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An 86-Year-Old Woman With Cardiac Cachexia Contemplating the End of Her Life

Review of Hospice Care

Jean S. Kutner, MD, MSPH, Discussant

DR DELBANCO: Mrs H is an 86-year-old retired health care professional and grandmother with severe cardiac cachexia. She is considering the best way to have her life end.

Mrs H has Medicare and supplemental insurance, receives Social Security payments, and has a few other funds providing modest support. She lives by herself on the second floor of a walk-up apartment building and has a personal care attendant to help during the day, paid for by her daughter, who has recently lost her job and may not be able to provide ongoing financial help.

Mrs H walks primarily with a walker and is dyspneic with minimal exertion (New York Heart Association class IIIB). She leaves her apartment rarely, and always with assistance. She is able to bathe, clothe, and toilet herself independently but requires assistance with meal preparation and other instrumental activities of daily living (IADLs). Her mobility is severely limited by arthritic joints and she has difficulty with balance. She has fallen several times, requiring hospitalization for minor injuries on numerous occasions.

Mrs H has had insulin-dependent diabetes since the 1980s. She experienced a myocardial infarction in 1996 and subsequently underwent placement of a stent. Following multiple percutaneous coronary interventions, intermittent episodes of atrial fibrillation, and implantation of a biventricular/implantable cardioverter-defibrillator (ICD) cardiac pacemaker, she has severe ischemic cardiomyopathy, with a left ventricular ejection fraction of 15%.

In addition, Mrs H has a long and complicated medical history, including hypothyroidism, breast cancer, depression, allergic rhinitis, degenerative joint disease, pneumonia complicated by empyema, removal of a ruptured appendix, cholecystectomy, uterine suspension, gastroesophageal reflux, diabetic neuropathy, diabetic foot ulcers, orthostatic hypotension, anemia, spinal stenosis, and recurrent hyperkale-

Mrs H is an 86-year-old woman with progressive congestive heart failure and multiple chronic conditions who is experiencing worsening function and quality of life despite maximum medical therapies. She seeks advice regarding control over the circumstances of the end of her life, be it by suicide or under hospice care. Typical of US populations older than 65 years with multiple chronic health conditions and functional decline who are facing the end of life, Mrs H's concerns are particularly about quality of life, not being a burden on loved ones, and maintaining control. As she demonstrates, psychological, existential, and social factors, particularly fear of being a burden, are more common reasons for desiring hastened death than those related directly to physical symptoms. Hospice, which provides a multidisciplinary approach to care at the end of life, can assist Mrs H and her family in making decisions that are consistent with her goals.

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mia. Her depression has been treated by her psychiatrist for many years with therapy and medications, currently fluoxetine. When she was no longer able to travel to his office, he made home visits and talked with her by telephone. He did not believe that her wish for suicide was related to depression but rather to her concerns about dependence and being a burden. At the hospital where she receives ongoing pri-

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mary and specialty care, during the past 17 years she has had 148 outpatient general medicine visits, 35 cardiology visits, 155 visits to other specialists, and 25 hospitalizations.

On recent physical examination, Mrs H looked quite well but was pale and bruised after hospitalization for a fall. She was unsteady while walking and used a walker. Her blood pressure was 110/70 mm Hg, heart rate was 50/min (paced), and respiratory rate was 16/min. Her jugular venous pressure was approximately 7 cm. Her lungs were clear, and cardiac examination revealed a soft, holosystolic murmur at the left border. She did not exhibit hepatjugular reflux but had 1-2+ pitting edema of the lower extremities. Neurological evaluation was consistent with peripheral neuropathy, but there were no lateralizing signs. Her feet did not reveal ulceration.

Recent laboratory findings included creatinine levels ranging from 1.2 to 2.4 mg/dL and serum urea nitrogen levels ranging from 27 to 63 mg/dL, depending on her level of hydration. Serum sodium levels have been generally normal, and she has not had proteinuria. Her hematocrit was 28% to 32%, and her glucose levels ranged from 160 to 220 mg/dL, with intermittent hypoglycemic episodes. Her hemoglobin A_{1c} hovers around 8%. Other laboratory test results were unremarkable.

Mrs H's medications include insulin, acetaminophen-codeine, fluticasone, furosemide, trimethoprim-sulfamethoxazole (for urinary tract prophylaxis after multiple infections), fexofenadine, clopidogrel, levothyroxine, omeprazole, fluoxetine, prednisone, simvastatin, nitroglycerin, aspirin, and a multivitamin.

Mrs H is frustrated by the decline of her health and worries frequently about the inevitability of continued deterioration. Considering herself fortunate for having lived a full and "exciting" life, she is considering suicide rather than facing a life of dependency, indicating that she would not want to continue a life filled with suffering. She does not want resuscitation attempts or intubation, which her primary care physician has documented; her daughter serves as her proxy. Her primary care physician is suggesting hospice care.

MRS H: HER VIEW

I think the thing that I miss most in the quality of my life is not being able to interact with my surroundings. When I go out on the street, I cannot stop thinking about where I'm stepping. I can't look at the beautiful flowers or see what somebody across the street is doing.

I'm still doing things and I still enjoy life, but I'm taking so many medicines, and each year I'm a little worse. I'm very afraid that I'm going to be incapable of doing anything—I had a grandfather who used to say, "Why doesn't God take me?" Well, my feeling is "Why doesn't my heart stop beating because it's in such bad shape?" I used to think when I got depressed that I could go and throw myself off the top of the building. Now I couldn't even get there.

I talked with my doctor about the fact that I was interested in the end of life and that I was thinking about discontinuing all my food and liquids and all my medicines,

including my insulin. She told me that if I stopped taking insulin I might have a very high blood glucose. My experience with high blood glucose was that I got very, very thirsty. And when I thought about it, I thought, "Well, that means I would die of thirst." I realized that didn't appeal to me.

"Suicide" has so many bad things connected with it. I think "ending your life" sounds like you are not doing something disgraceful or that would be hard for your children to take. I discussed suicide with my daughter, and she was very, very upset. I think I would have to convince her that it was for me. But I wouldn't do it unless she came around to it. Hospice could help me by talking to me and letting me know if my plan sounds sensible.

AT THE CROSSROADS: QUESTIONS FOR DR KUTNER

What is the epidemiology of end-of-life care in the United States? What are Mrs H's prognosis and her clinical options? What issues are most important to patients and families facing the end of life? What is hospice and what does it offer? How may hospice help Mrs H address the timing and mechanism of the end of her life? How do patients and families make decisions about enrolling in hospice? What are the outcomes (eg, patient, family, costs/utilization) of hospice care? What do you recommend for Mrs H and her family?

DR KUTNER: Mrs H presents a typical picture of "end of life" in the United States: "I was pretty good until I was in my early 70s. I had my first heart attack sometime before that . . . I've had diabetes since I was in my 50s. I have a lot of arthritis . . . and I've fallen a few times." Two-thirds of persons older than 65 years and almost three-quarters of those older than 80 years have multiple chronic health conditions; 68% of Medicare spending goes to individuals who have 5 or more chronic diseases.^{1,2} The incidence and prevalence of cardiovascular disease increase with age. As a result, cardiovascular disease is the leading cause of hospitalization, has the highest direct costs,³ and is the leading cause of death, accounting for just over 25% of US deaths in 2005.⁴

Epidemiology of End-of-Life Care

End-of-life care varies across the United States. Although almost 40% of deaths occur in hospitals,⁵ variation by geographic region is related more to hospital bed availability, reimbursement for hospice services, and number of physicians than to patient preference.⁶ In studies of persons with advanced chronic illness, 43% to 50% prefer to receive care at home when recovery from illness is considered unlikely.^{7,8} Patient characteristics affect the location of end-of-life care. A mortality follow-back survey of family members representing 1578 decedents, with a 2-stage probability sample used to estimate outcomes for 1.97 million deaths from chronic illness in the United States in 2000, found that women (67%) and those currently unmarried (88%) were more likely to die in a nursing home; that those who died with home hospice services were more likely to have had

cancer (68%); and that persons who died at home without formal services were more likely to have died of heart disease (77%) ($P < .001$ for all comparisons).⁵

While cause of death was similar across racial groups, analysis of a US national random sample of traditional fee-for-service Medicare beneficiaries aged 66 years or older who died in 2001 found that black and Hispanic Medicare decedents had significantly higher expenditures (\$26 704 and \$31 702, respectively) in the last 6 months of life than did white decedents (\$20 166). Most of the racial and ethnic differences in end-of-life costs were attributed to differences in use of life-sustaining interventions, including intensive care unit admission, mechanical ventilation, gastrostomy for artificial nutrition, resuscitation, and cardiac conversion. After controlling for all other factors, use of these aggressive interventions accounted for between 21% and 33% of the difference in total end-of-life costs.⁹

The type of physician a patient sees and the nature of the encounter influence the end-of-life experience. Active primary care is associated with less costly end-of-life hospital utilization. In a random sample of 116 318 Medicare beneficiaries aged 66 years or older who died in the last 6 months of 2001, more primary care visits in months 18 to 7 before death was associated with reduced hospital days, in-hospital deaths, costs, and preventable hospital admissions.¹⁰ In another study, terminally ill cancer patients and their informal caregivers who had end-of-life discussions with their physicians experienced less aggressive medical care near death and earlier referrals to hospice.¹¹

Prognosis and Clinical Options for Mrs H

Mrs H describes the uncertainty of heart failure prognosis: “. . . [O]ne thing [my doctor] said to me was that I've lived much longer than anybody would have expected me to live, knowing my heart . . . I've been expecting to die for the last 10 years . . . I could live for another 10 years with good care and everything . . . that's ridiculous.” The prospective Established Populations for Epidemiologic Studies of the Elderly (EPESE) compared dependency in ADLs among 4 groups 1 year prior to death: sudden death, cancer, organ failure, and frailty. Most relevant to Mrs H, the organ failure trajectory depicts an overall pattern of decline in function that is punctuated by decrements. One of these decrements is associated with mortality, but it is impossible to predict which one.¹² Similarly, Teno et al¹³ found that more than 40% of persons dying of diabetes mellitus, congestive heart failure (CHF), chronic obstructive pulmonary disease, or cerebrovascular accident had existing ADL impairments 1 year prior to death. Persons dying of noncancer causes (including CHF) had an increase from 1.6 to 2.3 ADL impairments in the last 5 months of life.

Despite advances in heart failure therapy, prognosis remains poor and survival is difficult to predict: approximately 25% survive 1 year, 50% survive 1 to 5 years, and 25% survive more than 5 years.^{14,15} The Study to Under-

stand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) concluded that the goal of determining with a high degree of accuracy which individual patients with CHF will die within 6 months is unrealistic.^{16,17} Patients tend to live for variable lengths of time in a continuous state of poor health punctuated by intermittent exacerbations, and the proximate cause of death is often a relatively sudden and unpredictable event. Clinicians may be reluctant to refer individuals with heart failure for palliative and hospice care because of uncertain timing of death.

Prognostication has important implications for therapeutic options and for patient and family decision making. Poor prognosis has been associated with clinical characteristics (ie, third heart sound, elevated jugular venous pressure, low systolic blood pressure, reduced ejection fraction, comorbidities, older age, male sex); laboratory findings (ie, anemia, hyponatremia, renal insufficiency, elevated brain-type natriuretic peptide); health and functional status, both physician-estimated (New York Heart Association class) and patient-derived (Kansas City Cardiomyopathy Questionnaire, 6-minute walk); medication use, especially angiotensin-converting enzyme inhibitors and β -blockers; and devices, such as implantable defibrillators.^{14,18-24}

Consider the application of 2 prognostic models to Mrs H: a 4-item risk score and the Seattle Heart Failure Model. The 4-item risk score, derived from patients aged 70 years or older admitted with a diagnosis of CHF, includes 4 independent clinical correlates of 6-month mortality measured at the time of hospital admission.¹⁴ Applying the 4-item risk score to Mrs H's March 2009 hospital admission yields a predicted 6-month mortality of 41% (this risk score does not apply exactly, since this admission was not for CHF). The Seattle Heart Failure Model, composed of 14 continuous and 10 categorical variables, was derived from a cohort of 1125 CHF patients and was prospectively validated in 5 additional cohorts (N=9942).²⁴ Using the Seattle Heart Failure Model, Mrs H has a predicted 1-year mortality of 30% and a mean life expectancy of 2.8 years.

One might expect that physicians have a good gestalt regarding their patients' prognoses, especially if they know a patient well. Not so: Physician prognoses are inaccurate, with error tending to be systematically optimistic. In a prospective cohort study of terminally ill patients and their physicians, 20% of predictions were accurate, 63% were optimistic, and 17% were pessimistic. Moreover, the likelihood of erroneous prediction increased as the duration of the patient-physician relationship increased.²⁵

Issues Most Important to Patients and Families Facing the End of Life

For the purposes of this discussion, I consider the “end of life” to begin with the onset of advanced illness that is beyond cure, rather than limiting it to the time of imminent death. Mrs H vividly describes what is important to her and expresses continued enjoyment of life despite her physical limitations. There is significant concordance among stud-

ies that have explored patient, family caregiver, and health care practitioner perspectives regarding a “good death.” Common priorities include spending time with family and friends, pain and other symptom management, maintaining dignity and self-respect, being at peace, minimizing burden on loved ones, avoiding prolongation of dying, achieving a sense of control, clear decision making, and contributing to others.²⁶⁻²⁸ However, the process of dying and death remains highly individualized, making it essential that clinicians both ask questions and listen to their patients to ascertain their priorities and facilitate achievement of their stated goals.

Hospice Care

All hospice care is palliative, but not all palliative care is provided by hospices. Hospice, as defined by the Medicare Hospice Benefit (MHB), is a health care delivery system focused on caring for the patient and family after treatment efforts aimed at changing the course of the terminal illness substantially are no longer effective or when the patient decides to stop treatment with curative intent. Under the MHB, the patient’s primary physician and the hospice medical director must certify that the patient has an expected life expectancy of 6 months or less if the disease trajectory follows its normal course, a criterion that may be difficult to meet in the uncertain heart failure disease trajectory. Patients remain eligible for hospice care under the MHB as long as these criteria are met. Patients can enroll in and disenroll from hospice any number of times, as their clinical condition and goals change over time.^{29,30}

Hospice offers services for pain and symptom management and psychosocial and spiritual support. Care is coordinated by an interdisciplinary team of physicians, nurses, social workers, home health aides, dietitians, therapists, chaplains, counselors, and volunteers with end-of-life care expertise. Hospice also provides medical equipment, medications, and supplies related to the terminal illness and family bereavement support. Care is provided in any setting, including the home, nursing home, assisted living facility, hospital, and freestanding hospice. Location of hospice care provision is determined by the patient’s functional status, available support, and acuity of symptom management needs. Hospital-based hospice care is generally reserved for those with acute symptom management needs or those who are actively dying. Around-the-clock caregivers are not required for hospice enrollment, but patients should have sufficient support to live safely in their environment of choice. The patient’s primary physician may provide overall management, supported and backed up by a hospice medical director. Hospice receives a set payment rate per day, based on level of care (ie, routine home care, continuous home care, general inpatient care, or inpatient respite care). While the MHB requires a core set of services, those provided by individual hospices vary significantly. Hospices that have Medicare certification tend to offer a broader range of services.^{29,31,32}

Hospice remains underused. Only 39% of all US decedents receive hospice care. The mean length of hospice stay

for these individuals is about 69 days; the median is about 21 days. About 35% of hospice patients have a hospice stay of fewer than 7 days.³³ Rates of hospice use by the Medicare population vary significantly with geographic location.⁶ Rural environments with lower population density consistently demonstrate lower rates of hospice use.³⁴ Large geographic areas of the United States lack access to home-based hospice. While hospices serve nearly 99% of metropolitan zip codes, only 76% of rural zip codes are served. Each year, more than 15 000 Medicare-enrolled elders die in areas not served by home-based hospice care.^{35,36}

The Role of Hospice for Mrs H and the End of Her Life

Mrs H is not thinking just about hospice. She is also considering how she envisions the end of her life. She is “afraid of being more incapacitated” and describes talking with her primary care physician “*about the fact that I was . . . thinking about discontinuing all my food and liquids and all my medicines . . .*” Hospice excels at helping patients and families plan for the circumstances of their last months, weeks, and days, expertise that Mrs H recognizes: “*I don’t expect to die in 6 months unless I actively pursue it. I don’t think that any professional caregiver would want somebody to commit suicide. But . . . I think that I would get guidance from hospice and maybe change my plan or something.*”

Factors associated with desire for hastened death are often complex and multifactorial. As is evident with Mrs H, psychological, existential, and social reasons, particularly fear of being a burden, are more prominent than those directly related to physical symptoms.^{37,38} Allowing patients who are still physically capable of eating and drinking to stop doing so voluntarily appears legally acceptable but remains morally controversial. By some, such a decision is considered a form of suicide. By others, it is a decision to forgo life-sustaining therapy.³⁹ A patient’s decision to refuse food and fluids has the ethical “advantage” of being neither physician-ordered nor -directed, which differentiates it from physician-assisted suicide, defined as the prescription of lethal doses of medication to enable a terminally ill individual to hasten his/her own death. In the United States, physician-assisted suicide is legal only in Oregon and Washington, with both states requiring referral to a mental health care professional if there is concern that the patient’s judgment is impaired by a psychiatric or psychological disorder or depression. Hastening death under these acts has been uncommon (<0.14% of all deaths per year in Oregon).⁴⁰ Effective palliative and hospice care may address many of the reasons patients request assistance in dying and appears to result in about half changing their minds about assisted suicide.^{41,42}

Honoring a decision to voluntarily cease eating and drinking requires support from the family, physician, and health care team, who must provide appropriate palliative care as the dying process unfolds.³⁹ Knowledge about such options may help patients expend their energy on other matters, as it diminishes fear of being trapped in a life filled with suffering. Most will not pursue such measures if they re-

ceive adequate palliative care.⁴³ Nevertheless, stopping eating and drinking voluntarily is not uncommon, even among those receiving hospice care. A survey of hospice nurses in Oregon found that 33% had cared for a patient in the prior 4 years who had deliberately hastened death by voluntarily refusing food and fluids, and the nurses rated most of these deaths as “good.”⁴⁴

If Mrs H is considering measures that would shorten her life, either by stopping medications or food and fluids, consideration should be given also to deactivating her ICD. Discussions about deactivating ICDs should be considered in the context of other goals of health care; a decision to deactivate the ICD may be consistent with Mrs H’s overall wishes.^{45,46}

Patient and Family Decisions About Enrolling in Hospice

Mrs H’s desire to include her family in the decision (“*When I think of the end of my life, I would discuss it with my daughter and make sure that she understands what I want . . .*”) is consistent with the literature regarding patient and family decisions about hospice enrollment. The decision to enroll in hospice is often made under challenging circumstances. Patients and families must consider large amounts of complex information about treatments, medications, and services that are available with and without hospice.⁴⁷ Despite recommendations that contingency plans be outlined early, late referrals occur often. Such discussions frequently recur at “turning points,” such as worsening symptoms or function, escalating needs for home care, or a decision to withhold or withdraw life-sustaining treatment.⁴⁷⁻⁴⁹

Clinical decisions that occur near the end of life fall into 2 broad categories: decisions for emergency conditions, such as respiratory failure, and decisions for situations that are nonemergent, such as deciding whether to continue therapies with high burden and poor odds of success.^{50,51} Deciding to enroll in hospice requires that patients both forgo potentially life-prolonging treatments and decide which treatment modes will maximize quality of life. For CHF and most noncancer diseases, for which functional decline is often protracted, no clear threshold defines when these decisions should occur. Thus, the patient’s individual end-of-life goals are critical. For patients with noncancer diagnoses, hospice enrollment is associated with a preference to receive low-burden treatments, being informed by their physician that they could die of their illness, concerns about being kept alive by machines, the patient’s global rating of quality of life, and impairments in IADLs.⁵² Motivators to enroll in hospice include the availability of core hospice services, including care at home, a team with expertise in pain and symptom management, and services for the caregiver.⁴⁹

A study of patient preferences among individuals aged 60 years or older with limited life expectancy found that patients can differentiate between expected outcomes relative to the burden of treatment: 99% would choose a treatment that was low burden and restored health, 27% would

choose a treatment that afforded survival but was accompanied by severe functional impairment, and 11% would choose a treatment that afforded survival but with severe cognitive impairment.⁵³ In another study among hospitalized patients aged 80 years or older, patients were able to assess their health values using the time trade-off technique, reflecting preferences for current health relative to a shorter but healthier life. Most were unwilling to trade much time for excellent health, but preferences varied greatly. Proxies were not able to gauge health values, suggesting that health values should be elicited directly from patients.⁵⁴

Patients tend to judge medical interventions as desirable if they have the potential to return the individual to his or her most valued life activities. The interventions themselves affect treatment decisions less than the outcomes of interventions, including cognitive and physical functioning, self-care, productivity, and emotional or caretaking burden on loved ones. Patients prefer to weigh facts and realities, talk with loved ones about decisions, and consider all available choices. Advanced age affects treatment decision making, as patients take into account personal losses experienced and fear of future losses, the perception that serious illness in old age carries a poor prognosis, and a relative emphasis on maintaining function rather than longevity.^{55,56}

Outcomes of Hospice Care

Higher satisfaction with hospice care is related to accessibility, coordination, competence, communication and relationships, education, emotional support, personalization, and support of patients’ decision making.⁵⁷ Perception of timing of the hospice referral, rather than the length of service, is associated with perceived quality of hospice care. The greatest satisfaction occurs among those for whom the timing of the hospice referral was “just right”; lowest satisfaction occurs among those for whom the hospice referral was “too late.”^{58,59} Family satisfaction with hospice care is associated with perceived adequacy of symptom management and with frequent communication between the hospice staff and the family caregivers; caregivers who had trouble contacting the hospice in the last 24 hours of life were less satisfied.^{60,61} When compared with nursing homes (56.2%; adjusted odds ratio [OR], 1.3; 95% confidence interval [CI], 1.1-1.5) or home health nursing services (70.0%; adjusted OR, 2.7; 95% CI, 1.7-3.1), bereaved family members report fewer unmet needs for pain and emotional support when the last place of care was hospice (34.6%).⁵ In addition, hospice care may indirectly benefit the health of family caregivers. One study found lower spousal mortality at 18 months (5.4% with no hospice vs 4.9% with hospice; adjusted OR, 0.92; 95% CI, 0.84-0.99) among bereaved wives of decedents who used hospice care vs those who did not. A similar but nonsignificant trend was noted for bereaved husbands: 13.7% with no hospice vs 13.2% with hospice.⁶²

Measuring and improving hospice quality is a regulatory requirement. In June 2008, the Centers for Medicare & Medicaid Services published new “conditions of participation” for

hospice organizations, thereby requiring a new approach to quality assessment and performance improvement.⁶³ Hospices are required to use a structured, data-driven approach to understand and demonstrate the quality of care they deliver and to develop strategies to improve processes and outcomes of care. Efforts are under way to standardize hospice quality measurement.⁶⁴⁻⁶⁶ The hospice industry tracks its own outcomes through the voluntary National Hospice and Palliative Care Organization national data set, which was developed as a means to understand demographics, practices, and outcomes of hospice care. Satisfaction data come from family surveys completed after patient deaths. Representative measures include the percentage of patients whose pain was at a comfortable level within 48 hours of admission, the percentage of caregivers willing to recommend hospice, and the percentage of caregivers who received effective emotional support.⁶⁷ In a recent article, Teno and Connor²⁹ outline questions to assess hospice quality.

There remains a pervasive myth that hospice care hastens death. A survival comparison using Medicare data found that the survival period for those who used hospice compared with those who did not was significantly longer for those with CHF (402 vs 321 days; $P = .05$), lung cancer (279 vs 240 days; $P < .001$), and pancreatic cancer (210 vs 189 days; $P = .01$). In regression analysis, hospice patients lived longer than non-hospice patients by 29 days. These findings suggest that hos-

pice may have a positive impact on longevity or, at least, not hasten death.⁶⁸

In the few studies that have evaluated the cost outcomes of hospice care, cost savings have ranged from \$784 to \$2309 per Medicare beneficiary, although these cost savings may differ by age, diagnosis, and length of hospice service. In one study, hospice use was associated with lower Medicare costs up until 233 days of care for patients with cancer and up until 154 days of care for patients without cancer. Another study found that hospice enrollment was associated with lower Medicare expenditures among younger decedents with cancer but higher expenditures among decedents without cancer and those older than 84 years.^{9,69,70}

RECOMMENDATIONS FOR MRS H AND HER FAMILY

Given Mrs H's disease status, estimated prognosis, and expressed goals, hospice is certainly an appropriate option. While she may live longer than the 6-month window required for hospice eligibility, she definitely has a limited life expectancy and has needs that could be addressed by hospice. Hospice would work with Mrs H to help her determine the story of the end of her life—how she lives her last months, weeks, days, and hours. In approaching Mrs H, I would first need to learn more about her and her particular situation to determine whether and when hospice will fit her needs. I would obtain the medical facts by

Table. Internet Resources for Hospice and Palliative Care Information

Organization	Web Site	Type of Resource
American Academy of Hospice and Palliative Medicine	http://www.aahpm.org	The American Academy of Hospice and Palliative Medicine is a physician specialty society for hospice and palliative medicine. The Web site provides information on professional education, board certification, fellowship training, and health policy and advocacy relevant to hospice and palliative medicine.
Center to Advance Palliative Care	http://www.capc.org	The Center to Advance Palliative Care Web site offers a multitude of palliative care resources, tools, training, and technical assistance.
Dartmouth Atlas	http://www.dartmouthatlas.org	The Dartmouth Atlas Web site permits creation of customized reports looking at geographic differences in end-of-life care costs and utilization (US).
Education for Physicians on End-of-Life Care	http://www.epec.net	The Education for Physicians on End-of-Life Care projects provide tools for educating health care professionals on the essential clinical competencies in palliative care.
Five Wishes	http://www.agingwithdignity.org/5wishes.php	Five Wishes is an advance care planning document that facilitates discussion of and documents treatment preferences.
Growth House	http://www.growthhouse.org	Growth House is a portal to resources for life-threatening illnesses and end-of-life care.
Get Palliative Care.org	http://www.getpalliativecare.org	Get Palliative Care.org is a consumer-oriented Web site that defines palliative care and provides links to local resources.
Hospice and Palliative Nurses Association	http://www.hpna.org	The Hospice and Palliative Nurses Association is the United States' largest and oldest professional nursing organization dedicated to promoting excellence in hospice and palliative nursing care.
National Consensus Project	http://www.nationalconsensusproject.org	Link to the Clinical Practice Guidelines for Quality Palliative Care
National Hospice and Palliative Care Organization	http://www.nhpco.org	The National Hospice and Palliative Organization is a membership organization of hospices that provides educational, organizational, and advocacy resources related to hospice and palliative care.
Palliative Doctors	http://www.palliativedoctors.org	Public-oriented Web site providing information about and links to palliative care resources
Social Work in Hospice and Palliative Care Network	http://www.swhpn.org	Links to information, education, training, and research for social workers

talking with her primary care physician and cardiologist to understand what is known about her current status, treatment options, and expected prognosis. In talking with Mrs H, I would ascertain her understanding of her prognosis. After clarifying her understanding and expectations, I would want to learn about her goals, asking such questions as “What do you hope for most in the next few months?” and “What are you afraid of?” I would identify both her symptoms and her psychosocial support needs, including caregiving needs, potential alternate living arrangements, and support needs of her family as they cope with the progression of her illness. In discussing hospice, I would introduce it as a service that might help meet her needs, including what it can and cannot offer in her current living situation.

In determining whether and when Mrs H should enroll in hospice, I would have to understand her desired place of death and how she envisions it. Is she willing to forgo returning to the emergency department and hospital and instead rely on hospice staff and her physicians to manage her symptoms at home or in another care setting? If she is interested in pursuing a comfort-only approach, then hospice may be appropriate for her at this time, especially if she wishes to pursue voluntarily stopping food and fluids or wishes to have her ICD deactivated, decisions that would likely decrease her life expectancy. If she is not currently ready to enroll in hospice, then outpatient-based palliative care, if available, would be appropriate to help her with her symptoms and her decision making over time until she is ready to pursue hospice care. There may be opportunities to decrease or prevent morbidity by reconsidering and potentially reducing her exposure to multiple medications for her comorbid conditions.^{71,72} I would recommend consultation with a palliative care team to assist her, her family, and her clinicians with these decisions. I would also remind Mrs H and her family that a decision to enroll in hospice is not permanent; she can enroll now and then disenroll over time if her condition improves or her goals change. And finally, I would provide additional resources, such as those listed in the TABLE, to assist Mrs H and her family in understanding their options.

QUESTIONS AND DISCUSSION

QUESTION: There is a catch-22 for hospice. I recently lost a patient who was on a milrinone drip, which was keeping him going with a reasonable quality of life. But it was incredibly expensive. If he went on hospice, hospice would have to pay for the drip, and they didn't have the money to do it.

DR KUTNER: Hospice is paid based on per diem as opposed to diagnosis-related groups. Hospices receive approximately \$126 per day to cover virtually all expenses related to addressing a patient's terminal illness, including staff time, medications, durable medical equipment, etc.⁷³ So when you hear from a hospice agency, “We are not going to provide milrinone,” it is because they want to keep their doors open. It is also why you see variation. Studies have shown that the services provided by hospice beyond the core services that are required by the Medicare hospice benefit vary greatly from hospice to hospice.⁷⁴ Larger

hospices can provide more expensive services because they can amortize them over a larger population.

QUESTION: Patients often ask us, as we send them home with hospice services, what the difference is in going home on hospice vs going to an inpatient setting. Are there any data to suggest where patients have better outcomes in terms of satisfaction?

DR KUTNER: While there are few data available, there doesn't appear to be a difference in satisfaction or quality of death based on location of hospice care. More important is whether the patient and their family's needs were addressed.⁶⁰

QUESTION: Are there any data on the outcomes of turning off a defibrillator in such a patient? Are we really changing the outcome? And an ICD is often also a pacemaker. Are you comfortable turning off a pacemaker function, which may cause patients to lose consciousness and possibly injure themselves in a fall?

DR KUTNER: Studies of outcomes when a defibrillator is turned off are just starting. Often what is done in practice is to turn off the defibrillator function but not the pacer function. The goal is to keep patients from repeated shocks at the end of life, episodes traumatic for everybody involved. But if you turn off the pacer function, people may have syncope episodes or uncomfortable arrhythmias that adversely affect quality of life.⁷⁵⁻⁷⁸

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