Building a Palliative Care Program at Your Community Cancer Center

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The development of multidisciplinary palliative care services offers community cancer centers the opportunity to:

- Improve their quality of care and patient satisfaction
- Provide better planning for end-of-life care
- Manage symptoms that impede the quality of life
- Control pain that does not respond easily to medication.

In addition, once they are established, palliative care programs can improve a cancer center's bottom line.

Although palliative care programs were developed primarily for patients with serious illnesses, any patient who is suffering from physical or emotional symptoms that impact quality of life can benefit from palliative care. Patients who work with a palliative care team receive services that are more consistent with their personal preferences. They are also more likely to have an end-of-life plan and more likely to die in the setting of their choice than those who do not receive this intervention.[1]

Palliative care is certainly appropriate for patients with cancer who are recognized as terminal, but the World Health Organization (WHO) states that "many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment." For instance, a young woman who has a suspicious breast mass should have treatment for her procedure-related pain and support to cope with her fears that she will die before her children grow up.

Palliative support becomes even more important as illness advances. Our medical system teaches us to diagnose and cure a patient's problem. We often do not ask ourselves what will happen if our treatments don't work; but patients and families are concerned about this possibility right from the beginning, even if they are afraid to ask the question.

Multidisciplinary palliative care teams are currently being established in medical centers around the United States. These teams provide support and symptom control for seriously ill patients with the goal of improving the quality of both living and dying. The palliative care philosophy acknowledges the emotional, social, and spiritual components of suffering as well as its purely physical elements. This holistic approach often alleviates distress and controls pain that has not responded to aggressive analgesic treatment or other interventional techniques.

A Palliative Care Team Model

Palliative care is provided by a consulting team or in a specialized unit that has interdisciplinary care. Many hospitals have chosen to create a team that can see patients throughout the institution or in the outpatient setting. Inpatient palliative care units, when available, often do not serve all the patients seen by an outpatient team.

A palliative care team works with both primary care and specialist physicians and typically includes a doctor, nurse, social worker, and chaplain, all with palliative care expertise. The team may also include a pharmacist, psychologist, dietitian, physical or occupational therapist, case manager, or a music or art therapist.

This interdisciplinary approach is critical to the success of the palliative care concept because the wide variety of suffering experienced by patients and their families requires a broad range of skills. In some patients, financial concerns may be causing the greatest impairment in quality of life, while others may be experiencing a crisis of meaning.

A palliative care consult includes a formal assessment of the patient's pain, including an evaluation of emotional or spiritual issues, financial and practical concerns, and family stressors that may be contributing to the patient's discomfort.

Palliative care providers often see patients whose pain is resistant to appropriate medications. In many cases, spiritual crises or family conflicts exist that make the pain more unbearable. While spiritual and emotional suffering are difficult to treat and require more time, pain control often depends on attention to these elements.

Unfortunately, pain symptoms are often not recognized or addressed by oncologists and other physicians. Studies have found that about 50 percent of terminally ill patients continue to experience moderate to severe pain when under a doctor's care.[2]

Physicians are usually not trained to deal with such a broad range of concerns. Western medical practitioners are taught to "fix" the medical problem, but much of the suffering experienced by patients with life-threatening illnesses is not fixable by medical means. In his book, *A Place for Healing,* Michael Kearney, M.D., states that only about half of a patient's experience of illness is responsive to scientific medical interventions.[3]

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The role of the palliative care team is to achieve control of the physical symptoms so patients feel comfortable and can find their own answers about the causes and meaning of their suffering. Administering chemotherapy that has little chance of prolonging a patient's life (and no chance of cure) does not adequately address a patient's fear of dying. This symptom is more effectively treated by helping a patient face these fears in a supportive environment.

The palliative care team focuses its efforts on the problems the patient finds most distressing, and makes patient and family education a priority. Barriers to appropriate treatment, such as misconceptions about pain medications, the availability of medications at community pharmacies, and the affordability of treatment can be addressed. The palliative care team also ensures continuity of care when the patient is discharged, which minimizes readmissions.

The Hospice Model

Hospice is the best-developed model of palliative care in the U.S. Founded by Cicely Saunders, who was trained as a nurse, medical social worker, and physician, the modern hospice movement defined total pain as having

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The Providence Health Experience

In 2000 Providence Health owned three community hospitals in the metropolitan Kansas City area. Hospital administrators at each of the three institutions decided to establish a palliative care program together to provide better services for dying patients and their families. Their goal was to develop a program that would help patients and their families set care goals, provide support for the families of ill patients, and coordinate discharge planning.

Their first step was to create a palliative care consult team that consisted of a part-time palliative medicine physician and a full-time advance practice nurse. The doctor and nurse traveled to all three hospitals and provided on-site training to social workers and chaplains, who then became palliative care team members.

In the first year of service, the palliative care team saw 200 patients. Even though one of the hospitals has closed, leaving only 240 inpatient beds in the system, the team continued to increase its volume of consults and saw 407 patients and families in its second year. A second full-time advance practice nurse was hired, and a half-time social worker is now assigned to the team.

The nurse and physician perform an initial assessment and treat symptoms, and an hour-long patient/family conference is planned within 48 hours (usually within 24 hours). The conference is often the first opportunity patients and their families have to assess the patient's medical condition, select options for future treatment, and look at potential outcomes together. Attending physicians are invited to these conferences, but they are generally unable to attend and the palliative care physician or nurse leads the discussion.

The leaders begin by asking the patient and the family members what they have been told about the patient's condition. The team addresses misconceptions and offers information to increase the family's understanding of the patient's condition and options. Equally important, the team seeks to learn the patient's and family's hopes, goals, fears, and concerns. Patients who are not able to face their prognosis are often dealing with emotions such as anger, or fear, or questions of meaning.

Despite these emotionally charged topics of discussion, patients and families have almost uniformly expressed gratitude for the meetings. Participants are relieved to understand their options more clearly, to know what issues they are facing, and to identify ways to cope.

Some patients and families have good reasons to believe that curative care is still indicated, and the palliative care team will help them speak to their attending physicians about these possibilities. Palliative care teams do not take hope away from patients and families, but gently encourage them to look at the big picture (including functional status and quality of life) and to consider options in case the hoped-for miracle does not occur.

The most common physical symptom (77 percent of patients) treated by our palliative care consult service is pain. In most cases, the patient's pain can be relieved by more aggressive doses of analgesics and the addition of adjuvant treatment for nerve or bone pain. During one recent quarter for which statistics were gathered, 100 percent of our patients who were able to rank their pain reported pain levels below 4 on a scale of 10 within 48 hours of the palliative care consultation.

The team also helps patients deal with the emotional and spiritual sources of their pain, and facilitates discharge care by 1) reviewing nursing home or hospice transfer orders, 2) ensuring that prescriptions are available to send to the pharmacy, and 3) identifying how the prescriptions will be covered financially.

Patients who are aware that they will have support and care even when curative approaches are exhausted feel more secure and are able to make end-of-life choices that fit their own values and goals. OI

Sarah Walters, R.N., A.R.N.P., palliative care practitioner (left) and Pat Dalrymple, R.N., M.S.N., palliative care coordinator, play an integral role in providing information to patients receiving palliative care at Providence Health hospitals (Providence Medical Center in Kansas City, Kan., and Saint John Hospital, Leavenworth, Kan.).

Dalrymple speaks with Walter Jackson, a former patient at Providence Medical Center who received palliative care.

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physical, emotional, social, and spiritual components. Currently, hospice is not available for hospitalized patients or for patients whose illness is not terminal.

Another limitation of hospice is that patients who are admitted to home care hospice often have minimal contact with physicians after hospice admission. While nurse-led teams function very effectively for most patients, patients with complex symptoms would benefit from more active physician involvement. Many terminal patients and their families also want advice from physicians as they consider their options for future care.

In general, patients cannot obtain counseling to help them deal with or accept their terminal illness until they enter hospice, but they are not allowed to enter hospice until they acknowledge that their illness is terminal. A palliative care team can work with patients and their families earlier in the course of the patient's illness and help them recognize when the time has come to change from primarily curative to primarily palliative care.

The Financial Impact

Proposals for palliative care programs are often greeted with skepticism from hospital administrators who say that such programs must prove they are cost effective. Growing evidence suggests that palliative care services improve patient satisfaction and quality of life without reducing survival, and at a lower cost than traditional care.

Providence Medical Center in Kansas City noticed a 50 percent reduction in the use of ancillary services (i.e., the clinical laboratory, the pharmacy, and the radiology unit) per day after the palliative care team was consulted (unpublished data). More importantly, patients and families did not believe that they were receiving fewer services, and their satisfaction levels remained very high.

Other palliative care programs have produced even greater reductions in the cost of care while keeping the quality of services high. The palliative care team at Virginia Commonwealth University Hospital, for example, reduced outpatient ancillary charges by 74 percent, and the overall charges for patients treated on the palliative care unit decreased by 66 percent.[4] Northwestern University Medical Center reported a daily care cost of $1,191 on their palliative care unit compared to $1,985 per day on the oncology unit.[5]

Most managed care companies are willing to pay for palliative care services,[6] perhaps because of the cost-savings produced by palliative programs. While Medicare covers 100 percent of hospice services for patients who elect the hospice benefit, palliative care services receive no special payment under Medicare.

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References

[1] Skalla KA, Dragnev K, Stevens M, et al. Identification and intervention at diagnosis of metastatic cancer: An effective model for outpatient palliative care. Abstract of the American Society of Clinical Oncology 38th Annual Meeting; May 19-21, 2002; Orlando, Fla.

[2] Weiss SC, Emanuel LL, Fairclough DL, et al. Understanding the experience of pain in terminally ill patients. *Lancet*. April 28, 2001;357:1311-1315.

[3] Kearney M. Beyond the medical model. *A Place of Healing*. New York, NY: Oxford University Press; 2000:3-6.

[4] Payne SK, Smith TJ, Coyne P, et al. A High Volume Specialist Palliative Care Unit and Team Reduces End-of-Life Costs. In: Program and Abstracts of the ASCO 37th Annual Meeting; May 12-15, 2001, San Francisco, Calif. Abstract No.1556.

[5] Muir JC, Paice JA, McKay A, et al. Quality Cancer Care at the End of Life: The Role of a Hospital-based Palliative Care Service. In: Program and Abstract of the ASCO 37th Annual Meeting; May 12-15, 2001, San Francisco, Calif. Abstract No. 1557.

[6] Brumley RD. Future of End-of-Life Care: The Managed Care Organization Perspective. *J Palliative Care*. April 2002;5:263-270.