



Palliative Care *for the Chronically Ill*

Palliative care has evolved as a subspecialty of medicine that helps patients and their families improve quality of life.

By Abbie Cornett

PALLIATIVE CARE IS A TERM often used interchangeably and incorrectly as a word for hospice. Palliative care and hospice care do bear some similarities. They use the same multidisciplinary approach and share the similar goal of making patients more comfortable by looking for ways to alleviate symptoms and manage pain.¹ Both also use a team approach to improve the quality of lives of patients and their families² using specially trained doctors, psychologists, nurses, social workers, massage therapists, pharmacists, nutritionists, chaplains and other health-care professionals.

What is different about hospice and palliative care in the U.S. is the time when patients utilize them. Hospice care is sought when all medical treatments have been exhausted or when patients wish no more extreme measures be taken to extend their lives. The goal of hospice is to ease patients' suffering with no curative intent. To receive benefits under Medicare for hospice services, a patient's hospice doctor and his or her regular physician must certify that the patient is terminally ill and has less than six months life-expectancy.³

Palliative care, on the other hand, is meant to relieve suffering and provide support in combination with curative treatments. The main goals of palliative care are "symptom management; establishing goals of care that are in keeping with the patient's values and preferences; consistent and sustained communication between the patient and all those involved in his or her care; psychosocial, spiritual and practical support to both patients and their family caregivers; and coordination across sites of care."⁴

Palliative care is designed for patients of all ages and their families who have been diagnosed with a chronic or life-threatening illness at any stage of disease.⁵ Palliative care patients fall into three categories. The first includes patients who have been diagnosed with a curable disease such as some types of cancers.⁶ The second is comprised of patients who have been diagnosed with a chronic illness such as common variable immunodeficiency who will undergo treatment throughout their lives. And, the third is devoted to those who have a progressive illness such as multiple sclerosis.

According to Marcia Penido, LCSW, MPH, ACM, director of care coordination at Huntington Hospital in Pasadena, Calif., "The goal of a hospital's multidisciplinary team is to maximize the quality of life for both the patients and their loved ones." At Huntington Hospital, their approach is to 1) relieve pain, symptoms and stress caused by serious illness; 2) provide care in hospital and outpatient clinical settings; and 3) offer consulting after diagnosis of a serious, progressive illness.

History of Palliative Care

Palliative care is not new. Its origins go as far back as medieval times when the terms *hospice* (derived from the root word *hospitality*) and *palliative* (derived from the Latin root word *palliare*, to cloak)¹ were used to describe rest for weary travelers. The first modern concept of hospice care can be traced back to work performed in 1948 by Dame Cicely Saunders who created St. Christopher's Hospice.⁷ But, in the past, the practice of medicine focused on curing disease with little discussion about quality of life for patients or their loved ones. In fact, much of the medical community viewed treatments such as morphine with suspicion, fearing the unintended consequence of treatments not meant to be curative.¹

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It wasn't until 2006 that palliative care was recognized as a subspecialty of internal medicine. Today, palliative care is looked at in a much different light, with the medical community embracing the idea of treating the whole patient, not just the illness. This requires taking a whole new look at the patient-physician relationship. When patients enter a palliative care program, they and their families become partners with the palliative care team. The team works together to explore options of treatment and manage any symptoms such as pain that patients may be experiencing. The team's goal is to improve the lives of patients by reducing their suffering and to offer support for their families.

Who Should Consider Palliative Care?

Palliative care should be considered for any patient who has been diagnosed with a life-threatening disease or chronic illness.

In fact, the American Academy of Hospice and Palliative Medicine recommends physicians “don’t delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.”⁸

IT’S BEEN SHOWN THAT PATIENTS WHO REDUCE THEIR STRESS AND SUFFERING ALONGSIDE STANDARD CARE LIVE LONGER.

It should be noted, however, that palliative care for adults and children differs. As the organization Get Palliative Care explains, “Children are not simply little adults.” Because of their unique anatomy and physiology, and because they are growing during the course of their illness, disease doesn’t necessarily progress the same way in a child as it does in an adult. As such, they need care that is individualized to them.⁹ The World Health Organization outlines specific principles to follow that are the same for adults but that also take into account the special needs of children and their families.¹⁰

Palliative care for the chronically ill makes sense for two main reasons. The first is that patients and their families in palliative care programs have a greater quality of life and demonstrate better outcomes. It’s been shown that patients who reduce their stress and suffering alongside standard care live longer. And, it’s been proven that if patients have untreated side effects such as nausea, pain and depression, the chances of them dying from complication increases.¹¹

A second reason palliative care makes sense is from a financial perspective. The cost of treating patients who receive palliative care during hospitalization is significantly less. In a 2008 study, researchers found that palliative care patients discharged alive had an adjusted net savings of \$1,696 in direct costs per admission and \$279 in direct costs per day; palliative care patients who died in the hospital had an adjusted net savings of \$4,908 in direct costs per admission and \$374 in direct costs per day.¹² Another study, which analyzed data from 38,475 inpatient stays

for people 18 or older hospitalized for seven to 30 days between January 2009 and June 2012, found that “among patients who died in the hospital, there was a significant cost savings from palliative care of \$3,426 per inpatient stay.” This was especially true for those who received palliative care within the first 10 days of hospitalization.¹³

Accessing Palliative Care

The number of palliative care programs has grown rapidly in recent years, although it has not kept up with need. According to the National Palliative Care Research Center’s 2015 State-by-State Report Card, an annual report that tracks the growth of hospital palliative care programs across the 50 states and identifies areas where persistent gaps in access remain, “access to palliative care remains inadequate for millions of Americans living with serious illness despite continuing growth in the number of U.S. hospitals reporting palliative care programs.” While, currently, 88 percent of hospitals report they have some type of program in place, one-third of hospitals report no palliative care services of any kind. And, although access to palliative care in community settings (home, nursing home, assisted living) is available in some areas, it is limited for people who are not hospice-eligible (actively dying).¹⁴

To locate a palliative care program, patients should consult their treating physician for a referral. However, if a physician is unaware of a program, there are three national resources to assist in locating one, including Get Palliative Care (getpalliativecare.org), Palliative Doctors (palliativedoctors.org) and the National Hospice and Palliative Care Organization (www.nhpco.org).¹⁵

Unlike in the past, most private insurance policies now cover palliative care. The care team, an additional level of support included in a palliative care program, can help patients understand what is covered. In addition, Medicare and Medicaid cover palliative care services in the hospital, in rehabilitation settings and in skilled nursing or hospice facilities. While Medicare and Medicaid don’t use the word “palliative,” the services are the same.¹⁶ However, where patients access palliative care under Medicare is different, and what services are available depends on whether they have Medicare Part A or B. What is covered by Medicaid also differs depending on the program.

Maximizing Quality of Life

Palliative care programs provide patients with a team of healthcare professionals whose goals for care are in accordance with theirs and their families. These programs offer a standard of care for all chronically ill patients to support them and their

families while focusing on symptom relief and comfort. According to studies, patients who receive palliative care “have improved quality of life with less depression and symptom burden; feel more in control; are able to avoid risks associated with treatment and hospitalization; and have decreased costs with improved utilization of healthcare resources.” And, caregivers, family and friends report “greater satisfaction with the quality of care and attention to caregiver needs.”¹⁷ “The most important outcomes of palliative care are that the patient’s quality of life is maximized and they receive the medically appropriate level of care that they want,” says Huntington’s Penido. ■

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Resources

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