease-modifying oncologic treatment with surveillance visits. However, with distance

barriers and no formal care coordination program, these veterans were often seen on an as-needed crisis basis. Near death, some veterans would seek hospital care locally or at FVHCS with a delay in initiation of hospice care and no optimal pain and symptom management at the end of life.

The FVHCS leadership recognized the need for better continuity and coordination of care for this vulnerable population as one of its top level priorities. Palliative care staff worked along with the oncology staff to develop and implement a new model of care coordination based on the AICCP. The goal of the AICC-PC

Program was to improve the care of veterans with advanced end-stage cancer by facilitating earlier access to palliative care.

Referrals to the AICC-PC Program were initiated by the oncologists at the time of diagnosis of advanced cancer. The AICC-PC Program was delivered in the outpatient oncology clinic with 7 individual, structured clinic visits. The design and context of the 7 visits were modeled after the *AICCP Manual* authored by Tobin and Larson.⁶ At each visit, a preassigned member of the AICC-PC interdisciplinary team interviewed patients, addressing specific themes related to EOL care (Table 1). The visits were documented in structured templates built in to the Computerized Patient Record System (CPRS). The delivery of the AICC-PC used a nondirective health-counseling format, patient and family education, discussions about the treatment plan, and care coordination. Improved communication with patients and their families was strongly emphasized during the process. The AICC-PC interdisciplinary team included a physician assistant (PA), a registered nurse, a social worker, a chaplain, a dietitian, and an occupational therapist, all of whom had expertise in palliative care. All visits included an assessment of pain, using the 0 to 10 Numeric Pain Rating Scale.⁹ All palliative care team members would refer the veteran to the PA for uncontrolled pain or symptoms needing management at the time of the visit as indicated.

METHODS
Study Population

The study population consisted of 80 veterans who had received treatment in the oncology clinic at FVHCS and died of advanced cancer with and without AICCP-PC.

Table 3. End-of-life care interventions among Advanced Illness Coordinated Care-Palliative Care (AICC-PC) Program and usual care (UC) patients

Intervention	AICC-PC ^a No. of patients (%)	UC ^a No. of patients (%)	P value
DNR in place \geq 5 days before death	34/37 (92)	27/39 (70)	= .01
More than 1 admission within last 6 months of life	21/40 (53)	11/40 (28)	= .02
ICU stay within last 30 days of life	2/40 (5)	2/39 (5)	= .98
Feeding tube placed within last 30 days of life	2/40 (5)	4/36 (11)	= .32
Restraints within last 5 days of life	1/40 (3)	2/36 (6)	= .49
IV hydration within last 5 days of life	3/40 (8)	7/36 (19)	= .12
Community hospice care	25/40 (63)	16/40 (40)	= .04
Inpatient hospice care	17/40 (43)	12/40 (30)	= .24
Chaplain visit within 2 months of death	28/40 (70)	23/40 (58)	= .24
Social worker visit within 2 months of death	26/40 (65)	26/40 (65)	= 1.0
Advanced directive in place before death	22/40 (55)	10/40 (25)	= .006
Pain score of \leq 3 at time of death	21/39 (54)	21/37 (57)	= .80
Routine laxative order in place \geq 5 days before death	22/30 (73)	13/29 (45)	= .03
Routine opioid order in place \geq 5 days before death	27/33 (82)	19/33 (58)	= .03

^aNot all denominators are equal to 40 due to unknown or missing data.
DNR = do not resuscitate; ICU = intensive care unit; IV = intravenous.

Through a retrospective chart review, the first 40 veterans who received care from the AICCP-PC Program and died during June 2005 through July 2007 were identified. The comparison group consisted of 40 consecutive veterans who received usual oncologic care and died during January 2003 through May 2005 (pre-AICCP-PC).

Data Collection

Data were retrospective and obtained by reviewing patients' medical records in the CPRS. Demographic data included age, gender, type of cancer, and location of death. EOL care interventions included the following: do not resuscitate (DNR) order in place \geq 5 days before death; more than 1 acute care admission in the last 6 months of life; intensive care unit (ICU) stay within the last

30 days of life; feeding tube placed within the last 30 days before death; restraints within the last 5 days of life; intravenous (IV) hydration during the last 5 days of life; referral to home hospice care; inpatient hospice care at FVHCS; social worker visit within 2 months of death; chaplain visits within 2 months before death; advanced directive in place; pain score \leq 3 at the time of most recent charting before death (if the veteran was not responsive, the last responsive pain score given from the veteran was used for this variable); laxative order and opioid order in place \geq 5 days before death.

Statistical Analysis

Data analysis was descriptive. Group comparisons were performed by the student *t* test. The study also included univariate and

bivariate analyses comparing patients who received palliative care with those who received usual care. SAS 9.1 for Windows (SAS Institute Inc., Cary, North Carolina) and Epi Info Version 3.3.2 were used for all statistical analyses.

RESULTS

There were 40 subjects in each group. The majority of subjects in both groups were male (Table 2). The mean age for the UC group was 69 years, and the mean age for the AICC-PC group was 64 years. Lung cancer was the most common diagnosis in the UC group; lung and colon cancer were the most common diagnoses in the AICC-PC group. Sixty-three percent of veterans in the UC group and 55% of veterans in the AICC-PC group died outside FVHCS. There were

no statistically significant differences between the 2 groups.

Bivariate analysis demonstrated that veterans receiving AICC-PC were more likely to have a DNR order in place > 5 days before death ($P = .01$) and were more likely to have an advanced directive in place before death ($P = .006$) (Table 3). Veterans in this group were also more likely to have routine orders for opioids ($P = .03$) and laxatives ($P = .03$). AICC-PC patients were also more likely to be referred to community hospice care ($P = .04$) and to have more than 1 admission within the last 6 months of life ($P = .02$).

DISCUSSION

The study described the impact of the AICC-PC Program on EOL care interventions for veterans with advanced cancer at FVHCS. It demonstrated that veterans enrolled in the AICC-PC Program were significantly more likely to have an advanced directive in place before death and a DNR order in place ≥ 5 days before death. Veterans enrolled in the AICC-PC Program also had higher referral rates to community hospice care and more frequently used opioids and laxatives compared with veterans who received UC.

This study found that veterans in the AICC-PC group had better advance care planning compared with the UC group. Previous studies evaluating outcomes associated with the AICC model documented similar findings. Engelhardt and colleagues demonstrated that the AICCP helped veterans and non-veterans with advanced illness develop and revise more advanced directives compared with patients who received usual care.⁷ In another study, Engelhardt and colleagues demonstrated that AICCP

improved communication, advanced care planning, and increased the number of DNR and do-not-intubate orders in patients with advanced diseases and enrolled in a managed care system.⁸

The study also demonstrated a higher referral rate to home hospice among AICC-PC patients. This indicates better EOL care planning and enhanced understanding and acceptance of hospice by the patients and their families. This finding supports the documentation in a study by Ciemins and colleagues, which evaluated the impact of an advanced illness management program on hospice referrals of outpatients with limited life span and who were enrolled in home health services.¹⁰ These authors demonstrated that an advanced illness management program, which emphasized EOL care communication, resulted in higher referral rates to hospice.¹⁰

Effective EOL care planning is possible only through proper communication. The authors believe that enhanced EOL communication provided by the AICC-PC team was one of the key factors that promoted better EOL care planning and hospice utilization in the AICC-PC group. The AICC-PC team aimed to increase the patients' understanding of their disease and their treatment options. Efforts were also made to prepare veterans and families for important EOL care decisions while honoring veterans' goals of care and promoting emotional and spiritual support. Once the relationship was established, an enhanced trust was noted. This trust created a freedom that allowed open discussions about prognosis and EOL care choices.

Several studies addressed the

significance of communication in the provision of EOL care. Early discussions between patients and physicians about EOL care preferences have been associated with less aggressive medical care and better QOL.^{7,8} According to Bailey and colleagues, "EOL care discussions are also significant because they represent a potential turning point in the trajectory of care away from a strictly disease-modifying, curative path to a more symptom-focused palliative care."¹¹ Poor communication between patients, their families, and providers can seriously interfere with the quality of the patients' remaining life.¹² Strategies for enhancing EOL care discussions are most productively linked to physicians' interpersonal communication skills, a patient-centered model of care, a focus on the quality of remaining life, and innovative clinical models for implementing these discussions earlier in the care process.¹²

This study also documented better use of opioids and laxatives in the AICC-PC group. Pain assessment and management was an integral part of the AICC-PC Program. Education about pain management, including dispelling myths, fears of narcotic use, and understanding how the narcotics work encouraged the veteran to medicate pain to improve QOL. Narcotic-induced constipation was also discussed, and laxatives were routinely used in conjunction with the narcotic. The AICC-PC team discussed recommendations for pain control and laxative use with patients' oncologists and primary care providers, which may have contributed to a higher utilization rate of opioids and laxatives in this group.

The authors found an increased number of admissions to acute care

within the last 6 months of life in the AICC-PC group. We believe that the regular follow-up provided by the AICC-PC team may have contributed to the hospitalization increase in the AICC-PC group. The AICC-PC team followed the veterans closely and encouraged hospitalization if the veteran needed better pain control and symptom management. Pain and symptom crisis are common in patients with advanced cancer and sometimes will require an inpatient stay for proper assessment and management. Because veterans were also followed by the oncology clinic, admissions to acute care could have been related to second- or third-line chemotherapy or for the management of acute medical problems (eg, infection, dehydration, and acute confusional state), which are common in patients with advanced cancer. Last, progressive frailty and lack of caregiver support in the home environment may also have led to more frequent hospital admissions to acute care.

These findings of an increased number of admissions among AICC-PC veterans differs from what Engelhardt and colleagues documented in their 2009 study on the effects of the AICCP Program on a managed care population with advanced diseases.⁸ In their study, AICCP participants had fewer inpatient admissions compared with patients who received UC. This contrast in study findings can be explained by the differences in study design and subject selection. The authors analyzed retrospective data on deceased cancer patients, whereas Engelhardt and colleagues prospectively enrolled patients with solid-tumor cancers with metastases, congestive heart failure, and end-stage pulmonary and renal disease.⁸ Additionally in their study, the

1-year survival rate was almost 70%. This study's population was frailer with greater needs for inpatient care during their last months of life.

LIMITATIONS

Several limitations existed. First, it was a retrospective chart review. Second, the population included white, older male veterans from a single medical center in the Midwest, which limits the generalizability of the findings to other settings. Last, because the study was retrospective, the authors could not assess veterans' QOL, satisfaction with care, or the caregivers' perspective. Despite these limitations, the study was able to demonstrate that the AICC-PC Program improved the utilization of several EOL interventions among veterans with advanced cancer at FVHCS.

Several programmatic improvements resulted from this study. In 2007, the AICC-PC study outcome data were presented to FVHCS leadership and VISN 23 leadership at a regional palliative care meeting. As a result, the AICC-PC study data were used to support a VISN-wide business proposal for expanding palliative care to the 8 VA facilities in VISN 23. Funding for this initiative was sought through the VA Strategic Initiative (SI) award. This annual award supports efforts or projects that promote the mission and goals of the VA. VISN 23 was awarded SI funds enabling support for a multidisciplinary palliative care team at each of the facilities in VISN 23. This award changed the authors' practice from collateral work, based on the goodwill of the employee, to being able to hire multidisciplinary staff positions in palliative care. The expansion of palliative care permeated various

venues of care, extending to outpatient clinics, telemedicine, inpatient consults, collaboration with home-based primary care, coordinating community hospice, and direct hospice care in FVHCS-based Community Living Centers.

CONCLUSION

As the Palliative Care Program expanded at FVHCS, palliative care has become "care without walls." The palliative care team has been providing continuity of care from time of initial consult to bereavement care for 1 year beyond death. Irrespective of location, the palliative care team remains in contact with the veteran and his or her family. The average length of stay from palliative care consult to death is > 100 days. In addition, the palliative care team has implemented several initiatives to promote facility-wide staff education in hospice and palliative care, such as Grand Rounds, monthly palliative care educational offerings, and monthlong rotations for internal medicine residents from the University of North Dakota in Grand Forks, North Dakota.

The palliative care services at FVHCS and throughout its VISN are now a fully-integrated mainstay of care that all VA staff members have come to depend on. The comprehensive approach to patient care originally promoted by the AICC-PC program continues to support the mission of the VA and remains the cornerstone of the care that is provided to veteran patients and their families facing advanced diseases. ●

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