





Palliative Care: What and Why

BY MARK CRAWFORD

It occurs far too often in today's health care system — people who are in pain and suffering do not get the relief they need from physical, emotional and spiritual distress. During this time of extreme vulnerability, both patients and families need the support provided by palliative care teams to keep them informed, manage pain, ensure continuity of care and meet their spiritual needs.

"It's well established that patients, families and caregivers benefit from this attention to body, mind and spirit. Still, less than 60 percent of hospitals have palliative care programs," said the Supportive Care Coalition's board of directors in a June 2010 case statement. Composed of 19 Catholic health organizations, the group promotes palliative and end-of-life care and is headquartered at Providence Health & Services in Portland, Ore.

WHAT EXACTLY IS PALLIATIVE CARE?

According to the Catholic CEO Healthcare Connection's Clinical Quality Leadership Forum, a palliative care program is a model of care for patients with chronic medical or life-limiting illnesses, delivered by a multidisciplinary team including doctors and nurses, social workers, pharmacists, ministers and volunteers.

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care that identifies and addresses the physical, psychological, spiritual and practical burdens of illness. "It expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members," said Indu Spugnardi, director, advocacy and resource development, for the Catholic

Health Association in Washington, D.C.

Palliative care can be applied early in the course of illness or with later-stage therapies that are intended to prolong life. Vigorous pain management and symptom control are integrated into all stages of treatment.

"Such care is appropriate to those suffering with cancer, heart conditions, liver failure, renal failure, Alzheimer's disease, spinal cord injuries and a number of other conditions," continued Spugnardi. "The palliative care team collaborates with professional and informal caregivers in each of these settings to ensure coordination, communication and continuity of care across institutional and home care settings."

"Knowing what their treatment options are, including the pros and cons of each treatment, helps patients make the best decisions," said Lois Lane, director of ethics for Catholic Health Initiatives, Englewood, Colo. "Palliative care is about respecting individuals, the people that care about them and re-establishing control in a situation where much, if not all, of their control is stripped away."

HOW IT DIFFERS FROM HOSPICE

Hospice care focuses on quality of life for people

who are terminally ill and generally have a life expectancy of six months or less. In addition, most people who seek hospice services do not pursue aggressive curative treatments.

In contrast, palliative care services provide comfort, control of pain and other symptoms, communication and coordination of care for anyone with a serious, chronic or life-limiting illness regardless of prognosis. Patients can receive palliative care at the same time they receive medical treatment aimed at a cure or to prolong life. It is appropriate for all patients who need it, whether they live for years or a matter of days.

“I think the most misunderstood aspect of palliative care is that health care providers and patients and families often believe that palliative care is hospice care,” Lane stressed. “Often physicians will not consult palliative care because they believe that curative treatments must stop if palliative care is consulted.”

This, however, is not the case. “As demonstrated in the *New England Journal of Medicine* [article “Early Palliative Care for Patients with Metastatic Non Small-Cell Lung Cancer,” by Jennifer S. Temel et al., Aug. 19, 2010], when palliative care was included in the interdisciplinary treatment of patients with metastatic small-cell lung cancer, their symptom burden and depression levels were significantly reduced,” said Lane. “Patients who received early palliative care had less aggressive care at the end of life and lived an average of three months longer than those who received standard care [alone].” (See related story on Page 16).

AN EVOLVING DEFINITION

In 2007 the National Consensus Project for Quality Palliative Care convened a nationwide consensus process to develop clinical practice guidelines

PALLIATIVE CARE RESOURCES

Supportive Care Coalition

www.supportivecarecoalition.org

National Consensus Project for Quality Palliative Care

www.nationalconsensusproject.org

Center to Advance Palliative Care

www.capc.org

Get Palliative Care

www.getpalliativecare.org

National Palliative Care Research Center

www.npcrc.org

National Hospice and Palliative Care Organization

www.nhpco.org

for palliative care. These guidelines were the basis of the National Quality Forum’s *A National Framework for Palliative and Hospice Care Quality Measurement and Reporting*.

“These latest guidelines have been adopted by most programs as the preferred way to deliver robust palliative care to patients and families,” said Sarah E. Hetue Hill, program coordinator for Ascension Health’s Palliative Care Initiative. “Eight domains are covered: structure and processes of care, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, spiritual, religious and existential aspects of care, cultural aspects of care, care of the imminently dying patient and ethical and legal aspects of care.”

The National Quality Forum document also provides a framework for improving palliative and hospice care and creating comprehensive quality measurement and reporting for both palliative care and hospice. It recommends 38 preferred practices for implementing pallia-

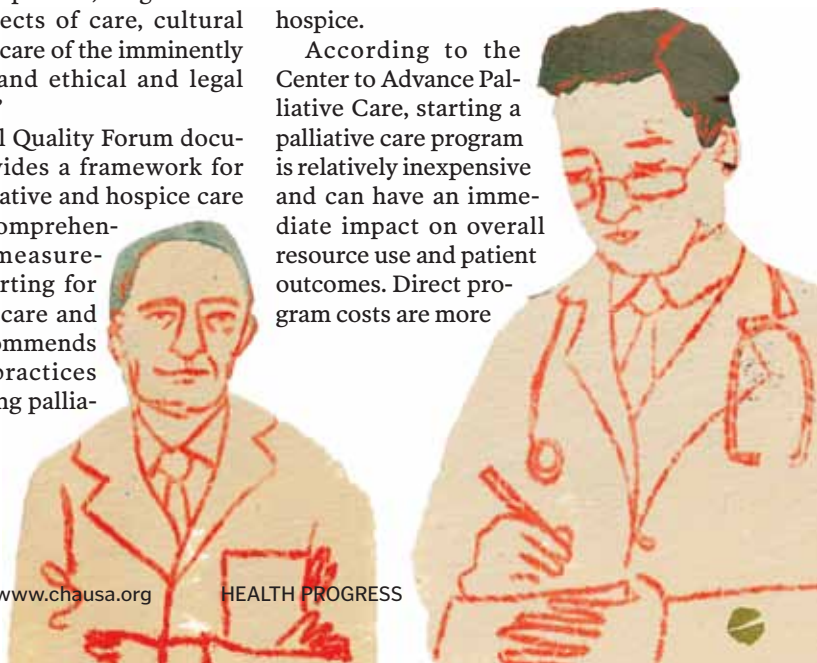
tive care and suggests a large number of research topics for each domain, including developing better performance measures, improving the delivery and financing of palliative care and learning more about the epidemiology of death and dying.

Organizations such as the Center to Advance Palliative Care, the National Quality Forum and the National Consensus Project for Quality Palliative Care continue to work on defining more specific metrics for the field of palliative care. “Research is a high priority for palliative care advocates because while the field of palliative care is growing fast, the evidence base that supports palliative care is inadequate to guide quality of care,” commented Spugnardi. “Advocates call for more federal funding of palliative care, specifically in the areas of pain and symptom management, communication skills, care coordination and models of care delivery.” (See related story on Page 46).

HIGH QUALITY, LOWER COST

As hospital operating margins shrink, palliative care helps maximize the use of limited resources, which translates into financial savings. Palliative care programs consistently demonstrate improved patient/family satisfaction, lower re-admission rates, reduced hospital costs per day and per hospitalization and earlier referrals to hospice.

According to the Center to Advance Palliative Care, starting a palliative care program is relatively inexpensive and can have an immediate impact on overall resource use and patient outcomes. Direct program costs are more





than offset by improved hospital efficiencies, allowing more people to be treated more effectively.

Patients are transitioned to appropriate levels of care, which often reduces their length of stay, especially in the intensive care unit. Hospitals often can reduce costs for redundant, unnecessary or ineffective tests and treatments. Thus an overall high quality of care can be maintained while increasing capacity and reducing costs through shorter lengths of stay and lower ancillary and pharmacy costs. In one study, the Center to Advance Palliative Care reported hospitals saved \$1,700 to \$4,900 on each admission of a palliative care patient. Annual savings related to reductions in pharmacy, laboratory and intensive care costs totaled more than \$1.3 million for a 300-bed community hospital and \$2.5 million for a typical academic medical center.

“Successful palliative care programs have used an array of delivery systems from consultative services to inpatient units, decreasing the length of hospital stays and easing patient transitions between care settings,” said Hetue Hill. “This results in increased patient and family satisfaction and compliance with hospital care quality standards.”

MOVING FORWARD

The Supportive Care Coalition is committed to improving quality and identifying measures that demonstrate the intrinsic link between palliative care and the Catholic mission. “As a coalition we promote excellence in palliative care, embracing a bio-psycho-social-spiritual model of care that attends to the needs of the whole person,” said Tina Picchi, executive director for the Supportive Care Coalition.

“Preserving human dignity and respect is an intrinsic part of our mission,” added Lane. “Palliative care gives

back some of the control that the disease takes away from patients. In order to maximize the length of life, and the quality of that life, however, palliative care must be initiated early.”

A key goal is establishing palliative care in hospitals and communities that are currently without these vital services. The need for palliative care in the U.S. also can be met through ongoing health-professional education in palliative care principles and practice. “The current culture of medicine views death as a failure rather than a natural part of life, said Spugnardi. This view can lead physicians to defer recommending palliative care for patients who would benefit from this care because they feel that they are failing the patient by not pursuing every possible cure.”

Other ways to boost awareness are improved access to palliative care specialists in hospitals, nursing homes and home care, promoting timely access to hospice services to all eligible patients, creatively integrating hospice and palliative care programs across treatment settings and defining appropriate

accountability and performance measures for palliative care services.

“Palliative care respects the values and goals of individuals, their families and other loved ones,” said Hetue Hill. “It will assist them to live fully in community, optimize function, facilitate goals and decision-making, provide opportunities for personal growth and healing and support families, other survivors and communities in their bereavement.”

As such, said the Supportive Care Coalition’s board of directors in their case statement, “palliative care must be an integral part of health care reform implementation in our country. The imperative to improve quality, access and value is undisputed. Making palliative care a national priority will reduce harm, reduce disparities and reduce waste. It represents what the future requires: comprehensive, holistic, patient- and family-centered care.”

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WORLD HEALTH ORGANIZATION DEFINITION OF PALLIATIVE CARE

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends to neither hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness and in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy

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