

Consultation in Palliative Medicine

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Palliative medicine is an emerging medical discipline in the United States, modeled after similar efforts in Great Britain, Australia, and Canada. Increasingly, academic medical centers are starting clinical programs in palliative medicine including inpatient consultation services. A description of the essential components of a palliative medicine consultation is presented, based on the author's experience of more than 600 patient encounters at the Medical College of Wisconsin in Milwaukee. A palliative medicine consultation consists of 6 features: assessment and management of physical symptoms; assisting patients to identify personal goals for end-of-life care; assessment and management of psychological and spiritual needs; assessment of the patient's support system; assessment and communication of estimated prognosis; and assessment of discharge planning issues.

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Palliative medicine is defined by the World Health Organization, Geneva, Switzerland, as "the active total care of patients whose disease is not responsive to curative treatment."¹ The need to develop education and clinical care programs in palliative medicine has been recommended by the World Health Organization to all its member nations.¹ Since the 1980s many developed countries have moved forward to improve palliative medicine education and clinical care.²⁻⁴ Palliative medicine is now a recognized medical specialty in Great Britain. In Canada and Australia palliative medicine is recognized with departmental stature in its medical schools. The United States lags behind other countries in the development of palliative medicine as a recognized aspect of its national health care system. However, in the past 10 years several US academic medical centers have developed clinical, educational, and/or research programs in palliative medicine.⁵⁻¹⁰ Most US physicians currently providing palliative medicine consultations have a background in medical oncology, geriatrics, general internal medicine, or family medicine.

The discipline of palliative medicine includes control of physical and psychological symptoms, communication skills, awareness of bioethical principles, and understanding the various home care and institutional providers of care for dying patients. As a cohesive entity, these concepts are not widely taught in undergraduate or postgraduate medical training programs. Although inadequate control of cancer-related pain has been highlighted as the most tangible focus of poor palliative care on both a national and international basis, in fact, there is similarly poor management of other nonpain symptoms, poor utilization of communication skills in conveying end-of-life options, and widespread misunderstanding of hospice philosophy, eligibility, and covered services.^{1,11}

In a move to improve the care of the dying at the Medical College of Wisconsin, Milwaukee, a palliative care consultation service was begun in 1993.¹⁰ Designed as a model of physician-nurse collaborative care, the Medical College of Wisconsin Palliative Care Service has participated in more than 600 inpatient consultations. The Palliative Care Service serves a 300-bed tertiary care academic hospital, Froedtert Memorial Lutheran Hospital in Milwaukee. The most com-

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mon underlying diagnoses are cancer (65%) and acquired immunodeficiency syndrome (20%), but consultations have been received for all major diagnoses including end-stage heart, lung, liver, and kidney diseases and dementia. Consultation demographics include a majority of male patients (62% men, 38% women). Patient ethnicity is most commonly white (59%) or African American (34%).

The clinical goals of the Palliative Care Service include providing assistance to patients, families, and the medical team regarding symptom control, end-of-life decision making, and serving as a resource for coordination of discharge planning. Palliative Care Service consults must be ordered by a physician, but nurses or social workers may initiate a consult if coordinated by a physician. The palliative care consult includes both a physician and nurse assessment and treatment plan, along with assistance from social service and other appropriate disciplines (eg, psychology, chaplaincy, or ethics committee). This model of collaborative care is ideal for meeting the diverse needs of patients and families. This article explores the components of a palliative medicine consultation.

CONSULTATION IN PALLIATIVE MEDICINE

The core features of a palliative medicine consultation are the following: assessment and management of physical symptoms; assisting patients in the identification of personal goals for end-of-life care; assessment and management of psychological and spiritual needs; assessment of the patient's support system; assessment and communication of estimated prognosis; and assessment of discharge planning issues. Although the initial consultation question is often focused around 1 issue (eg, pain control), it is typical for there to be a host of related issues that need to be resolved, or at least considered, before arriving at an optimal treatment program. For example, knowing the estimated survival and level of family support is crucial in determining the best treatment strategy for pain control, including method of drug delivery and

use of adjunctive treatments. Thus, a palliative medicine consultation must include a wide range of issues, including current physical and psychological symptoms, coping mechanisms, family support, and expected prognosis.

ASSESSMENT AND MANAGEMENT OF PHYSICAL SYMPTOMS

Consultation in palliative medicine starts with understanding the current level of symptom distress. The frequency of common end-of-life symptoms has been well reported.¹² Pain, nausea, dry mouth, dyspnea, anorexia, edema, and fever are among the more common symptoms that need evaluation and treatment. General principles of symptom assessment include symptom history—onset, location, aggravating and relieving factors, quality, intensity, and effect on activities of daily living; prior measures used for symptom relief and their impact; patient understanding of symptom causality; patient goals for symptom relief; frequent reassessment to monitor effects of treatment; and determination of medical appropriateness and patient desire for further diagnostic evaluation. For the dying patient and the palliative medicine consultant, this last issue is often the most difficult—deciding when *not* to pursue further aggressive diagnostics and therapeutics. For example, at what point is a workup for dysphagia, traditionally evaluated by a barium swallow and/or endoscopy, no longer indicated based on patient goals and expected survival? Coming to an understanding of this issue is crucial to provide patients with the necessary autonomy to make rational end-of-life decisions and to avoid overtreatment, a common problem in end-of-life care.¹¹

Management of end-of-life symptoms represents a true medical challenge requiring knowledge of the pathophysiology of common end-of-life symptom syndromes (eg, metastatic plexopathy, terminal delirium, anorexia-cachexia syndrome), skill in the use of drug and nondrug treatments, and knowledge of when to refer patients for specialized techniques.

ASSISTING PATIENTS TO IDENTIFY PERSONAL GOALS

At some point, the care of every dying patient needs to shift away from a life-prolonging approach to one focusing on short-term goals oriented toward comfort. The role of the palliative medicine consultant is to help the patient review his or her current medical treatment and identify end-of-life goals (eg, improve pain control, return home, or no further hospital admissions) and then to decide which current interventions are advancing those goals and which are adding unnecessary burden. If new interventions are needed to help attain the patients' goals, these can be added (eg, oral antibiotics for a painful infection). Throughout this process, helping patients and the medical team focus on end-of-life goals is paramount. This means helping the patient to identify those aspects of care that are most meaningful to them.

In the inpatient hospital setting, the decision to shift away from a life-prolonging orientation is typically traumatic, requiring a fundamental change in the way the medical teams view not only the patient but also their own role as health care providers. Patients usually need to be given explicit permission to question the medical tests and/or routines that physicians and nurses assume to be ordinary care. This includes everything from continuing chemotherapy, tube feedings, or daily blood tests. Measures seen as ordinary in an acute care hospital, such as intravenous fluids and vital signs, are usually inappropriate and burdensome to the care of the dying. Common end-of-life issues that patients and their medical team struggle with include the continued use of or anticipated need for future cardiopulmonary resuscitation; ventilatory support; kidney dialysis; antineoplastic chemotherapy or radiation therapy; hospital admissions or emergency department visits; intensive care unit admissions; parenteral or oral antibiotics; nonoral feeding; artificial hydration; continuous pulse oximetry; and vital sign monitoring.

Arriving at the decision to withdraw or withhold aspects of care is

often difficult for family members and the medical team. The commonly encountered issues and/or barriers to treatment withdrawal for physicians and nurses are the following: fear of ethical impropriety (eg, withdrawing artificial hydration), fear of negative psychological impact to the patient, fear of litigation, inability to recognize that

physicians and patients both need to have some concept of prognosis to evaluate the appropriateness of different medical interventions

death is near, inability to recognize limitations of further aggressive medical care, and psychological attachment to the patient—difficulty letting go. The family issues are the following: psychological attachment to the patient—difficulty letting go; inability to recognize that death is near; inability to accept the limitations of further aggressive medical care; continued hope for miracles; fear of negative psychological impact to the patient; and fear of ethical or religious impropriety. Among those listed, probably the most common surround the psychological meaning of treatment withdrawal and concern about the ethics of withdrawing artificial hydration and nonoral feeding. Although the legal and ethical acceptance of treatment withdrawal is now well established in American medicine, there is still widespread confusion and concern about these issues.¹³ An important role of the palliative medicine consultant is to help explore with the family and the medical team how their personal motivations to continue aggressive care may be in conflict with patient goals.

ASSESSMENT AND MANAGEMENT OF PSYCHOLOGICAL AND SPIRITUAL NEEDS

Fear of dying, anxiety about the afterlife, denial of impending death, concerns about family, finances, or

a search for meaning within personal suffering are just a few of the common psychological and spiritual issues reported by the dying. Goals of a palliative medicine consultation include understanding the intensity of these issues and how they may be affecting decision making and developing intervention strategies that are appropriate for the clinical situation. Many issues can be explored and resolved during routine consultation visits by using skills of active listening and counseling. The consultant can help patients at the bedside by normalizing feelings (eg, being angry

about dying is common), provide information (eg, discuss prognostic information), and encourage short-term goal setting (eg, getting home). Other interventions to help patients with their psychological and spiritual needs include facilitating patient-family meetings to openly discuss the future; working with other medical team members to help them find ways to assist the patient-family unit; facilitating communication with clergy; and making a referral for psychological and/or psychiatric support.

ASSESSMENT OF THE PATIENT SUPPORT SYSTEM

Who is available to help the patient through the dying process? Although some patients have supportive families, able and willing to provide the necessary physical, emotional, and spiritual support, many will not. Even when available, it is common for patients to have concerns about being a burden to others, concerns that have the effect of constricting an otherwise available support system. The palliative medicine consultant needs to explore these issues to help the patient identify appropriate resources and to come to terms with the personal meaning of asking for support. Such resources may include family, friends, community (eg, church, work, or neighborhood), and volunteers.

ASSESSMENT AND COMMUNICATION OF ESTIMATED SURVIVAL

The palliative medicine consultant has an important duty to help clarify a patient's prognosis. This issue, often avoided by health professionals by such comments as "we really don't know" or "there is no way to tell," is often the core piece of information needed by the consultant to determine the most appropriate symptom control measures and discharge planning recommendations.

Coming to an understanding of the expected prognosis is central to end-of-life care since virtually all dying patients and/or their families will at some point ask, "How long do I have to live?" The reason for this question may range from a concrete need to make important end-of-life plans (eg, advance directives, wills, or family plans) to a more spiritual and/or existential inquiry. Patients may want to reassure themselves that death is not imminent or, conversely, to confirm their impression that death is near. Patients who ask this question generally want to receive a definitive answer, although typically not a specific date.

Physicians and patients both need to have some concept of prognosis to evaluate the appropriateness of different medical interventions. The patient with 1 week compared with 3 months to live will likely view various treatment options differently. Patients and families need to know their prognosis for important psychological reasons. For patients, understanding their prognosis helps them to begin a life review, a time to look back on their lives, their accomplishments, and their relationships. For families, understanding prognosis helps with anticipatory grief—the important phase of mental preparation before death that helps the grieving process after death. Finally, understanding that death is coming allows health care providers, patients, and families to mobilize community support services. One such service is home hospice care. Under the Medicare hospice benefit, the single largest payer of hospice care in the United States, a physician must cer-

tify that a patient has an expected prognosis of 6 months or less based on an assessment that the underlying disease will follow a typical natural history. The reluctance or inability of physicians, often owing to the lack of awareness of prognostic factors, to certify patients as eligible for hospice care is a major barrier to patient referral for hospice care.

There is an extensive data source to help clinicians establish end-of-life prognosis for cancer, less so for end-stage heart or lung disease, acquired immunodeficiency syndrome, and dementia.¹⁴⁻²⁴ Several common themes in the prognosis literature deserve mention. First, acute, catastrophic causes of death (eg, massive hemorrhage, pulmonary embolism, or sepsis) cannot be predicted. Second, experienced clinicians are better able to predict prognosis than inexperienced clinicians, suggesting that they observe "patterns of illness in terminal care."¹⁴ Third, predicting prognosis with any certainty beyond 3 to 6 months becomes increasingly difficult as the number of confounding variables increase.

General indicators of survival (any terminal diagnosis) of days to a few weeks include being 100% bed bound, little if any oral intake, anuria, and terminal delirium. The best predictor of end-of-life prognosis among patients with cancer is performance status. In particular, patients with cancer with a performance status of 50 or less using the Karnofsky scale (disabled, needs frequent medical care) have a median survival of only 3 months.¹⁹ Related factors to performance status (which likely reflects total body tumor burden) that also have predictive power include impairment with nutrition, dyspnea, and deterioration of mental status. In noncancer diseases (eg, end-stage heart or lung disease), being symptomatic despite maximal medical therapy and frequent need for hospitalization are surrogate markers of poor performance status, indicating a poor prognosis. Among patients with acquired immunodeficiency syndrome, markers of poor survival (<6 months) include frequent hospital support, visceral Kaposi sarcoma, non-Hodgkin lymphoma, and uncontrolled diarrhea.

Communicating prognostic information to patients and families must be done carefully. Patients who ask direct questions should be answered as truthfully as possible and be provided a time frame (eg, 1-3 weeks, 2-4 months). Conversely, there is no need to force prognostic information on patients who directly state a desire not to be told. However, in situations where patients' decisions seem inappropriate to their prognoses (eg, a patient with advanced metastatic cancer who wants to have cardiopulmonary resuscitation), a clear discussion of prognosis is appropriate.

ASSESSMENT OF DISCHARGE PLANNING ISSUES

Hospitalized patients and families are confronted with an ever-increasing and confusing list of options for end-of-life care. These include remaining in an acute care hospital, returning home with or without home care or home hospice services, long-term care with or without contracted hospice services, and inpatient hospice care. Most physicians, nurses, and many hospital discharge planners have little knowledge of the various symptom control, emotional support, and financial issues that are relevant in determining the optimal place for end-of-life care.

The patients' goals are the starting point for consideration. Most patients want to be home, although many are afraid of the burden this will place on their family and/or friends. To facilitate home transfer a series of questions needs to be addressed:

- What is the expected prognosis? Are there caregivers who can provide patient support for the expected length of time until death?
- What level of caregiver support is needed in the home—around the clock, nighttime only, while a spouse is at work?
- What is the physical and emotional condition of the caregiver(s)? What is the emotional support system for the caregiver(s)?
- What are the patient's symptom control needs? What level of support technology is needed to keep the patient comfortable at home (eg, oral medications, intrave-

nous infusions, oxygen, or suction)? Can the caregiver realistically manage the symptom control needs in the home?

- What type of home care or hospice insurance does the patient have? Is the patient eligible for a Medicare, state, or private insurance hospice benefit?

These questions can only be answered by combined input from the patient and family, physician, nurse, and discharge planner or hospital social worker. Physician input is crucial and an area in which the palliative medicine consultant can play a major role. Specific physician issues include estimation and communication of prognosis and designing a symptom control program that facilitates home care (eg, use of oral vs parenteral medications).

For patients in whom there is lack of caregiver support, or a symptom control burden that is unmanageable in the home, other options will need to be explored. The variables in deciding on the optimal disposition in this setting include patient and family goals, local resources (eg, availability of a nearby inpatient hospice facility), and insurance status. The role of the physician here is crucial in helping to provide counsel, guidance, and ongoing support.

CONCLUSIONS

The idea of requesting a palliative medicine consultation, unheard of 10 years ago in the United States, is now gaining acceptance. This article has presented a framework for conceptualizing a palliative medicine consultation based on the author's experience of more than 600 patient encounters. Acceptance of the concept of a palliative medicine consultation has not been widespread. At the Medical College of Wisconsin, the vast majority of consults come from internal medicine and medical oncology physicians with a relative paucity from surgery physicians. There is no doubt that the nature of our consultation is threatening to some physicians, as they view palliative care to be one facet of routine medical care that every physician should be able to deliver. While this may be a reasonable goal of future medical educa-

tion, physicians with special interest and training in end-of-life care possess attitudes, knowledge, and skills not shared by many physicians.

The purpose of any consultation is to provide the referring physician with information and guidance in communicating new findings and making patient care recommendations. Thus, the palliative medicine consultant is in a special position to help physicians who are struggling not only with patient care problems but often with their personal fears and concerns about end-of-life care. This feature, whereby physicians can dialogue with their colleagues about end-of-life care, using a traditional and familiar consultation setting, is what distinguishes a palliative medicine consultation from other available patient-centered end-of-life support services.

The role of palliative medicine in the American health care system is in rapid evolution. A growing number of physicians are devoting a significant portion of their practices to clinical end-of-life care, as well as education and research of such care, especially within academic medicine. Many have already begun or are considering starting a clinical program in palliative medicine that includes a consultation service. Consultation services in palliative medicine will certainly spread in the coming decade and are an effective way of helping to improve end-of-life patient care and providing a venue for health professional education.

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