

Providing Palliative Care in the Ambulatory Care Setting

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Palliative care that provides specialized attention to pain and symptom management is important for patients with cancer. Palliative care aims to reduce pain and other symptoms through an interdisciplinary approach involving physicians, nurses, social workers, and other members of the healthcare team. Families are included in care planning. Patients and families benefit from the availability of palliative care services early in the disease process, particularly when symptoms impact quality of life. One way to implement early palliative interventions is the establishment of an ambulatory care clinic dedicated to palliative care. This article describes the experience of an outpatient palliative care clinic at a large teaching hospital by using case studies to highlight the benefits of ambulatory palliative care and concluding with recommendations for research.

The World Health Organization ([WHO], 2010) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (para. 1). According to WHO (2010), the goal of palliative care is to alleviate pain and other distressing symptoms via an interdisciplinary approach that addresses the physical as well as psychosocial and spiritual aspects of care. Families also are involved in care planning. WHO emphasizes that palliative care is “applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (WHO, 2010, para. 1).

Patients and families benefit from having palliative care services available early in the disease process, particularly when symptoms affect quality of life. The Institute of Medicine and National Research Council (Foley & Gelband, 2001) recommend that patients be offered palliative care as well as aggressive, curative therapies. Ideally, palliative care should be initiated at diagnosis, with an expectant increase in frequency and intensity of interventions as disease progresses. Foley and Gelband (2001) stated, “The goal is to maintain the best possible quality of life, allowing cancer patients the freedom to choose whatever treatments they so wish throughout the course of the disease, while also meeting the needs of patients with advanced disease through adequate symptom control” (p. 9). Early palliative interventions can be implemented by establishing an ambulatory care clinic dedicated to providing this care. This article provides an overview of an outpatient palliative care clinic at a large teaching hospital.

At a Glance

- ◆ The goal of palliative care is to relieve pain and other symptoms by using an interdisciplinary approach that addresses the physical, psychosocial, and spiritual aspects of patient care.
- ◆ Patients can receive timely, appropriate interventions for distressing symptoms in the ambulatory setting, thus improving quality of life.
- ◆ Frequent follow-up by telephone can ensure that recommended interventions are effective and help minimize burdensome side effects.

Literature Review

Various models of palliative care exist. The Center to Advance Palliative Care (2010) provides valuable leadership for the development of palliative care programs. Many hospitals have developed palliative care consult services that facilitate symptom management and end-of-life decision making with attention to goals of care. Some hospitals have designated palliative care units

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to provide an interdisciplinary approach to care for patients and their families, often in a home-like environment. Patients may be admitted to a palliative care unit for focused attention to pain and symptom management with the goal of transitioning a patient to home with hospice care if appropriate. Patients also may be admitted to units where the team provides expert end-of-life care to those who are dying.

Several studies demonstrate the benefits of palliative care programs. Gelfman, Meier, and Morrison (2008) showed improved patient and family satisfaction, recognizing that palliative care is inclusive of the patient and the patient's family. In a study by Ringdal, Jordhoy, and Kaasa (2002), patients and families followed by a palliative care intervention team demonstrated higher satisfaction with care provided, particularly care related to symptom assessment, pain management, physician availability, and information shared about the disease process, prognosis, and advanced care planning.

Patients and families can initiate early access to palliative care services in the ambulatory care setting. The outpatient palliative care clinic provides follow-up for symptom management, focusing on goals of care and quality of life. Continuity of care is enhanced with the availability of an ambulatory palliative care clinic (Casarett, Hirschman, Coffrey, & Pierre, 2002). Follwell et al. (2008) demonstrated improvement in symptom control and satisfaction among patients in an oncology palliative care clinic. Rabow, Dibble, Pantilat, and McPhee (2004) implemented a consultative approach to provide palliative care services in the ambulatory setting, following patients with cancer and advanced chronic obstructive pulmonary disease and congestive heart failure. As a result of palliative care involvement, more patients completed advanced directives. Dyspnea, sleep quality, and spiritual well-being improved, but pain and depression scores did not. Rabow et al. (2004) attributed the lack of improvement in pain and depression to the consultative approach, which made recommendations that the primary care provider may or may not have implemented.

Strasser et al. (2004) used a multidisciplinary team approach in a half-day outpatient setting in a comprehensive cancer center. The palliative care physician; nurse; pharmacist; physical, occupational, and speech therapists; social worker; chaplain; nutritionist; and psychiatric nurse practitioner met with patients and provided input to their care plans. As a result of the team approach, patients reported improvement in symptoms, particularly in pain, nausea, depression, anxiety, sleep, dyspnea, and well-being. High levels of patient satisfaction also were reported (Strasser et al., 2004).

According to Meier and Beresford (2008), who reviewed several programs that provide outpatient palliative care services, "outpatient clinics are a new frontier for palliative care," providing continuity of care and filling a gap for patients who are not eligible for hospice care. Byock, Twohig, Merriman, and Collins (2006) reviewed several demonstration projects funded by the Robert Wood Johnson Foundation under the Promoting Excellence in End-of-Life Care Project. The goal of the demonstration projects was to integrate palliative care into existing clinical settings. Several projects provided programs in the outpatient setting. Meier and Beresford (2008) concluded that "expanding availability and access to palliative services for patients with progressive, life-limiting illness can improve quality of care"

and "prevent or manage crises that would otherwise require hospitalization" (p. 145). Although cost of care in the last months of a patient's life remained high, cost of care in the projects did not increase, and some showed moderate reduction in total healthcare costs.

Palliative Care Clinic

At the University of Virginia (UVA), the palliative care clinic is part of the UVA Cancer Center. The clinic began seeing patients in 2001 as an extension of the inpatient consult service. The program was championed by a palliative care physician and quickly gained the support of the cancer center's administration, oncologists, and oncology nurses. The palliative care clinic follows patients recently discharged from the hospital and welcomes referrals from oncologists and other physicians. Nurses from various settings frequently make recommendations for referrals to the clinic.

The palliative care clinic is available for symptom management for patients with any stage of cancer, HIV or AIDS, and other life-limiting illnesses. The clinic uses an interdisciplinary team approach to care; team members include physicians, nurses, social workers, a psychologist, a chaplain, a nutritionist, and a massage therapist. A music therapist has been added to the cancer center, and volunteers are available. In addition, pharmacists are available to the team.

Services are provided in the UVA Cancer Center by the existing ancillary staff. Palliative care physicians rotate one week in the clinic and the other week on the inpatient consult service. The nurse is in the clinic full-time. The physicians and nurse collaborate and are the key providers of care, with prompt access to the other team members. The team initiates symptom management care plans that are individualized to each patient's specific needs. Patients are seen by the nurse and physician during scheduled appointments. A primary role of the nurse is to reconcile current medications and assess and evaluate the effectiveness of interventions while monitoring for adverse effects. Patients receiving palliative care require frequent medication adjustments, and much time is spent on education to ensure that patients and their families understand the care plan. Thorough documentation is vital for interdisciplinary communication. A palliative care physician is available 24 hours a day, seven days a week for patient issues or concerns. The nurse is the primary contact for patients during business hours.

The authors queried a locally developed clinical data warehouse, the UVA Clinical Data Repository, to examine use of the palliative care clinic since its inception and to characterize patients who have received care at the clinic and the specific types of symptoms addressed. Repository data were available through the end of 2008. The authors measured cancer prevalence by identifying any cancer diagnosis (identified with clinical classification codes available from the Agency for Healthcare Research and Quality) that was coded for a patient anywhere at UVA before his or her initial visit at the clinic. To characterize the symptoms managed within the clinic, the authors limited diagnoses to those coded at clinic visits and grouped them into categories for reporting purposes.

The palliative care clinic has grown steadily since its inception in the summer of 2006. The clinic initially provided one session

per week. Figure 1 shows the number of visits per calendar year from 2001–2008. About 200 new patients are seen each year. A total of 1,633 patients have received care to date, and most (n = 1,318, 81%) have a cancer diagnosis. Table 1 shows the distribution of the most common malignancies. Eighty-nine (6%) patients have a diagnosis of HIV or AIDS. With the availability of improved antiretroviral therapies, patients with HIV now are living with a chronic illness. The authors chose to follow patients with HIV in the clinic because of their complex symptoms, including neuropathic pain and psychosocial issues. The clinic also sees patients with congestive heart failure, chronic lung disease, and end-stage kidney failure.

Table 2 lists the most common symptoms managed during clinic visits. Of 8,538 total clinic visits, the most commonly coded diagnoses were pain (61%), fatigue (13%), nausea and vomiting (11%), depression (10%), and weight loss (7%). Other common symptoms addressed in the palliative care clinic include constipation, anxiety, insomnia, edema, dyspnea, and ascites. The following case studies demonstrate the efficacy of care provided in the clinic.

Case Study 1

Mr. S, a 48-year-old patient with squamous cell carcinoma of the tonsil, was referred to the palliative care clinic by staff in the radiation oncology department, where he was receiving radiation therapy. On a numeric scale from 0–10, with higher scores indicating greater pain, Mr. S rated his throat pain as a 10. He and his wife were concerned about weight loss associated with dysphagia and odynophagia, which severely compromised his ability to eat. Mr. S declined a feeding tube. He also had severe depression. An active member in his community, Mr. S was unable to work because of the disabling side effects of treatment. Mr. S was given methadone for long acting pain control with hydromorphone for breakthrough pain. He also was given lorazepam prior to meals to reduce anxiety related to anticipatory pain associated with oral intake. The clinic nurse provided close telephone follow-up with Mr. S and his wife to titrate methadone for effective pain management. He also was seen weekly in the clinic. With improved pain control, Mr. S was able to tolerate four cans of liquid supplement daily, and his weight stabilized. His depression was treated with an antidepressant, and within

Table 1. Common Cancers Among Clinic Patients

CANCER TYPE	n	%
Gastrointestinal	429	33
Lung or respiratory	311	24
Gynecologic	241	18
Head and neck	212	16
Breast	191	15
Brain	130	10
N = 1,318		

a month he was able to resume work on a part-time basis. Mr. S completed his radiation treatment and surgical resection. To date, Mr. S is cancer free. He has weaned off all pain medications and anxiolytics but remains on an antidepressant, which his primary care physician now manages. Mr. S's case study demonstrates the importance of aggressive symptom management during treatment.

Case Study 2

Mrs. H, a 93-year-old patient with bladder cancer, was referred by the radiation oncology team for management of nausea, anorexia, and weight loss. Mrs. H was assessed by the palliative care team and was started on very low doses of metaclopramide and dexamethasone. Her symptoms improved significantly, her oral intake improved, and her weight stabilized. A bowel regimen for constipation also was prescribed. Mrs. H was able to complete her radiation treatment. Close contact was maintained with the patient's caregiver. Within six months, Mrs. H's cancer progressed and the palliative care team facilitated a transition to hospice care. The palliative care team continued to remain involved in Mrs. H's care. She died peacefully at home with her family present. This case study demonstrates the importance of symptom management as well as remaining involved with the patient and family and facilitating the transition to hospice care.

Case Study 3

Mrs. C, a 49-year-old patient with metastatic breast cancer, was referred to palliative care by her oncologist. She began seeing the palliative care clinic team for pain control related to left breast tumor burden and back pain. Initially, her pain was controlled easily with oxycodone ER (extended release) and immediate-release oxycodone for breakthrough pain. Mrs. C remained stable on the regimen for a year. However, when her disease progressed, her symptoms intensified. Mrs. C developed complications of a right upper extremity thrombosis and lymphedema, and her pain intensified. She was closely followed for opioid rotation to methadone, which was effective. As Mrs. C's disease progressed further, the palliative care team remained closely involved, focusing on goals of care and symptom management. Eventually, Mrs. C was hospitalized in the palliative care unit for severe dyspnea. Mrs. C's pain and dyspnea were managed with IV dilaudid via a patient-controlled analgesia device. She was discharged to home with hospice care and later transferred to a local hospice house, where she died peacefully with her family present. Through all of Mrs. C's transitions, palliative care remained an integral part

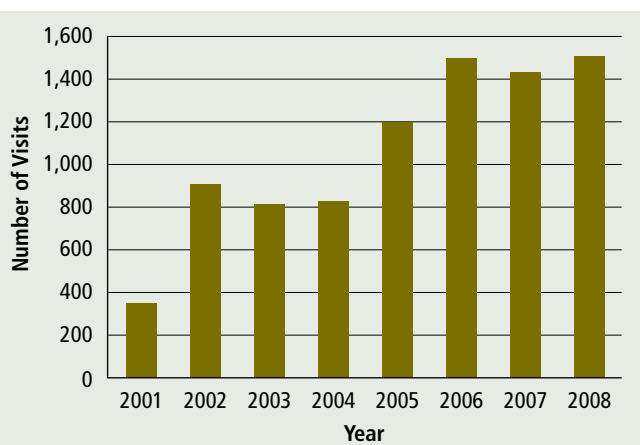


Figure 1. Clinic Visits by Year

Table 2. Most Common Symptoms Managed During Clinic Visits

SYMPTOM	n	%
Pain	5,245	61
Fatigue	1,088	13
Nausea and vomiting	946	11
Depression	848	10
Weight loss or anorexia	610	7
Constipation	519	6
Anxiety	515	6
Neuropathy	243	3
Gastroesophageal reflux disease or reflux	156	2
Insomnia	153	2
Substance or tobacco abuse	150	2
Edema	125	2
Dyspnea	102	1
Ascites	83	1
Diarrhea	69	1
Thrush	57	1

N = 8,538

of her care. This case study exemplifies attention to symptom management and continuity of care.

Case Study 4

Mrs. J, a 32-year-old patient with AIDS, was referred to palliative care for management of pain, nausea and vomiting, and depression. Prior to her initial clinic visit, Mrs. J's viral load was 350,000 copies/ml and her CD4 count was 2 cells/mcl. Mrs. J was unable to take her antiretroviral regimen because of severe nausea. Her compliance with prophylactic therapies for opportunistic infections also was compromised. The palliative care team formulated a plan with Mrs. J and her husband that addressed pain, acute and anticipatory nausea and vomiting, and depression. Mrs. J responded well to these interventions. Six months later, her viral load is undetectable and her CD4 count is 733 cells/mcl. Her functional status and quality of life have significantly improved. This case study exemplifies the importance of managing symptoms to promote patient compliance with disease-modifying therapies.

Discussion

The palliative care team at the UVA Cancer Center is recognized as a resource in symptom management. Referrals are received from all oncologists, including those in radiation oncology and neuro-oncology. Other referral sources include otolaryngology, infectious disease, renal, cardiology, pulmonary, neurology, and gastroenterology. The palliative care clinic collaborates closely with the teams as well as with the chronic pain service, to which the clinic often refers patients for local injections, epidural injections, and consideration for intrathecal pumps when appropriate. The clinic staff also works closely with home care and hospice teams. Overall, the increase in demand for palliative care in the ambulatory setting has resulted in eight clinic sessions per week (three full days and two half days). One clinic day has been moved to the radiation oncology clinic, which has improved access to

care for patients receiving radiation therapy. The clinic also has begun seeing patients in the ambulatory amyotrophic lateral sclerosis clinic, using a consultative approach.

Much attention is given to patient follow-up. The palliative care nurse communicates with patients and families frequently via telephone to ensure that recommended interventions are effective for pain and symptom management without causing burdensome side effects. In discussion with the palliative care physician, medication dosages are adjusted frequently as needed. The clinic uses an obsessive titration approach to symptom management with frequent, small changes in dosing to prevent over- or undermedication. Timely and regular follow-up can ensure that a patient is relieved of suffering, and families are supported in this process.

Physicians in the palliative care clinic generate revenue for the program through patient billing. However, reimbursement does not cover the full cost of services provided. The physicians are part of the larger palliative care program that includes the inpatient consultation service, so the medical center subsidizes the physicians' salaries. The cancer center provides budgetary provisions for supporting the nurse. Ancillary staff also are provided by the cancer center. The cancer center and the medical center are committed to the palliative care program. Current economics are challenging, and staff continue to look for means to improve the palliative care clinic's self-sufficiency, such as potential options for billable nurse-practitioner services.

Palliative care is essential for patients with a life-threatening illness and their families. In an ambulatory setting, patients can receive timely, appropriate interventions for troubling symptoms, thus improving quality of life. Feedback from patients, families, oncologists, and other providers as well as from homecare and hospice staff has been overwhelmingly positive. The authors anticipate that the palliative care service will continue to grow. A goal is to extend clinic services to other ambulatory clinics within the UVA health system and to local long-term care facilities.

Additional research is warranted, particularly focusing on the use of palliative care services in the ambulatory setting and the effectiveness of interventions on symptom management. Poor symptom control may impact a patient's ability to participate in curative or disease-modifying therapies. Research is needed to validate this hypothesis and the effect of palliative care on survival. The benefits of early versus late referrals to palliative care also should be compared. Another area of research would be addressing advance directives and timely referrals to hospice care. Given current economic challenges, data to support the benefits of palliative care are crucial. Oncology nurses, with their attention to holistic care and quality of life, are encouraged to participate in these research agendas.

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