



Online article and related content
current as of February 10, 2009.

Referring a Patient and Family to High-Quality Palliative Care at the Close of Life: "We Met a New Personality . . . With This Level of Compassion and Empathy"

Joan M. Teno; Stephen R. Connor

JAMA. 2009;301(6):651-659 (doi:10.1001/jama.2009.109)

<http://jama.ama-assn.org/cgi/content/full/301/6/651>

Supplementary material

eTable

<http://jama.ama-assn.org/cgi/content/full/301/6/651/DC1>

Correction

[Contact me if this article is corrected.](#)

Citations

[Contact me when this article is cited.](#)

Topic collections

Patient-Physician Relationship/ Care; End-of-life Care/ Palliative Medicine; Quality of Care; Quality of Care, Other; Perspectives on Care at the Close of Life
[Contact me when new articles are published in these topic areas.](#)

Subscribe

<http://jama.com/subscribe>

Permissions

permissions@ama-assn.org

<http://pubs.ama-assn.org/misc/permissions.dtl>

Email Alerts

<http://jamaarchives.com/alerts>

Reprints/E-prints

reprints@ama-assn.org

Referring a Patient and Family to High-Quality Palliative Care at the Close of Life

“We Met a New Personality . . . With This Level of Compassion and Empathy”

Joan M. Teno, MD, MS

Stephen R. Connor, PhD

THE PATIENT'S STORY

Mr K is a 49-year-old man with metastatic spindle cell cancer who was admitted directly to the palliative care service (PCS) of a large metropolitan hospital, for management of intractable pain, following a week of telephone consultation between his primary care physician and the PCS. The PCS provides more than 400 consultations per year in a 1900-bed hospital that is part of a health care system that includes both home care and hospice programs. The PCS team consisted of 3 physicians, a clinical nurse specialist, a social worker, and a chaplain.

The patient's primary care physician had tried treating Mr K's pain with long-acting opioids (oxycodone long-acting 340 mg twice daily) and dexamethasone but without success. The patient had a complex history of back problems dating to adolescence, with a diagnosis of spindle cell sarcoma in the fall of 2006. The tumor had progressed to involve the T2, T3, and T4 vertebrae. Because of instability, one of the patient's ribs was harvested and wrapped in a titanium cage in an attempt to stabilize his spine. However, following surgery, the harvested rib slipped, requiring that the operation be redone 4 days later. He was then referred to a quaternary care facility for 16 rounds of proton beam therapy, returning home in July 2007. Since then, his pain had been escalating and magnetic resonance imaging (MRI) showed malignant involvement of the T1, T5, T7, and T9 levels. Despite long-acting opioids and dexamethasone, he now rated his pain as “10 out of 10” and at times wondered how he could go on and bear the pain.

Mr K is a retired engineer, receiving disability since the 1990s. His wife is a psychiatric nurse and acupuncture practitioner. Mr and Mrs K have 3 sons, aged 18, 13, and 12 years. Mr K is Lutheran and his beliefs provide him solace.

Palliative care services are increasingly available to primary care physicians for both expert consultations and services to seriously ill patients. The United States now has more than 1400 hospital-based palliative care teams and more than 4700 hospice programs. We use an illustrative case of a palliative care hospitalization and intervention for a middle-aged man with severe pain from spinal metastases to discuss 4 key questions that a primary care physician faces in caring for the seriously ill patient with difficult symptom management: (1) Should I refer a patient to a hospital-based palliative care team or to hospice services for difficult symptom management? (2) If the patient is referred to a hospital-based palliative care team, what should I, as the primary care physician, expect? (3) When should I refer to hospice services a patient initially referred to a hospital-based palliative care team? and (4) How can I choose a hospice program that will provide competent, coordinated, and compassionate patient- and family-centered care? Primary care physicians now may choose among hospice programs, and the programs may vary in their quality of care. Validated tools to measure patient and family perceptions of the quality of hospice care are now available but progress in defining and measuring the quality of hospice care is still needed before actionable information will be available to guide the choice of hospice programs for physicians and consumers.

JAMA. 2009;301(6):651-659

www.jama.com

Author Affiliations: Community Health and Medicine, Warren Alpert School of Medicine at Brown University, Providence, Rhode Island (Dr Teno); and Research and International Development, National Hospice and Palliative Care Organization, Washington, DC (Dr Connor).

Corresponding Author: Joan M. Teno, MD, MS, Community Health and Medicine, Warren Alpert School of Medicine at Brown University, 2 Stimson Ave, Providence, RI 02912 (Joan_Teno@brown.edu).

Perspectives on Care at the Close of Life is produced and edited at the University of California, San Francisco, by Stephen J. McPhee, MD, Michael W. Rabow, MD, and Steven Z. Pantilat, MD; Amy J. Markowitz, JD, is managing editor.

Perspectives on Care at the Close of Life Section Editor: Margaret A. Winker, MD, Deputy Editor.



CME available online at www.jamaarchivescme.com and questions on p 679.

Upon admission, the palliative care physician, Dr G, noted that Mr K and his wife requested visits from both the social worker and chaplain. Mr K's goals were improvement in pain and longevity, although he acknowledged his terminal illness. Mr K expressed his desire for "full code" status, although he understood the concern that chest compressions could result in spinal paralysis. On admission, Mr K shared his concern that he be present at his middle son's Eagle Scout induction the following weekend.

Within a short time, the PCS team addressed a number of important family issues. First, Dr G outlined a care plan and instilled a sense of hope regarding pain management options. A temporizing pain regimen of methadone, ketamine, and a single intravenous dose of zoledronic acid was instituted and provided relief. An interventional radiology procedure to place a catheter for intrathecal opioid administration was arranged for the Monday following the Eagle Scout ceremony. Second, noting the previous fragmentation of Mr K's medical care, Dr G arranged for him to see a sarcoma specialist to establish a realistic prognosis. Third, Dr K's care plan was shaped by both social work and spiritual staff. Mrs K had important concerns about how best to prepare their 3 sons for the impending death of their father. Finding appropriate resources was challenging because Mrs K came from a small community and she felt it was important to find resource personnel with whom she did not have collegial or professional relationships. The PCS chaplain, Mr V, who was a Lutheran pastor, provided affirmation and supportive listening for Mr K, who was accepting but at times fearful of dying. In addition, Dr G arranged for Mr K to be seen by the psychiatry service, which recommended olanzapine as an adjunctive agent for pain; the psychology service, which made further recommendations for coping with pain; and the medical orthotics service, which decided to cast a thoracic vest to support and protect his spinal cord.

Mr K was discharged to attend his son's ceremony and readmitted the following week for intrathecal catheter placement. At that time, his protective vest was ready. Ms C, the social worker, provided a list of local resources for the family. Following successful start of intrathecal opioid therapy, Mr K was discharged with outpatient follow-up by the PCS and pain management service.

PERSPECTIVES

In September 2007, a Perspectives editor interviewed Mr K, Mrs K, and members of the palliative care team, including Ms C, the social worker, Dr G, the PCS physician, and Mr V, a Lutheran pastor.

MRS K: It's nice to have a compassionate individual involved in giving care. We met a new personality in medicine that we have never met before, with this level of compassion and empathy.

DR G, THE PCS PHYSICIAN: I think the passion for anyone who works in this field is trying to get down to what really is

important for this person's life and does this make sense for them. . . . [W]e're happy to support that.

The past decade has seen rapid growth of both hospice and hospital-based palliative care programs in the United States.^{1,2} The first US hospice program started in 1974; now, the National Hospice and Palliative Care Organization estimates that there are more than 4700 programs. According to the American Hospital Association's annual survey, in 2007 there were about 1400 hospital-based palliative care teams. More than 75% of hospitals with at least 250 beds have a hospital-based palliative care program and nearly 100% of all Veterans Administration hospitals have a program.³ The primary care physician caring for Mr K was faced with 4 questions: (1) Should I refer Mr K to a hospital-based palliative care team or to a hospice? (2) If the patient is referred to a hospital-based palliative care service, what should I, as the primary care physician, expect in terms of services for this seriously ill person and his family? (3) When should I refer a patient in a hospital-based palliative care service to a hospice? and (4) How do I choose a hospice program that will provide competent, coordinated, and compassionate patient- and family-centered care?

Should the Patient Be Referred to a Hospice or Hospital-Based Palliative Care Team?

Mr K's primary care physician was faced with an array of referral options, including hospice and hospital-based palliative care services. The TABLE provides key differences between hospice and hospital-based palliative care services. In short, all care provided by hospices is palliative; however, not all palliative care is provided by hospices. The World Health Organization (WHO) defines palliative care as

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.⁵

Hospice, as defined by the Medicare Hospice Benefit, is a health care delivery system under which the patient opts out of curative treatments for the terminal illness. Under the Medicare Hospice Benefit, hospices provide a package of services that include physician, nursing, social work, home health aide, volunteer, physical therapy, occupational therapy, speech therapy, counseling, dietary, and spiritual professionals; medications related to the terminal illness; medical supplies and equipment; short general inpatient and respite care; 12 months of bereavement follow-up; and any other services reasonable and necessary for palliation of the terminal illness.⁶ Each hospice determines coverage policies for expensive treatments, such as the intrathecal pump that Mr K received. Hospices can admit patients receiving intrathecal opioid therapy. However, the \$10 000 (or more) cost of implanting an intrathecal pump is prohibitively expensive for a hospice being paid a routine home care daily

rate of approximately \$140. Therefore, in our experience, complex patients often receive these interventions before they are referred to hospice. The hospice program can monitor the pump therapy and ensure that the patient's pain is effectively managed and that infection is prevented. Given that hospice coverage policies for expensive treatments vary, primary care physicians should ask the local hospice about its coverage policies to assist them in determining when a patient receiving a given treatment is more appropriate for hospice or hospital-based palliative care services, if available. As in this case, there may be opportunities for both types of services to provide care at appropriate points. For patients not using the Medicare Hospice Benefit, eg, those

with private insurance, the eligibility and type of palliative services provided vary by the insurer and over time. Full discussion of these benefits is beyond the scope of this article.

Hospital-based palliative care programs can provide any or all of the palliative services mentioned above and vary greatly from program to program. A hospital-based palliative care program could range from having 1 specially trained nurse visiting patients throughout a facility to including a complete interdisciplinary team with a dedicated inpatient unit, home care program, and outpatient program. Presently, hospital-based palliative care programs may offer fewer volunteer, spiritual, and bereavement services than do hospice programs. Hospital-based palliative care pro-

Table. A Comparison of Hospice to Hospital-Based Palliative Care Service^a

	Hospice Services	Hospital-Based Palliative Care Services
Patient population	Patients with life-limiting illness and a likely prognosis of 6 months or less if the illness runs its normal course Patients with a prognosis of less than 1 year should be educated about hospice and in some states may receive hospice care	Patients at any stage of advanced or life-limiting illness
Sites of care	Home Nursing home Assisted living facility Hospital Free-standing inpatient units	Hospital Provision of service elsewhere in the community (eg, in outpatient programs and nursing homes) varies by program
Services provided	Pain and symptom management, psychosocial and spiritual support, coordination of care Delivered by an interdisciplinary team including physicians, nurses, social workers, home health aides, therapists, chaplains, counselors, and volunteers Medical equipment, medications, supplies Family bereavement support for 1 year after death	Services vary by program from a single health care provider to an interdisciplinary team
Financing system	Set payment per day enrolled, at 1 of 4 levels of care Routine home care Continuous home care General inpatient care Inpatient respite care Charitable support funds not-for-profit hospices	Reimbursement through existing payment channels, including billing through CPT codes, hospital DRGs Also can be supported by core hospital facility, and charitable contributions Payment for individual professional or facility services
Length of stay	Average length of stay is 2 months; median, 21 days	Varies, may be episodic provision of care based on identified needs
Choice	In most communities there are multiple hospices to choose from	At health care facilities there is usually only 1 service Large medical centers are more likely to have dedicated palliative care services
Role of PCP	Usually continues to provide overall management of care Hospice medical director consults and backs up PCP	PCP often requests a formal consult from the palliative care team PCS or hospitalist physician may manage care during inpatient stays
Typical staffing	A hospice team with a daily census of 30 patients may have 3 nurses, 1 to 2 home health aides, a full-time social worker, a part-time chaplain, volunteers, part-time medical director, and contract therapists Staff certified in palliative care is desirable	Palliative care teams ideally include physicians, nurses, social worker, and may include a pharmacist, a psychologist, and other therapists as needed Staff certified in palliative care is desirable
Key differences	Focus is on caring for patient and family or caregivers at the end of life after efforts at curative treatment for the terminal illness are no longer effective or the patient decides to stop treatment with curative intent Patient opts out of regular Medicare coverage for terminal illness and receives services that meet his/her terminal care needs across all settings of care	Focus is on providing expert palliative care throughout the continuum of a life-limiting illness Can be delivered concurrently with continuing curative or life-prolonging therapies

Abbreviations: CPT, Current Procedural Terminology; DRG, diagnosis related group; PCP, primary care physician; PCS, palliative care service.

^aIn part, adapted from *Center to Advance Palliative Care Manual*.⁴

grams are funded from reimbursement through existing payment channels, including billing through Current Procedural Terminology (CPT) codes and hospital diagnosis related groups (DRGs) and also can be supported through the hospital's core facility budget. Many hospitals support their palliative care programs to reduce the length and cost of intensive care unit and inpatient stays.⁷

Hospice and palliative care physicians have had the opportunity to be certified by the American Board of Hospice and Palliative Medicine and now if their specialty organizations participate, they can achieve subspecialization credentials in hospice and palliative medicine that is recognized by the American Board of Medical Specialties. Being certified in hospice and palliative medicine is one indication that physicians working in a hospice or palliative care program have the requisite skills to provide competent palliative care.

Under the Medicare Hospice Benefit, a primary care physician and the hospice medical director must certify that the patient has an expected prognosis of 6 months or less if the patient's disease trajectory follows its normal course. Persons dying from cancer have a more predictable disease trajectory with progression of disease, gradual functional decline, and increased time in bed, providing evidence that the patient is in his/her last months of life. For persons dying of congestive heart failure, chronic obstructive pulmonary disease, and dementia, prognostication can be more difficult. In these cases with less predictable prognoses, palliative care physicians with hospital-based palliative care services or local hospices can help estimate survival time. In addition to their experience of having seen many dying patients, their new perspective can be useful because prognostic accuracy declines the longer the physician has known the patient.⁸

The central difference between hospice and hospital-based palliative care programs is that the latter can admit and serve patients who are still receiving curative therapies. There is no specific prognostic requirement for patients referred to a hospital-based palliative care service. When considering whether to refer a patient to hospice or to a palliative care service, the primary care physician must weigh numerous factors. A first step is to understand where the patient and family are in their own journey with the illness. Have they reached the critical turning point to change the major focus of care from life extension to comfort measures? The primary care physician should actively listen to the patient to understand how this life-threatening illness is affecting quality of life, and determine the patient's wishes and goals concerning continued curative treatment. Often, the primary care physician needs to sensitively educate the patient about prognosis, treatment options, and when appropriate, availability of hospital-based palliative care or hospice services. Many patients make decisions about whether to continue or discontinue curative therapy with the reactions of their family in mind. Patients and families may main-

tain a "conspiracy of silence" about the seriousness of the patient's condition. Some patient-family units may need permission from the physician (perhaps using a "hope for the best, but prepare for the worst" approach) to consider a less aggressive approach. Previous Perspectives articles have explored how to approach these difficult conversations, including the opportunities to find growth and transcendence at the end of life⁸ and how to initiate conversations at the end of life.⁹ The theory and practice of conversations with those facing the end of life has also been reviewed.¹⁰

To refer patients appropriately, a primary care physician must learn what resources are available for patients in their community. With the exception of a small number of rural areas, all regions in the United States have access to hospice services,¹¹ whereas hospital-based palliative care services are relatively new and may not be available in some urban and many rural areas. In addition, each type of program has important strengths and weaknesses; thus, the primary care physician must decide which service best fits the patient and family's needs at a given time. As this case illustrates, physicians practicing in rural areas without requisite resources may need to refer their complex patients to tertiary referral centers.

What Should the Physician Expect of the Hospital-Based Palliative Care Service?

What should primary care or specialist physicians caring for seriously ill patients and their families expect from a palliative care service? What defines high-quality palliative care services? Over the past 3 decades, a consensus definition was developed with input from experts, consumers, legislators, and judges and was ratified into *A National Framework and Preferred Practices for Palliative and Hospice Care* of the National Quality Forum.¹² Key components are holistic care provided by interdisciplinary teams that attend to the patients' desired physical comfort and emotional support through evidence-based practice, the promotion of shared decision making, attention to the needs of the family for information and skills in participating in care for the patient, provision of bereavement services prior to and after the patient's death, and coordination of care across settings of care and the patient's disease trajectory. Most importantly, a palliative care service should be patient- and family-centered. The modern hospice movement's founder, Dame Cicely Saunders, eloquently observed, "We never lost sight of the values that were so important to David [David Tasma, founding donor of St Christopher's Hospice]: 'commitment to openness, openness to challenge, and the absolute priority of patients' own views on what they need.'"¹³

BOX 1 outlines the expectations a primary care physician may have of a hospital-based palliative care service, based on review of existing guidelines, conceptual models of the quality of care, and the National Quality Forum framework.¹² The central structural element is an interdisciplinary team, including physician, nurse, social worker, phar-

Box 1. Expectations of a Palliative Care Service**Evidence-based symptom palliation and psychological support**

An interdisciplinary team of physician, nurse, social worker, pharmacist, spiritual counselor, and others who are certified and participate in ongoing education

Skillful screening, assessment with standardized measures, and formulation of a care plan that meets the goals of the patient and appropriately monitors that plan

Anticipates and prevents problems

Education of the patient and family regarding pharmacological and nonpharmacological interventions to promote patient comfort and emotional well-being. Patient and family are educated about what to expect, what they should monitor, and when to contact health care clinicians for concerns

Routine patient and family conferences

Coverage 24 hours a day, 7 days a week

Promotes shared decision making and patient choice in care; supports family and caregivers

Educates patient and family about prognosis and about the benefits and risks of treatment

Patients or their appropriate representative are involved in medical and everyday decisions such that care reflects their values and expectations

Provides emotional support and appropriate referrals for additional services when needed

Treats the patient and family with dignity and respect for cultural values

Compassionate care that respects the values and cultural traditions of the patient

Provides access to translation services

Attends to the needs of the patient and family for practical, financial, and legal assistance

Provides services and referrals to obtain assistance in paying for medical care, completing advance directives, making a will, arranging for a funeral

Coordinates care across health care settings and disease trajectory

Ensures that one health care clinician (preferentially, the patient's primary care physician) is charged with overseeing medical care

Adapted from the National Consensus Project,¹⁴ National Quality Forum, A National Framework and Preferred Practices for Palliative and Hospice Care Quality¹², National Hospice Foundation guide on choosing a hospice program,¹⁵ and Teno and colleagues.¹⁶

macist, spiritual counselor, and allied health professionals who are available 24 hours a day, 7 days a week. Having physicians and nurses who are certified in palliative care is an important consideration to judge the quality of a hospital-based palliative care service. Palliative care programs must be open to critical self-reflection through audits of care and application of continuous quality improvement.

Even at this early stage in the evolution of quality measurement, substantial agreement exists on the key domains (the eTable summarizes a literature review of key goals and palliative care in a structure-process-outcome framework and is available at <http://www.jama.com>). These domains were validated¹⁷ through surveys of health care professionals, seriously ill patients, and family members, after analysis and synthesis of a systematic review,¹⁶ the National Quality Forum framework,¹² focus groups,¹⁶ and in-depth interviews.¹⁸ Nearly 70% of reviewed citations agreed on the importance of the domains of symptom palliation, emotional support, promoting shared decision making and advance care planning, meeting the needs of patients and those who care for them, addressing grief and spirituality, and coordination of care.

A useful mnemonic is the 3 Cs: high-quality care is competent, compassionate, and coordinated. Competent care involves an interdisciplinary team that provides evidence-based symptom palliation and psychological support in the key domains of physical comfort, psychological support, social support, bereavement services, and life closure includ-

ing spirituality and transcendence. Compassionate care treats the patient and family with respect, honors cultural traditions, and provides holistic care. Finally, the care is coordinated and seamless across the setting of care and the disease trajectory. Lack of care coordination is common and can result in the patient being subjected to unnecessary tests, medical errors, and lack of continuity of the care plan.¹⁹ The hospital-based palliative care team to which Mr K was referred did an admirable job in fulfilling each of the 3 Cs, as discussed below.

MRS K: *One of the big questions is: have you tried it all? Is there something you missed? Dr G . . . helped us figure that out.*

DR G: *I think some of the most important work and growth that happens at the end of life can't happen if there are uncontrolled symptoms . . . [Then] part of the work is finding meaning in terms of one's life journey.*

In a relatively short period, the PCS met and understood the patient's medical history and his family's needs and expectations and had formulated an individualized care plan. As with all seriously ill patients, whether cared for by a hospital-based PCS or hospice, a key question for this dying man and his family was whether all treatment options for his pain and his cancer had been exhausted? For his pain, the hospital-based palliative care team quickly synthesized the options, temporizing with an oral regimen to allow Mr K to be present at an important family event, and then providing state-of-the-art management with an intrathecal opioid pump,²⁰ thus minimizing the adverse effects of high-dose opioids and

other medications that he would otherwise have required. For his cancer, Dr G recognized the need to involve a sarcoma expert to provide important prognostic information and to ensure that Mr K was informed of any remaining treatment options.

MR V, THE CHAPLAIN: *I really feel that if someone is able to share his story and reflect . . . then that person will find within the resources and the way to go himself. This patient really only needed affirmation . . .*

MS C, THE SOCIAL WORKER: *The wife was concerned for herself and her sons' adjustment once he did die . . . One complicating factor, given her profession as a psychiatric nurse, [was] whom we referred her to.*

The hospital-based palliative care team exemplified a second C, compassionate and holistic care. Mrs. K's words attest to the compassion and empathy of Dr G. But each member of the interdisciplinary team understood the expectations and tailored interventions and referrals for both husband and wife.

MRS K: *The social worker checked to make sure that we could get follow-up care, support or counseling, in our area. She called the hospice people in our area to make sure they were going to be available to us.*

The third C is coordination of care. Too often, seriously ill people feel as though they are lost among myriad specialists focused on body organs, with no physician specifically charged with providing critical assistance and ensuring continuity and coordination of the plan of care at all stages of the disease trajectory.¹⁶ Seriously ill patients and their families need to know whom they can call for help, what they should monitor, and when they should call. Clearly, Mrs K believed there was an orchestrated and clear plan of follow-up.

When Should Patients Be Referred to Hospice Services?

With a change in Mr K's condition, a referral to hospice services could again be considered.¹² Hospice provides a relatively consistent package of services and benefits designed to meet the needs of patients and families facing life-limiting illness. Hospital-based palliative care programs vary considerably in the services and benefits they provide due to the lack of a specific payment mechanism. Hospital-based palliative care programs often lack the extensive use of volunteers that hospice programs use to extend their staff services. Palliative care programs may offer some after-death bereavement support, but hospice programs are mandated to provide 12 months of bereavement follow-up to every family they serve.⁶

Ultimately, the decision to refer a patient to hospice is based on the patient's informed preferences. The process of referral is a delicate one. It is generally best to help the patient and family to clarify their goals of care and quality of life and to present all available options, rather than only the next available treatment. Connecting the patients' goals to

the services provided by hospice makes these difficult conversations much easier.²¹ Timely referral to hospice services is important in that family members who perceive that the referral was late reported more concerns with the quality of care, higher unmet needs, and lower overall satisfaction.²² Additionally, patients with short length of hospice care receive fewer services, and they may not benefit from the full input of the interdisciplinary team.²³

Choosing a High-Quality Hospice Program

Even if patients are being cared for by a hospital-based palliative care service, there may come a time when hospice would best meet their needs. BOX 2 provides a set of questions a primary care physician may ask of local hospice programs to help guide the referral. Although the origins of hospice were developed as volunteer programs that did not have federally endorsed national standards or certification programs, Medicare now has conditions of participation that require an interdisciplinary team of physicians, nurses, and other health care professionals; use of volunteers; bereavement services; availability of rehabilitative services including speech, physical, and occupational therapies; short-term inpatient care; and home health aides. The implementation of these conditions of participation has improved the range of services and professionalism of hospice programs.²² Ninety-three percent of hospice programs are now Medicare certified.² Still, there is variation in the delivery of these services and the quality of care.²⁴⁻²⁶

Referral to a hospice program should be weighed with the same gravity as one would when referring a patient to a cardiovascular surgeon for bypass surgery. Although hospice does not yet have the mandatory reporting of outcomes required of acute care hospitals, nearly one-third of hospice programs are already voluntarily submitting data to the National Hospice and Palliative Care Organization,^{26,27} reporting benchmarks of structure (eg, registered nurse staffing, use of volunteer services), and process and outcomes of care (eg, bereaved family evaluations using the Family Evaluation of Hospice Care).

Hospices providing excellent quality of care at the close of life will comprehensively assess patient pain to understand its cause and both pharmacological and nonpharmacological approaches to its management, including the appropriate use of adjuvant medications, such as gabapentin for neuropathic pain. Policies and procedures should be in place to ensure that the use of opioids and other sedating medications are based on patient choice. All members of the interdisciplinary team should be available at time of a crisis, regardless of when it arises. A minority of patients dying while in hospice care will need an intensive caring unit, usually a free-standing inpatient hospice unit, to enable changes in the administration of medications on an hourly basis, including those rare cases in which the use of palliative sedation is the only possible means of symptom relief.

Box 2. Questions to Assess the Quality of Palliative Care or Hospice Programs**Competent Care Provided by Interdisciplinary Staff**

Has the hospital-based palliative care service or hospice obtained accreditation or certification through a recognized national organization?

If it is a hospice, is it Medicare certified?

Is care provided by an interdisciplinary team with appropriate training?

Are staff certified in hospice and palliative medicine?

Are the following services provided: medical, nursing, social work, volunteer, bereavement, and spiritual?

What is the average caseload of the registered nurse? Social worker? Home health aide? Spiritual counselor? Volunteer? How many hours per week do the medical director and physician staff work?

Is staff available 24 hours a day, 7 days a week, including visits by spiritual and social work services on the nights and weekend if there is a patient or family need?

Is there a dedicated inpatient hospice or palliative care unit? How many beds? How long can the patient stay in that unit? Is there a waiting list for the unit?

Does each team member use a standardized assessment tool? How is this information conveyed back to the primary care physician?

What policy and procedures are in place to ensure that patients receive their desired level of comfort? If patients want to remain alert while dying, how does the program work with patients to achieve that goal?

What are the policies and procedures regarding palliative sedation? How often is it used?

Is there a formulary? Which medications are covered? If the patient has a special need for a particular category of opioid, how easy is it to get that drug approved?

How are decisions regarding the use of x-rays, laboratory treatments, and expensive diagnostic tests made?

What palliative treatments can patients receive while in hospice?

What special types of programs are available (eg, life review, pet therapy)?

Does the program use complementary therapies (eg, music therapy, Reiki, massage, or therapeutic touch)?

Does the program provide care to dying patients in all settings? At home? Nursing home? Hospital? Assisted living?

Are intravenous services provided in various settings (eg, in the home, nursing home)?

What bereavement services are provided? What is the frequency of contact?

Where do bereavement groups meet? Are meetings held during nonworking hours?

Continuity and Coordination of Care

What steps does the program take to coordinate care across settings of care?

Is there one case manager assigned to the patient?

How does the service coordinate the care plan with other health care professionals, especially the primary care physician?

Patient- and Family-Centered Care

How is the care plan developed and evaluated to ensure adequate input from the patient and family?

What education is in place for the patient and family?

Is the staff trained in cultural competency?

Are interpreter services available 24 hours a day, 7 days a week?

Are there special outreach programs available for minority communities?

Access to Care

What range of services and access to specialist care is available to patient, family, or both?

What organizational relationships are in place to ensure the patient has access to proper care across the disease trajectory and during transitions in settings of care?

Commitment to Quality

How does the program monitor and improve its quality of care?

How many patient and family complaints were received in the last year? How were they resolved?

Does the program monitor for medical errors or sentinel events? How does the program respond?

How many patients revoke hospice services? For what reasons?

How many families contribute donations to the program after the death of the patient?

Does the program participate in national quality initiatives and benchmarking?

Adapted in part from the National Hospice Foundation guide on choosing an hospice program.¹⁵

Like hospital-based palliative care programs, hospice programs must evidence understanding and respect of the unique values of the patients' culture. For non-English-speaking patients, the availability of appropriately trained translators is an important first step. Supporting families and friends in their caregiving role is essential, as one family member in a recent focus group summarized, "You know what to

expect [with the patient disease course], how you can help, and what you can expect [from hospice]."¹⁶ Evidence of families' frequently taking patients to and from the emergency department may highlight inadequate family education and lack of on-call staff to consult with and support at-home symptom management. Hospices must ensure seamless transitions of care across the setting of care, including transi-

tions to the emergency department or acute care hospital. A hospice striving for excellence will support the primary care physician's role as being in charge of care, will keep him/her informed of all critical changes, and will develop a care plan with his/her involvement.

As required by the new Medicare conditions of participation, all certified hospices must engage in quality assessment and performance improvement activities and be able to articulate to referring physicians how they measure quality and the number of complaints received and how they were resolved. Brown University's Center for Gerontology and Health Care Research and the National Hospice and Palliative Care Organization have partnered over the past decade to provide actionable data collection tools and resources for hospices with the goal of helping ensure that care is competent, compassionate, and coordinated.²⁶ Medical record review and surveys of bereaved family members have been used to evaluate the quality of hospice. Chart-based indicators are relatively simple and currently being validated.^{28,29} Yet careful thought needs to be given to what counts as documentation. For example, is a physician note "met with family to talk about CPR [cardiopulmonary resuscitation]" adequate evidence of a family meeting? Additionally, the medical record reflects the health care professional's view and may not reflect the patient or family's perceptions of a conversation.

Consumers' perceptions are fundamental to any assessment of whether care at the close of life is patient-focused and family-centered. Although the ideal assessment is interviewing patients, the short length of stay in hospice care results in a very biased group of patients being interviewed, and there are important respondent burdens in interviewing dying patients.³⁰ Thus, bereaved family members are an important source of information on the quality of hospice services.

The Family Evaluation of Hospice Care Survey²⁶ is the only tool to examine the quality of hospice care that has been endorsed by the National Quality Forum.³¹ Not only must data be collected, but actionable reports must be prepared that allow the hospice team to monitor and improve quality of care. A voluntary repository for hospices enables them to collect and analyze bereaved family member surveys plus receive quarterly benchmarks and information on improving care. Nearly 1500 hospices are currently participating, but most reports are not publicly available. However, quality of care for patients with dementia in hospice³² and disparities among bereaved black family members compared with white family members have been published.³³

To provide clinicians, patients, and families with the information they need to make informed decisions, the Centers for Medicare & Medicaid Services should report publicly on the quality of hospice care services, using an instrument that measures key processes and outcomes of care based on what both consumers and experts believe are

important and should be responsive to interventions and changes in hospices over time.

CONCLUSION

Increasingly, primary care physicians will debate the choice faced by Mr K's physician—how and when do I refer a patient to a hospital-based palliative care service or hospice? Ultimately, this decision should be based on which array of services best meet the goals and needs of that patient and family. Although there is substantial variation in existing hospital-based palliative care services, the array of services for hospices is defined by the reimbursements, Medicare conditions of participation, and National Hospice and Palliative Care Organization Standards of Practice for Hospice Programs. Even when the patient is initially referred to a hospital-based palliative care service, a point in the disease trajectory is reached when most patients, will choose to enroll in a hospice. Although the majority of hospice programs strive for excellence, the quality of care varies and a reporting system is needed that will help primary care physicians, patients, and families choose a hospice based on publicly reported outcomes. Whether the dying patient receives care from a hospital-based palliative care service or a hospice, the guiding principles must be to strive for competent, compassionate, and coordinated care.

Financial Disclosures: Drs Teno and Connor report no conflicts. However, they report that Brown University is the copyright holder to the Family Evaluation of Hospice Care tool discussed in the article, but that tool is available to researchers, hospices, and National Hospice and Palliative Care Organization without a licensing fee. Hospices that participate in the voluntary data repository pay no fee beyond their membership fee.

Funding/Support: The Perspectives on Care at the Close of Life section is made possible by a grant from the Archstone Foundation.

Role of the Sponsor: The funding source had no role in the preparation, review, or approval of the manuscript.

Additional Information: The online table and Web resources are available at <http://www.jama.com>.

Additional Contributions: We thank Cindy Williams, BA, Brown University, for assistance in manuscript preparation, which is part of her regular duties. The creation of the voluntary Family Evaluation of Hospice Care data repository would not have been possible without the participation of more than 1500 innovative hospice programs. We thank them for their vision and leadership.

REFERENCES

1. Pan CX, Morrison RS, Meier DE, et al. How prevalent are hospital-based palliative care programs? status report and future directions. *J Palliat Med*. 2001; 4(3):315-324.
2. Organization NHPCO. NHPCO facts and figures: hospice care in America. http://www.nhpco.org/files/public/Statistics_Research/NHPCO_facts-and-figures_2008.pdf. Accessed December 2, 2008.
3. *Palliative Care in US Hospitals: Implications for Access to Quality Healthcare: Hearings Before the US Senate Special Committee on Aging*. 110th Cong 2nd Sess (2008) (statement of Diane E Meier, MD). <http://aging.senate.gov/events/hr203dm.pdf>. Accessed October 19, 2008.
4. von Gunten CF, Ferris FD, Portenoy RK, Glajchen M. Center to Advance Palliative Care manual: how to establish a palliative care program; 2001. <http://64.85.16.230/educate/content/elements/differencebetweenhpc.html>. Accessed on October 19, 2008.
5. World Health Organization. WHO definition of palliative care. <http://www.who.int/cancer/palliative/definition/en>. Accessed October 19, 2008.
6. Medicare and Medicaid programs: hospice conditions of participation. 2008; Fed Regist. 2008;73(109):32089-32220. <http://edocket.access.gpo.gov/2008/pdf/08-1305.pdf>. Accessed October 13, 2008.
7. Morrison RS, Penrod JD, Cassel JB, et al; Palliative Care Leadership Centers' Outcomes Group. Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168(16):1783-1790.

8. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ*. 2000;320(7233):469-472.
9. Quill TE. Initiating end-of-life discussions with seriously ill patients: addressing the 'elephant in the room.' *JAMA*. 2000;284(19):2502-2507.
10. Larson DG, Tobin DR. End-of-life conversations: evolving practice and theory. *JAMA*. 2000;284(12):1573-1578.
11. Virnig BA, Kind S, McBean M, Fisher E. Geographic variation in hospice use prior to death. *J Am Geriatr Soc*. 2000;48(9):1117-1125.
12. National Quality Forum. *National Framework and Preferred Practices Palliative and Hospice Care*. <http://www.qualityforum.org/publications/reports/palliative.asp>. Accessed October 19, 2008.
13. Saunders C. *Monograph in Commemoration of the 30th Anniversary of St Christopher's Hospice*. London, England: St Christopher's Hospice; 2001.
14. National Consensus Project for Quality Palliative Care Clinical practice guideline for quality palliative care; 2004. <http://www.nationalconsensusproject.org>. Accessed January 10, 2008.
15. National Hospice Foundation. How to select a hospice program. [http://www.caringinfo.org/userfiles/file/pdfs/hospiceCare/hospice_care\(1\).pdf](http://www.caringinfo.org/userfiles/file/pdfs/hospiceCare/hospice_care(1).pdf). Accessed January 19, 2008.
16. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *J Pain Symptom Manage*. 2001;22(3):738-751.
17. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*. 2000;284(19):2476-2482.
18. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA*. 1999;281(2):163-168.
19. Schoen C, Osborn R, How SK, Doty MM, Peugh J. In chronic condition: experiences of patients with complex health care needs, in eight countries, 2008. *Health Affairs (Millwood)*. 2008;28(1):w1-w16.
20. Smith TJ, Coyne PJ. Implantable drug delivery systems (IDDS) after failure of comprehensive medical management (CMM) can palliate symptoms in the most refractory cancer pain patients. *J Palliat Med*. 2005;8(4):736-742.
21. Casarett D, Crowley R, Stevenson C, Xie S, Teno J. Making difficult decisions about hospice enrollment: what do patients and families want to know? *J Am Geriatr Soc*. 2005;53(2):249-254.
22. Teno JM, Shu JE, Casarett D, Spence C, Rhodes R, Connor S. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007;34(2):120-125.
23. Rickerson E, Harrold J, Kapo J, Carroll JT, Casarett D. Timing of hospice referral and families' perceptions of services: are earlier hospice referrals better? *J Am Geriatr Soc*. 2005;53(5):819-823.
24. Carlson MD, Schlesinger M, Holford TR, Morrison RS, Bradley EH. Regulating palliative care: the case of hospice. *J Pain Symptom Manage*. 2008;36(2):107-116.
25. Lorenz KA, Ettner SL, Rosenfeld KE, Carlisle DM, Leake B, Asch SM. Cash and compassion: profit status and the delivery of hospice services. *J Palliat Med*. 2002;5(4):507-514.
26. Connor SR, Teno J, Spence C, Smith N. Family evaluation of hospice care: results from voluntary submission of data via website. *J Pain Symptom Manage*. 2005;30(1):9-17.
27. Connor SR, Tecca M, LundPerson J, Teno J. Measuring hospice care: the National Hospice and Palliative Care Organization National Hospice Data Set. *J Pain Symptom Manage*. 2004;28(4):316-328.
28. Dy S. *Quality Measures for Hospice and Palliative Care*. Tampa, FL: Annual Assembly of Hospice and Palliative Medicine; 2008.
29. Hanson L. *Measuring Quality of Care in Hospice and Palliative Care*. Tampa, FL: Annual Assembly of Hospice and Palliative Medicine; 2008.
30. Teno JM. Measuring end-of-life care outcomes retrospectively. *J Palliat Med*. 2005;8(suppl 1):S42-S49.
31. National Quality Forum. Prevoting review for "The National Quality Forum National Voluntary Consensus Standards for Symptom Management and End-of-Life Care in Cancer Patients" [memorandum to NQF members]. June 6, 2006. <http://www.qualityforum.org/pdf/cancer/eol.pdf> accessed November 21, 2008.
32. Mitchell SL, Kiely DK, Miller SC, Connor SR, Spence C, Teno JM. Hospice care for patients with dementia. *J Pain Symptom Manage*. 2007;34(1):7-16.
33. Rhodes RL, Teno JM, Connor SR. African American bereaved family members' perceptions of the quality of hospice care: lessened disparities, but opportunities to improve remain. *J Pain Symptom Manage*. 2007;34(5):472-479.

Web Resources for Palliative Care

AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

<http://www.aahpm.org>

Palliative care physician–membership organization hosts conferences and provides guidance to assist health care professionals in treating patients.

CENTER TO ADVANCE PALLIATIVE CARE

<http://www.capc.org>

Center to Advance Palliative Care provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.

CARING CONNECTIONS

<http://www.caringinfo.org>

A consumer Web site, Caring Connections is devoted to providing information on caregiving and choices for those with life-threatening illnesses.

EPIDEMIOLOGY OF DYING AND END-OF-LIFE EXPERIENCE

<http://www.edeledata.org>

An access point for clinicians, health policy experts, and advocates to search health services and epidemiological data on end-of-life care in the United States.

HOSPICE AND PALLIATIVE NURSES ASSOCIATION

<http://www.hpna.org>

This is a membership organization for nursing teams working in the specialty of hospice and palliative care across the life-span continuum.

INSTITUTE FOR HEALTHCARE IMPROVEMENT

<http://www.ihl.org/ihl>

The Institute for Healthcare Improvement is a not-for-profit organization leading the improvement of health care throughout the world.

NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE

<http://www.nationalconsensusproject.org>

The National Consensus Project for Quality Palliative Care promotes the implementation of clinical practice guidelines that ensure care of consistent and high quality and that guide the development and structure of new and existing palliative care services.

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

www.nhpco.org

The National Hospice and Palliative Care Organization is the membership organization for hospice and pal-

liative care programs and professionals in the United States and is committed to improving end-of-life care and expanding access to hospice and palliative care with the goal of enhancing the quality of life for people dying in the United States and their families.

NATIONAL QUALITY FORUM

www.qualityforum.org

The National Quality Forum is a not-for-profit membership organization created to develop and implement a national strategy for health care quality measurement and reporting.

CICELY SAUNDERS INTERNATIONAL

<http://www.cicelysaundersfoundation.org/>

Cicely Saunders International focuses on carrying out quality research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it.

TOOLKIT OF INSTRUMENTS TO MEASURE END-OF-LIFE CARE

<http://www.chcr.brown.edu/pcoc/toolkit.htm>

This Web site offers an authoritative bibliography of instruments to measure the quality of care and quality of life for dying patients and their families.