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The Concept of a Good Death Includes Relief of Suffering, Comfort Care, and Family Support

As the focus of medical care for terminally ill patients changed in the last decades of the 20th century from avoidance of medical failure (i.e., death) to the recognition that dying patients and their families need personalized support through the experience, the concept of a good death changed, too. And that concept is still evolving, according to a report in the *American Journal of Hospice & Palliative Medicine*.

Philadelphia researchers conducted a literature review to identify aspects of a good death as seen by health care professionals, patients, and families. Their analysis is based on data gathered from the first reports in 1995, through studies from 2010.

GENERAL ATTRIBUTES

Common attributes of a good death, as identified by health care professionals and patients/families, include:

- Relief from pain and suffering/appropriate pain and symptom management
- Keeping hope alive
- Awareness of the patient's dying
- Patient autonomy
- Family support
- Preparing for departure

PATIENT/FAMILY PERSPECTIVE

Additional attributes of a good death identified by patients and families include:

- Avoiding a prolonged dying process
- Accepting the timing of one's death
- Making the decision about where to die
- Attaining a sense of control
- Strengthening relationships with family and friends

PHYSICIAN PERSPECTIVE

Attributes of a good death from a physician's perspective include:

- Death that is expected, peaceful, and timely
- Comfort care that is considered rational and appropriate
- Effective communication with patient, family, and care team

For nurses, a good death requires a high standard of care involving optimal symptom management and holistic care provided to both the patient and family. Palliative care nurses identified attributes related to the patient, the family, and the care team, as well as to the type of death (no suffering, maintenance of dignity) and the death scene (peaceful and supportive).

The authors emphasize that ultimately, the characterization of a good death is subjective. Evaluation of aspects of the dying process have been based mostly on studies of family satisfaction with care received. They suggest that future studies focus on the impact of a good death on surviving loved ones, health care professionals, and health organizations.

Source: "Concept Analysis of Good Death in Terminally Ill Patients," American Journal of Hospice & Palliative Medicine; December 2012; 29(8):632-639. Granda-Cameron C and Houldin A; Palliative Care Program, Joan Karnell Cancer Center at Pennsylvania Hospital; and University of Pennsylvania School of Nursing, both in Philadelphia.

Emergency Physicians Have ‘Window of Opportunity’ for Timely Hospice Referral

Experts offer practical tips for communicating with the seriously ill, elderly patient

Recent research shows a high rate of emergency department (ED) visits by elderly patients with serious, advanced illnesses in the final months and weeks of life, with many repeat visits. Identifying unmet palliative needs and initiating hospice enrollment are vital components of the emergency physician’s role, according to an article published in *Clinics in Geriatric Medicine*.

“Elderly patients with declining health and functional status and advanced disease have frequent ED visits, particularly in the last months of life, presenting a window of opportunity to assess patient needs and goals of care and initiate discussions about hospice in eligible patients,” write the authors, a team of experts in emergency medicine, geriatrics, and palliative medicine.

Numerous studies have demonstrated the benefits of hospice care, point out the authors. These include: optimal symptom management; improved well-being of family and caregivers; increased patient, family, and physician satisfaction with care; and reduction in health care expenditures.

“Hospice remains an underutilized resource, however,” the authors observe. Although hospice is now widely available, the median length of service is about 20 days, with approximately one-third of patients receiving hospice care for seven days or less. “Thus, many eligible patients considered for hospice are enrolled too late in the course of disease to realize the full benefit of hospice.”

Hospice and palliative medicine is a recognized subspecialty of ten medical specialties, including emergency medicine, internal medicine, and family medicine. It has also been recognized as a medical subspecialty by the federal Centers for Medicare and Medicaid Services.

In the ED setting, the clinical team’s role is to identify and convey the need for transition of a patient to palliative and/or hospice care. At minimum, note the authors, ED clinicians must identify these needs and get a palliative consult or communicate the need for transition of care, “the same as would be done with a bowel obstruction and surgical consult.” This means discussion of patient goals of care in “real time” in the ED.

DISCUSSING GOALS OF CARE

The authors offer the following suggestions for discussing goals of care with the seriously ill, elderly patient in the ED:

- Communicate prognosis.
- Elicit the patient’s values. Ask, “*What is most important to you in your life right now? What kind of results are you looking for? What do you hope to avoid at all costs?*”
- Use appropriate language to describe goals of care. Avoid statements such as “Do you want us to stop aggressive care?” Instead, consider saying, “*We want to ensure that you receive*

the kind of treatment you want.” Or, “*Let’s discuss how we can work toward keeping you at home.*”

- Recommend a care plan consistent with the established goals of care.

The preferred setting for hospice care is the location the patient calls home, note the authors. If the patient cannot be discharged home safely prior to hospice admission (which usually takes place within 24 to 48 hours), physicians can initiate an observation status, rather than a short inpatient hospital admission.

The article also includes tables delineating common palliative emergencies prompting patients with advanced disease to visit the ED, the management of common symptoms and complaints seen in these patients, and the signs of imminent death.

Source: “Palliative Medicine and Geriatric Emergency Care: Challenges, Opportunities, and Basic Principles,” Clinics in Geriatric Medicine; February 2013; 29(1): 1-29. Rosenberg M, Lamba S, Misra S; Department of Emergency Medicine, St. Joseph’s Regional Medical Center, Paterson, New Jersey; Department of Emergency Medicine UMDNJ-New Jersey Medical School, Newark, New Jersey; and Division of General Internal Medicine and Public Health, Veterans Administration Medical Center, Vanderbilt University Medical Center, Nashville, Tennessee.

Stepwise Approach to Hospice Referral from the Emergency Department

1. **Assess the patient’s eligibility for hospice care.** This is the key initial step. Determine if the patient has a prognosis of six months or less, and use the “surprise” question: Would I be surprised if this patient died within the next six months?
2. **Discuss referral to hospice with the patient’s primary care provider.** Consider the patient’s current condition, prognosis, and any previous goals-of-care discussions.
3. **Determine if the patient’s goals of care are consistent with the hospice philosophy.** “*What have you been told about your illness and what to expect in the future? Has anyone talked to you about how much time you likely have? Are there any plans for treatments aimed at extending your life? What do you know about hospice?*”
4. **Introduce hospice.** Explain the core aspects of hospice as a care system, identifying specific elements that can help the patient and family (e.g., on-call, 24/7 assistance, home visits for symptom management, social worker and chaplaincy support). Clarify any misconceptions and address concerns. Use positive language, grounding the recommendation in the patient’s needs and wishes. “*I think that hospice care would be the best way for you to remain at home, avoid the hospital, and stay as fit as you can.*”
5. **Make a referral and write orders.**

— Rosenberg, et al, *Clinics in Geriatric Medicine*

Elements of Early, Integrated Palliative Care Encounters Identified

Clinicians urged to incorporate a palliative care approach into their practices

Ample literature now demonstrates the benefits of palliative care (PC) services delivered to patients with advanced disease in the inpatient setting, but there is little descriptive data on the content and nature of early and ongoing PC discussions during outpatient visits. Boston researchers have found that these encounters with cancer patients begin with building a rapport and understanding the illness experience, then in later encounters moving to discussion of hospice and end-of-life wishes.

“Our analysis sheds light on the clinical components of early integrated PC in the ambulatory care setting, which may serve as a clinically useful foundation for developing these services to enhance the care of patients with advanced cancers,” write the authors of a report published in *JAMA Internal Medicine* (formerly, *Archives of Internal Medicine*).

Investigators conducted a secondary, qualitative analysis of clinic visit notes on 20 patients with non-small-cell lung cancer who were part of the PC group in an earlier, randomized trial of integrated PC vs standard oncologic care (Temel JS, et al: “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *The New England Journal of Medicine*; August 19, 2010; 363(8):733-742.)

Patients who received early palliative care in the 2010 study had significant improvement in quality of life, lower rates of symptoms of depression, and lived a median of nearly three months longer compared with patients receiving standard care only. Researchers in the current study stratified patients by survival time, identifying key elements of the ambulatory PC clinic visits as disease progressed.

INITIAL PC VISITS INCLUDED:

- Building an empathetic relationship with the patient
- Establishing the patient’s understanding of the illness and awareness of prognosis
- Eliciting the patient’s preferences for receiving information

- Discussing the psychosocial effects of cancer treatment and the illness experience with the patient

ALL PC VISITS INCLUDED:

- Addressing symptoms
- Addressing coping
- Revisiting the patient’s understanding of his/her current illness status
- Engaging family members

LATER PC VISITS (AFTER CLINICAL DETERIORATION) INCLUDED:

- Discussion of decision making regarding any changes to plans for cancer treatment
- Discussion of limitations of life-sustaining treatment
- Presentation of the option of hospice referral, with discussion of the reasons for selecting hospice

“[W]e observed that the specific content of the early PC visits varied according to timing along the disease trajectory and clinical events, rather than following a generally prescribed checklist,” the authors point out. “This novel finding may serve to guide clinicians in providing early PC tailored to specific individual needs, depending on their phase of illness.”

PALLIATIVE CARE IS NOT A ‘TRADE-OFF’

Clinicians build relationships with their seriously ill patients in the hopes of “finding a way through the symptoms and distress, a way to cope with the illness experience, and a way to make each day as good as it can be,” writes Alexander K. Smith, MD, Department of Medicine, University of California, San Francisco, in his commentary accompanying the report. **“The focus of PC is not browbeating patients into accepting hospice and avoiding resuscitation or hospitalization, as some might assume. Palliative care is at its heart a relationship-centered profession.”**

Smith further suggests, “Patients might benefit if all internists incorporated this ap-

proach, seeking supplementary training in PC. And some benefits, like survival, might be surprising.” The prolonged survival finding of the landmark 2010 study challenges an ingrained belief that offering palliative care represents a trade-off between the palliative approach and an aggressive, but “life-prolonging” approach, Smith points out.

“This assumption is buried deep in the language clinicians use in everyday discussions about goals of care, such as, ‘All things considered, do you want to focus on quality of life and comfort, even if it means not living as long? Or, living as long as possible, even if it may mean enduring more pain and discomfort?’” The reality is, not only is there no evidence that palliative care shortens life, there is also a growing body of evidence demonstrating that palliative care may actually extend the life span of some patients, Smith observes.

Meanwhile, the elements of clinical palliative care visits found in the secondary analysis by Yoong and colleagues point to a way for clinicians to approach the integration of palliative care into their practices. “The progression of PC clinic visits from initial encounter to death are in some ways a model for how all effective outpatient visits should proceed for patients with serious illness,” declares Smith.

However, not many patients currently have access to a palliative care clinician in the outpatient setting, although they probably do visit an internist. “While we are waiting for the science in this area to progress, the general approach described by Yoong, et al, has such strong face validity that all internists should consider incorporating it into their practices.”

*Source: “Early Palliative Care in Advanced Lung Cancer: A Qualitative Study,” JAMA Internal Medicine; February 25, 2013; 173(4):283-290. Yoong J, Park ER, Greer JA, Jackson VA, Gallagher ER, Pirl WF, Back AL, Temel JS; Massachusetts General Hospital, Boston; and Fred Hutchinson Cancer Research Center, University of Washington, Seattle. “Palliative Care: An Approach for All Internists,” *ibid.*, pp. 291-292. Smith AK, Department of Medicine, University of California, San Francisco, and San Francisco Veterans Affairs Medical Center, San Francisco.*



WHEN TO REFER TO HOSPICE

Call us if your patient exhibits the following indicators:

- Physical / functional decline
- Weight Loss >10% in last 6 months
- Multiple comorbidities

When life expectancy can be measured in weeks or months, hospice is usually the best option. For patients with **pulmonary disease (COPD)**, look for the following indicators:

- Dyspnea at rest
- Poor response to bronchodilators
- Recurrent pulmonary infections
- Right heart failure
- Unintentional weight loss
- Bed to chair existence

Call us any time, any day.

Geoffrey Coleman, MD
Medical Director
Montgomery Hospice



Completion of Advance Directives Urged as Routine Part of Patient Care

In light of the increasingly complex medical care choices faced by the growing number of Americans with chronic illness and multiple comorbidities, experts from the Johns Hopkins School of Public Health Policy and Management in Baltimore urge that discussion of advance directives (ADs) become a standard part of most medical examinations.

National efforts must be made to ensure that advance directives, which are “free, legal, and readily available,” are completed by all patients, to ensure that their wishes are honored in a medical crisis and at the end of life, suggest the authors of an article published in the *American Journal of Public Health*. In the article, they argue that “advance directives should be part of the public health policy agenda and health reform.”

RECOMMENDATIONS INCLUDE:

- Fair reimbursement to physicians, nurses, and other health care professionals for holding end-of-life conversations with patients
- Making completion of ADs a routine part of patient encounters and a measure of quality care
- The establishment of universally available AD registries, particularly in electronic format

- Inclusion of the importance of ADs in medical training and education, as part of cultural competency
- Discussion of end-of-life issues added to the agendas of businesses and places of worship
- A coordinated campaign by political and cultural leaders to promote the use of ADs

A recent study by lead author Dan K. Morhaim, MD, for the Maryland General Assembly found that although 60% of the state’s general population wanted their end-of-life wishes respected, only about one-third had completed an AD. The authors note that, as Maryland’s demographics are similar to those of the nation as a whole, this finding may have a broader application.

Reasons reported for not having completed an AD included lack of information about ADs, feeling oneself too young or healthy to be concerned, and fearing that AD completion would be too costly or time consuming.

Source: “End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis,” *American Journal of Public Health*; Epub ahead of print, April 18, 2013; DOI: 10.2105/AJPH.2013.301316. Morhaim DK, Pollack KM; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland.