Increased Patient Satisfaction, More Hospice Use Found with Patient-Centered Management

Complex-Care Team Approach Reduces Costs, Improves Quality of Life Without Shortening Life

The use of intensive patient-centered management (PCM) for managed care patients with life-limiting diagnosis and multiple comorbid conditions (“complex patients”) can sharply reduce costs and utilization while increasing patient satisfaction. PCM also improves reported quality of life with no adverse effects on survival, a recent study has shown.

“Patient-centered management is an emerging, comprehensive patient-focused collaboration that includes end-of-life and pain management, education, provider coordination, and patient advocacy,” write the authors of a report published in *The American Journal of Managed Care*.

Researchers examined the effect of PCM on utilization and patient outcomes in a cohort study of 756 complex patients (cancer diagnosis, 75%) covered by a large health maintenance organization in California from February 2003 through December 2004.

In addition to the traditional case management received by the control cohort, those in the PCM group received:
- Patient education
- Home visits
- Frequent contact
- Goal-oriented care plans

Each patient in the PCM cohort had a complex-care team, which included nurse care and team managers and an on-call physician to anticipate the patient’s medical problems, provide the team with medical care information, and offer clarifications and suggestions in support of care plans provided by the treating physician.

Compared with patients in the control group, PCM patients had:
- 62% more hospice days
- 38% fewer inpatient admissions
- 36% fewer inpatient hospital days
- 30% fewer emergency room visits
- 22% more home care days

— Sweeney, et al, *The American Journal of Managed Care*

Key findings include:
- Overall costs were reduced by 26%.
- Proportions of decedents across cohorts were statistically similar: 26% of PCM

Greater Support of Spiritual Needs Strongly Linked to Improved Quality of Life

Although the vast majority (88%) of terminally ill cancer patients view religion and/or spirituality as personally important, many feel that their needs for spiritual support are not being addressed by their faith community or in their medical care, according to a recent report published in the *Journal of Clinical Oncology*.

“Our study showed that support of patients’ spiritual needs was associated with an important clinical outcome — improved quality of life,” write lead author Tracy A. Balboni, MD, of the Harvard Radiation Oncology Program, and colleagues. Yet, “many advanced cancer patients do not have support from a religious community or from the medical system at a particularly vulnerable period of their illness trajectory.”

Investigators analyzed interview responses of 230 patients (mean age, 56.8 years; nonwhite race/ethnicity, 39%) with diagnosis of advanced cancer (expected
Increased Patient Satisfaction, More Hospice Use Found with Patient-Centered Management

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patients died compared with 28% of usual management patients.

- 42% fewer oncology patients in the PCM cohort than in the control group received either chemotherapy or radiation.

“Given the reported death data, the ‘extra’ chemotherapy and radiation experienced by the usual case management cohort did not seem to produce any survival benefit,” comment the authors. “This result supports earlier findings that palliative end-of-life care planning is underused.”

As well, the authors add, “Prior work showed that patterns of hospice use by older Medicare beneficiaries were consistent with the system of care and not necessarily with appropriate need and preference, leading to underutilization.”

Patient education seems to have influenced not only patient choices and decision making, the authors note, but also patient behavior by encouraging a more proactive adherence to care plans. For example, PCM patients had fewer diagnoses indicative of uncoordinated care,” such as: nausea (44% reduction), anemia (33% reduction), and dehydration (17% reduction).

Results of a patient/family survey following case closure include:

- 78% of respondents were “extremely satisfied” with the PCM services, with only 3% reporting they were not satisfied.
- 98% considered PCM to be a useful service for very ill patients.
- 86% felt PCM had improved their quality of life or that of their loved one.


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Half of All Countries Lack Palliative Care Services

About one-half of the world’s 234 countries have no established system for hospice or palliative care provision, and 33% lack any known initiatives for developing the capacity to deliver such care. Further, in only 15% of countries (such as the U.S. and Canada) has palliative care achieved measurable integration with mainstream service providers.

That is according to a report entitled “Mapping Levels of Palliative Care Development: A Global View,” which was released in January 2007 by the International Observatory on End-of-Life Care (IOELC), located at Lancaster University, Lancaster, United Kingdom.

“Despite increasing international calls for high quality end-of-life care to be recognized as a human right, there is clearly a long way to go before it is within reach of most of the people in the world,” says lead author Michael Wright, PhD, senior research fellow at IOELC.

The authors point out opportunities for improving delivery of palliative care, which they note, “is still a young discipline.”

Challenges to formalized palliative care provision include:

- Low public awareness
- Lack of government commitment
- Unavailability of opioids
- Unfamiliarity with multidisciplinary team work
- Uncertainty about the relationship between palliative medicine and other specialties

“There are many barriers to service development; often palliative care is not regarded as a core healthcare service, which of course it is,” says Wright. “There can also be political or cultural opposition — for example, to the use of morphine — and factors associated with a country’s geography, population, and infrastructure can also throw up big challenges.”

The report was commissioned jointly by the National Hospice and Palliative Care Organization of the U.S. and Help the Hospices of the U.K.

The full report is available online at www.nhpco.org.
Greater Support of Spiritual Needs Strongly Linked to Improved Quality of Life

Key Findings Include:
- 88% of participants stated that religion/spirituality was important to them (very important, 68%; somewhat important, 20%).
- Spiritual support by the religious community or medical system was significantly associated with quality of life ($P = .0003$).
- 47% of patients reported minimal or no support of their spiritual needs by a religious community.
- 72% of respondents reported little to no support of spiritual needs by the medical system.

— Balboni, et al, Journal of Clinical Oncology

The George Washington University Institute for Spirituality and Health (GWish) maintains an online resource for promotion of a “more compassionate and integrated” system of health care through the recognition of the spiritual dimension of health and suffering.

The website (www.gwish.org) offers general recommendations for physicians taking a spiritual history, as well as internet links to relevant outside websites, pertinent publications, and references. FICA, the acronym for a physician spiritual assessment tool developed by GWish founder and director Christina M. Puchalski, MD, of the university’s school of medicine, is available online or can be ordered in pocket card format.

**FICA Spiritual Assessment Tool**

- **Faith, belief, meaning:** “Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? If not, what gives your life meaning?”
- **Community:** “Are you part of a spiritual or religious community? Is this of support to you, and how? Is there a group of people you really love or who are important to you?”
- **Address/Action in care:** “How would you like me, your health care provider, to address these issues in your health care?”

— Copyright 2006, Christina M. Puchalski, MD
Opioid Use Poses ‘Extremely Small Risk’ of Hastened Death in Hospice Patients

Survival among patients with advanced illness is affected by a complex interplay of variables, among which final opioid dose — but not percent of dose increase — was found to be a very weakly associated factor. That is according to the authors of a study published in the *Journal of Pain and Symptom Management*.

“Most clinicians understand the value of using opioids to relieve suffering at the end of life, but the fear of hastening the death of seriously ill persons contributes to unnecessary suffering,” says co-author Stephen Connor, PhD, president of research and international development for the National Hospice and Palliative Care Organization. “This study reassures clinicians that their effective use of opioids in the seriously ill will not hasten death and will lead to better quality care.”

The investigators examined the association between survival and opioid dosing characteristics and other variables among 725 hospice patients (mean age, 76.6 years; cancer diagnosis, 42%) who received opioid therapy with at least one dose change prior to death. The study group was divided into subsamples based on maximum daily opioid dose administered. Findings include:

- No significant relationship was found between high-dose opioid treatment and the interval between final dose change and death (mean number of days, 12.5; median, 5 days; range: 0 to 231 days).
- Shorter survival was associated with cancer diagnosis, higher opioid dose, and lack of consciousness, but none of these variables accounted for more than 10% of the variation in survival time.

“The implication that opioid dose poses an extremely small risk of hastened death in this population was supported further by the relatively long intervals between final dose change and death, and the lack of higher opioid risk in subsamples receiving high doses,” write lead author Russell K. Portenoy, MD, of Beth Israel Medical Center, New York City, and colleagues.

Much of the moral justification for aggressive opioid therapy in the literature on end-of-life care is based on the ethical principle of double effect, which assumes a substantial risk of hastened death due to the opioid, note the authors. Similarly, literature on physician-hastened death assumes that opioid toxicity is substantial and can be used to shorten life at the end of life.

“These assumptions contrast with the common clinical experience of specialists in pain management or palliative medicine, who typically use opioid drugs in whatever doses are needed to achieve analgesia, and rarely encounter a scenario consistent with a primary opioid-related death,” they state.

“In a hospice population, survival is influenced by complex factors, many of which may not be measurable. Based on these findings, concern about hastening death does not justify withholding opioid therapy,” the authors conclude.


Fewer Concerns with Physician Communication, Greater Use of Hospice Linked to Presence of ADs

Bereaved family members express fewer concerns regarding communication about medical decisions and report fewer unmet needs for information about the dying process when their loved ones have completed an advance directive (AD), reports a team of Rhode Island researchers in the *Journal of the American Geriatrics Society*.

The team analyzed survey responses gathered 9 to 15 months postdeath from relatives of a nationally representative sample of 1587 adults who died nontraumatic deaths in 2000. Nearly 71% of decedents had completed a written AD, a rate higher than reported in previous studies, the authors note.

Completion of an AD was associated with:
- Greater use of hospice
- Less likelihood of terminal hospitalization
- Less use of life-sustaining treatment during the last month of life
- Fewer concerns with physician communication

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Assessment and Palliative Treatment of Fatigue: A Clinical Approach

Physicians Can Lessen the Burden of Fatigue at the End of Life

The most common chronic symptom associated with cancer and other progressive diseases — fatigue — is also the one symptom most likely to diminish quality of life by interfering with physical and social activity, according to an article published in the Journal of the American Medical Association.

“For patients...who at the end of life wish to focus solely on interventions that may improve symptoms rather than underlying conditions, evaluation of common, potentially treatable causes of fatigue is appropriate,” write the authors, who are palliative care experts at the University of Texas M.D. Anderson Cancer Center, Houston.

Due to such challenges as the subjective, variable nature of fatigue, its assessment and treatment in patients near the end of life can be complex, the authors note. Their article offers a discussion of the prevalence and causes of fatigue, and an approach to its evaluation and management.

Challenges to management of fatigue include:
• Its subjective nature and variability in source, expression, and perception
• Its multidimensional character: fatigue often has multiple causes, with contributing physiological, psychological, and situational factors.
• An incomplete understanding of its pathophysiology
• A limited evidence base for treatment

“Treatment strategies for fatigue must be multidimensional and often require an interdisciplinary team,” the authors state. “When discovery of the specific sources for the cause is not possible, treating the symptoms should be the focus of care.”

The article includes a table of tools for initial assessment of fatigue and ongoing monitoring of symptoms in patients with cancer and other conditions. There is also a listing of suggested modalities for determining the causes of unexplained fatigue.

In addition, the authors provide a list of medications found to be useful for treating the symptom of fatigue when identifying the cause is not possible, as well as a summary of studies and clinical trials on the symptomatic treatment of cancer-related fatigue.

Quality of life is influenced by the gap between patients’ hopes and expectations and their actual experience, note the authors. Understanding this gap can help physicians lessen the burden of fatigue in patients at the end of life. For instance, patients can be encouraged to adjust their expectations by focusing on non-physical activities they enjoy. Other measures that may improve quality of life include physical therapy evaluation and orthotics, as well as the use of walkers and wheelchairs to improve function.

“In suggesting treatment, it is important for physicians to set specific goals regarding comfort, function, and cognition with the patient and family,” write the authors.

Further, they note that it is “essential” that physicians:
• Be available for continued access on short notice
• Conduct continuing assessment of symptoms
• Emphasize comfort and maximizing of function

“Excellent patient-physician communication, including expressive supportive therapy and empathic listening, is critical particularly at the end of life,” conclude the authors. “Finally, simply being present can provide patients and families great comfort, even with progressive illness and severe symptoms.”

The use of a communication strategy for discussing a change in treatment plan with relatives of patients dying in the intensive care unit (ICU) has been found to reduce symptoms of stress, anxiety, and depression among bereaved family members, report the authors of a study published in *The New England Journal of Medicine*.

As compared with customary end-of-life ICU conferences, the proactive strategy “resulted in longer meetings in which families had more opportunities to speak and to express emotions, felt more supported in making difficult decisions, experienced more relief from guilt, and were more likely to accept realistic goals of care,” write the authors.

Investigators conducted a randomized controlled trial of the effects of a proactive end-of-life communication strategy, using a system known by the mnemonic VALUE, which was developed by co-investigator Randall Curtis, MD, of the University of Washington, Seattle. Participants were relatives of 126 patients dying in 22 ICUs in France. Those in the intervention group were also given a brochure on bereavement.

Compared with controls, participants in the intervention group:

• Experienced longer conferences (median, 30 minutes vs 20 minutes)

• Spent more time talking (median, 14 minutes vs 5 minutes)

• Had a significantly lower median score on instruments measuring for post-traumatic stress disorder (PTSD) at 90-day follow up, with a lower prevalence of PTSD-related symptoms (45% vs 69%)

• Had less prevalence of clinically significant symptoms of anxiety (45% vs 67%) and depression (29% vs 56%)

The longer, more structured conferences allowed families to:

• Ask questions and address concerns

• Discuss the patient’s values

• Express emotions

• Alleviate feelings of guilt

• Arrive at a more realistic expectation of the outcome

“This study is groundbreaking in its demonstration of a statistically and clinically significant improvement in symptoms of anxiety, depression, and PTSD among family members, and it shows that expanding the focus of critical care to include family-centered outcomes is appropriate and desirable,” write the authors of an editorial accompanying the report.

The increasing use of critical care in this country has led to a rise in the number of Americans who die in the ICU, as well as to the increased number of patients who survive with desirable outcomes, point out Craig M. Lilly, MD, University of Massachusetts Medical School, Worcester, and Barbara J. Daly, PhD, RN, Case Western University, Cleveland, noting that “nearly every American family will be affected by the loss of a loved one in an ICU, and the effect of this loss can be mitigated by high-quality care.”

Lilly and Daly conclude: “All providers of critical care should receive training that will allow them to offer the kind of support that they would want if they had a family member who was facing death in an ICU.”

**Fewer Concerns with Physician Communication, Greater Use of Hospice Linked to Presence of ADs**

Feeling more informed about what to expect throughout the dying process

“Despite this increase in the use of ADs, persistent and important concerns remain with how we as a society care for frail, older, dying persons,” warn the authors. “With the demographic projections of the ‘baby boomers,’ the ability to provide competent, coordinated, and compassionate care to older adults throughout the course of illness and the dying process is becoming increasingly urgent.”

**Source:** “Association between Advance Directives and Quality of End-of-Life Care: A National Study,” Journal of the American Geriatrics Society; February 2007; 55(2):189-194. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T; Center for Gerontology and Health Care Research, Brown Medical School; Department of Community Health, Brown University; Division of Geriatrics, Rhode Island Hospital; and Miriam Hospital, Providence, Rhode Island.
Online Resources Help Physicians Assess Appropriateness of Palliative Care

The Center to Advance Palliative Care (CAPC) has launched a website resource (www.getpalliativecare.org) offering information to assist physicians and their patients with serious illness in making decisions about the appropriateness of palliative care.

“Palliative care relieves suffering and ensures the best possible quality of life,” says Diane Meier, MD, CAPC director. “We are especially interested in making it clear that palliative care is appropriate at any stage of a serious illness.”

Patient information includes a brief questionnaire to help determine the appropriateness of palliative care, a three-step process for obtaining such care (Step 1 is “Talk to your doctor”), and a national directory of palliative care providers.

Physicians are offered a set of criteria for assessing whether a palliative care consultation would be of benefit to them and their patients, along with a downloadable one-page patient/family handout entitled “What Should You Know about Palliative Care?”

General palliative care referral criteria include:

**PRESENCE OF A SERIOUS, CHRONIC ILLNESS**

- Difficulty managing physical or emotional symptoms related to serious medical illness
- Patient, family, or physician uncertainty regarding prognosis and/or goals of care
- Patient, family, or physician query about the appropriateness of hospice

**INTENSIVE CARE UNIT CRITERIA**

- Multi-organ failure
- Prolonged or difficult ventilator withdrawal
- Family distress impairing surrogate decision making

**ONCOLOGY CRITERIA**

- Metastatic or locally advanced cancer progressing despite systemic treatments with or without weight loss and functional decline

**EMERGENCY DEPARTMENT CRITERIA**

- More than one recent prior hospitalization with same symptoms/problems
- Patient, caregiver, or physician desire for hospice
- Consideration of ventilator and/or intensive care unit admission in a patient with: moderate to severe dementia; metastatic cancer and functional decline; or chronic disease(s) and poor baseline functional status

CAPC (www.capc.org), located at Mount Sinai School of Medicine, is a national organization supporting health care professionals who wish to start and sustain palliative care programs for patients facing serious, complex illness.

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End-of-Life Care Websites

- [www.aahpm.org](http://www.aahpm.org)
  American Academy of Hospice and Palliative Medicine
- [www.eperc.mcw.edu](http://www.eperc.mcw.edu)
  End of Life/Palliative Education Resource Center (EPERC)
- [www.epec.net](http://www.epec.net)
  The EPEC Project (Education in Palliative and End-of-Life Care)
- [www.nhpco.org](http://www.nhpco.org)
  National Hospice & Palliative Care Organization
- [www.caringinfo.org](http://www.caringinfo.org)
  National consumer engagement initiative to improve end-of-life care
- [www.promotingexcellence.org](http://www.promotingexcellence.org)
  Promoting Excellence in End-of-Life Care
- [www.hospicefoundation.org](http://www.hospicefoundation.org)
  Hospice Foundation of America
- [www.americanhospice.org](http://www.americanhospice.org)
  American Hospice Foundation
- [www.hpna.org](http://www.hpna.org)
  Hospice and Palliative Nurses Association
- [www.medicaring.org](http://www.medicaring.org)
  Palliative Care Policy Center
- [www.abcd-caring.org](http://www.abcd-caring.org)
  Americans for Better Care of the Dying
- [www.mcw.edu/pallmed/](http://www.mcw.edu/pallmed/)
  Medical College of Wisconsin Palliative Care Center
- [www.painpolicy.wisc.edu/](http://www.painpolicy.wisc.edu/)
  University of Wisconsin Pain and Policy Studies Group
- [www.capcsmss.org](http://www.capcsmss.org)
  Center to Advance Palliative Care
- [www.stoppain.org](http://www.stoppain.org)
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The HPNA text Conversations in Palliative Care is a resource on communicating with patients and families, spiritual care, and more. It is available by clicking on the hyperlink above.

HPNA developed a Spiritual Care Position Statement which is posted on our website. There are several Patient Family Teaching Sheets also posted on the HPNA website related to these topics: Managing Fatigue, Assisting Families to Manage Fatigue, Managing Pain, Spiritual Distress. Spanish translations of these Patient Family Teaching Sheets are also available on the website.

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