Palliative Care

R. Sean Morrison, M.D., and Diane E. Meier, M.D.

An 85-year-old man with New York Heart Association class IV heart failure, hypertension, and moderate Alzheimer’s disease is admitted to the hospital after a hip fracture. His postoperative course is complicated by pneumonia, delirium, and pressure ulcers on his heels and sacrum. He is losing weight and is unable to participate in rehabilitation because of his confusion. This is his fourth hospitalization in the past year. His 84-year-old wife, who has been caring for him at home, feels overwhelmed by his medical and personal care needs. The patient’s physician is increasingly frustrated by his frequent readmissions. What might she do to address his needs, alleviate his suffering, and facilitate his discharge from the hospital and subsequent care at home?

By 2030, 20 percent of the U.S. population will be over the age of 65 years. For most people, the years after the age of 65 are a time of good health, independence, and integration of a life’s work and experience. Eventually, most adults will have one or more chronic illnesses with which they will live for years before they die. These years are often characterized by physical and psychological distress, progressive functional dependence and frailty, and increased needs for family and external support. Studies suggest that medical care for patients with serious and advanced illnesses is characterized by the undertreatment of symptoms, conflict about who should make decisions about the patient’s care, impairments in caregivers’ physical and psychological health, and depletion of family resources.

The role of palliative care

There are many reasons why patients who have advanced illnesses receive inadequate care, but most of those reasons are rooted in a medical philosophy that is focused almost exclusively on curing illness and prolonging life, rather than on improving the quality of life and relieving suffering. Traditionally, medical care has been articulated as having two mutually exclusive goals: either to cure disease and prolong life or to provide comfort care. Given this dichotomy, the decision to focus on reducing suffering is made only after life-prolonging treatment has been ineffectual and death is imminent. In the United States, this forced choice is driven largely by the reimbursement system — that is, regular Medicare covers curative therapies and the Medicare hospice benefit covers comfort care. That division of services results both in the provision of burdensome and costly life-prolonging treatments when they are no longer beneficial and in preventable suffering during all stages of advanced illness. In contrast, patients would benefit most from care that included a combination of life-prolonging treatment (when possible and appropriate), palliation of symptoms, rehabilitation, and support for caregivers.

Meeting the needs of patients will require that physicians employ skills that are
Palliative care aims to relieve suffering and improve the quality of life for patients with advanced illnesses and their families through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services. Palliative care should be offered simultaneously with all other medical treatment.

**Physician—Patient Communication**

Communicating with patients is a core skill of palliative medicine. Studies suggest that in a typical clinical encounter, clinicians elicit fewer than half of patients’ concerns and consistently fail to discuss patients’ values, goals of care, and preferences with regard to treatment. Empirical evidence supports the effectiveness of clinicians’ use of specific communication skills in enhancing disclosure of the issues of concern to a patient, decreasing anxiety, assessing depression, and improving a patient’s well-being and the level of the patient’s and the family’s satisfaction with the treatment. Those communication skills include making eye contact with patients, asking open-ended questions, responding to a patient’s affect, and demonstrating empathy. When a physician is informing a patient about a poor prognosis, conducting an open, “patient-centered” interview (in which the emphasis is on empathy, openness, and reassurance), rather than the traditional closed, “physician-centered” interview (in which the physician is focused on the task), has been associated with an improved level of satisfaction on the part of patients and their families.

Guidelines have been developed for establishing goals of medical care, communicating bad news, and withholding or withdrawing medical treatments (Fig. 1). Whether the use of these protocols actually helps patients and their families has not been empirically determined, but we and others have found these guidelines to be useful in clinical practice. One randomized trial in the United Kingdom showed that a postgraduate course in communication skills that had cognitive, behavioral, and affective components led to improved communication skills among the physicians. Similar courses are offered annually in the United States. Palliative care begins with establishing the goals of care. Outlining realistic and attainable goals assumes an increased importance in the setting of advanced disease, in which treatments intended to cure the disease and prolong life may be more burdensome than beneficial. Whereas the goal for...
some patients may be to prolong life at any cost, studies suggest that what most seriously ill patients want is to have their pain and other symptoms relieved, improve their quality of life, avoid being a burden to their family, have a closer relationship with loved ones, and maintain a sense of control.9,20

Establishing clear goals can facilitate decision making regarding treatment. For example, in the case of a patient with end-stage dementia who has dysphagia, placement of a percutaneous endoscopic gastrostomy (PEG) tube may be considered. If the primary goal is to reduce suffering and enhance the quality of life, then placing a PEG tube is unlikely to meet these goals, since it requires a painful, invasive procedure; eliminates the pleasurable oral sensations of eating and drinking; is associated with an increased use of restraints; can cause cellulitis, vomiting, diarrhea, and fluid imbalances; and is unlikely to reduce the risk of aspiration.21 Even in cases in which a primary goal is to prolong life, the role of a PEG tube remains questionable; no survival benefits have been shown in observational studies in which patients with dementia who received feeding tubes were compared with similar patients who did not receive feeding tubes.21

Expert opinion suggests that clinicians can assist patients and their families in establishing their own goals by means of open-ended and probing questions. Some examples of the types of questions include “What makes life worth living for you?” “Given the severity of your illness, what are the most important things for you to achieve?” “What are your most important hopes?” “What are your biggest fears?” and “What would you consider to be a fate worse than death?”16 The goals that patients establish may overlap, be contradictory, rise and fall in importance, and shift with the progression of the disease.12,16 Warning signs of poorly established or conflicting goals can include frequent and lengthy hospitalizations; feelings of frustration, anger, or powerlessness on the part of the physician; and feelings of being burdened on the part of caregivers.15

Once goals are established, they can be used to construct advance directives about the types of care that patients want. Most studies,22 although not all,23,24 have shown that few patients have advance directives and that the documents they do have are relatively ineffectual in enhancing physician–patient communication, facilitating decision making about resuscitation,25 or influencing terminal care in hospitals.22 It is possible that the gradual rise in the prevalence of advance directives over the past decade will improve their effectiveness, as physicians and patients become more familiar with them and physicians become more comfortable using them for assistance in guiding the care of cognitively impaired adults. A recent report suggested that the focus of advance care planning should shift from discussing specific treatments to defining an acceptable quality of life and setting goals for care under various likely clinical scenarios.26,27 Whether this goal-centered approach to advance care planning will affect clinical outcomes is unknown.

ASSESSMENT AND TREATMENT OF SYMPTOMS
A fundamental goal of palliative care is the relief of pain and other symptoms.9-20 Successful approaches to the assessment and management of pain and some physical and psychological symptoms have been established in controlled trials.12,20-30 Despite these advances, undertreatment of symptoms persists in the majority of patients and settings.2,31

Relief of suffering begins with routine and standardized symptom assessment with use of validated instruments. Routine assessment has been shown to identify overlooked and unreported symptoms, facilitate treatment, and enhance patient and family satisfaction.32,33 Clinically useful assessment instruments can be found on the Web sites of the Center to Advance Palliative Care (www.capc.org) and of Brown University’s Center for Gerontology and Health Care Research, which features a tool kit of instruments to measure end-of-life care (www.chcr.brown.edu/poc/toolkit.htm).

Improved treatment of symptoms has been associated with the enhancement of patient and family satisfaction, functional status, quality of life, and other clinical outcomes.32,34 Although a comprehensive review of strategies for assessment and therapy of symptoms is beyond the scope of this review, Table 1 summarizes approaches to commonly encountered symptoms in advanced illnesses.

PSYCHOSOCIAL, SPIRITUAL, AND BEREAVEMENT SUPPORT
Providing psychosocial, spiritual, and bereavement support to patients and caregivers is a key component of palliative care. Patients who experience spiritual and psychological distress are more likely to express a desire for death than are other patients,45 and their family members are more likely to have an extended or complicated grief and bereavement process (defined as grief that lasts for
### Table 1. Approaches to the Management of Pain and Other Common Symptoms.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Assessment</th>
<th>Treatment</th>
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<tbody>
<tr>
<td>Anorexia and cachexia</td>
<td>Is a disease process causing the symptom, or is it secondary to other symptoms (e.g., nausea and constipation) that can be treated? Is the patient troubled by the symptom?</td>
<td>Consider megestrol acetate or dexamethasone.</td>
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<tr>
<td>Anxiety</td>
<td>Does the patient exhibit restlessness, agitation, insomnia, hyperventilation, tachycardia, or excessive worry?</td>
<td>Recommend supportive counseling and consider prescribing benzodiazepines (in the elderly, avoid benzodiazepines with long half-lives).</td>
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<tr>
<td>Constipation</td>
<td>Is the patient taking opioids? Does the patient have a fecal impaction?</td>
<td>Prescribe a stool softener (ineffective alone) plus escalating doses of a stimulant; if escalation of the dose is ineffectual, agents from other classes (e.g., osmotic laxatives and enemas) should be added.</td>
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<tr>
<td>Depression</td>
<td>How does the patient respond to the question “Are you depressed?” Does the patient express or exhibit any of the following feelings: helplessness, hopelessness, anhedonia, loss of self-esteem, worthlessness, persistent dysphoria, and suicidal ideation? (Somatic symptoms are not reliable indicators of depression in this population.)</td>
<td>Recommend supportive psychotherapy, cognitive approaches, behavioral techniques, pharmacologic therapies, or a combination of these interventions; prescribe psychostimulants for rapid treatment of symptoms (within days) or selective serotonin-reuptake inhibitors, which may require three to four weeks to take effect; tricyclic antidepressants are relatively contraindicated because of their side effects.</td>
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<tr>
<td>Delirium</td>
<td>Was the onset of confusion acute? Is the patient disoriented or experiencing changes in the level of consciousness or minute-to-minute fluctuations? Is the condition reversible?</td>
<td>Identify underlying causes and manage symptoms; recommend behavioral therapies, including avoidance of excess stimulation, frequent reorientation, and reassurance; ensure presence of family caregivers; prescribe haloperidol, risperidone, or olanzapine. (Chlorpromazine can be used for agitated or terminal delirium, but benzodiazepines have been found to exacerbate delirium and should be avoided.)</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Does the symptom have reversible causes?</td>
<td>Prescribe oxygen to treat hypoxia-induced dyspnea or to provide symptomatic relief, when hypoxia is absent, through stimulation of the V2 branch of the trigeminal nerve. Opioids relieve breathlessness without measurable reductions in respiratory rate or oxygen saturation; effective doses are often lower than those used to treat pain. Consider anxiolytics (e.g., low-dose benzodiazepines) and use reassurance, relaxation, distraction, and massage therapy.</td>
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<tr>
<td>Nausea</td>
<td>Which mechanism is causing the symptom (e.g., stimulation of the chemoreceptor trigger zone, gastric stimulation, delayed gastric emptying or “squashed stomach” syndrome, bowel obstruction, intracranial processes, or vestibular vertigo)?</td>
<td>Prescribe an agent directed at the underlying cause. Multiple agents directed at various receptors or mechanisms may be required.</td>
</tr>
<tr>
<td>Pain</td>
<td>How severe is the symptom (as assessed with the use of validated instruments)?</td>
<td>Prescribe medications to be administered on a standing or regular basis; as-needed or rescue doses should be available for breakthrough pain or pain not controlled by the standing regimen; start a regimen to prevent constipation for all patients receiving opioids. For mild pain: use acetaminophen or a nonsteroidal antiinflammatory agent (consider opioids in older adults). For moderate pain: titrate short-acting opioids. For severe pain: rapidly titrate short-acting opioids until pain is relieved or intolerable side effects develop; start long-acting opioids (e.g., sustained-release morphine or oxycodone and transdermal fentanyl) once pain is well controlled; use methadone only if experienced in its use. Rescue doses: prescribe immediate-release opioids consisting of 10% of the 24-hour total opioid dose to be given every hour (orally) or every 30 minutes (parenterally) as needed. Comitant analgesics (e.g., corticosteroids, anticonvulsants, tricyclic antidepressants, and bisphosphonates) should be used when applicable.</td>
</tr>
</tbody>
</table>

* For details of recommendations and more information about the management of symptoms, see Foley, Luce and Luce, Casarett and Inouye, Strasser and Bruera, Block, and Regnard and Comiskey.
at least 14 months after the death and results in a failure of the survivor to return to his or her normal activities) and are at higher risk for illness and death.43

Studies suggest that patients welcome inquiries about their spiritual well-being from their physicians,44 although interventions to address spiritual distress have not been well developed or well evaluated. Support groups have been found to reduce stress and depression experienced by caregivers.45,46 Although many formal interventions to address complicated grief and bereavement have been described, data are lacking on their effects on outcomes.47 Two recent studies reported lower morbidity and mortality48 and better emotional support49 among surviving family members of hospice patients than among family members of patients who did not receive hospice services, although it is uncertain whether this difference reflects the nature of families who elect hospice care rather than the effects of the intervention.48

COORDINATION OF CARE

Several studies demonstrate that the personal and practical care needs of patients who are seriously ill and their families are not adequately addressed by routine office visits or hospital and nursing home stays and that this failure results in substantial burdens — medical, psychological, and financial — on patients and their caregivers.3–5,49,50 In the context of chronic progressive disease, the ability of physicians to coordinate an array of social and medical services on behalf of patients and families assumes increased importance.

Various comprehensive care programs are available to help physicians manage the care of their patients who have serious and complex illnesses. Palliative care programs within home care organizations, hospitals, and nursing homes are increasingly prevalent in the United States and provide comprehensive interdisciplinary care for patients and families in collaboration and consultation with primary care physicians.51 Hospice services, under the Medicare benefit, are available in most U.S. communities and provide palliative care, primarily at home, for patients with a life expectancy of six months or less who are willing to forgo insurance coverage for life-prolonging treatments. Studies suggest that referral to palliative care programs and hospice results in beneficial effects on patients’ symptoms, reduced hospital costs, a greater likelihood of death at home, and a higher level of patient and family satisfaction than does conventional care.49,50,52,53

Other programs that coordinate care for patients who have complex illnesses are available in most communities. Programs that coordinate home care services for patients with chronic conditions (e.g., depression, heart failure, or the acquired immunodeficiency syndrome) have been associated with increased patient and family satisfaction and reductions in mortality, use of hospital services, visits to physicians’ offices, and admission to nursing homes.54–56 Case management is usually provided by managed-care organizations, Medicare managed-care services, commercial insurers, some home health care agencies, and privately hired case managers. The quality, cost, and extent of the services provided are highly variable.

Comprehensive multidisciplinary home care programs that serve frail older adults have been evaluated under Medicare and the Veterans Health Administration (VHA). The Program of All-Inclusive Care for the Elderly (PACE) is a capitated Medicare and Medicaid benefit for frail older adults that offers comprehensive medical and social services at 25 adult day health centers, in homes, and at inpatient facilities. (More information about the program is available online at www.cms.hhs.gov/pace/.) Patients who use the services provided by PACE have higher rates of completing advance directives for their care57 and lower rates of admission to nursing homes,58 hospitalization,59 and death in the hospital60 than do patients who do not use the services. Similar programs of team-coordinated home-based care exist within the VHA.60

Until comprehensive palliative care programs become widely available, the responsibility for coordination of care falls to the primary care physician, since patients and their families frequently have problems negotiating the current health care system. Table 2 details the range of palliative care services that should be considered at various stages of a serious illness; Table 3 lists services that are covered by Medicare.

AREAS OF UNCERTAINTY

Physicians have few data to guide them in improving their communication with patients and in their management of pain and other symptoms. The communication guidelines presented in Figure 1, although widely taught and used by palliative care experts, have not been shown to be associated with
improved outcomes. Similarly, although data are available to guide the treatment of pain due to cancer, data are lacking regarding the treatment of other pain syndromes, symptoms other than pain (such as dyspnea, fatigue, delirium, and anxiety), spiritual distress, and complicated grief and bereavement.

**GUIDELINES**

The National Comprehensive Cancer Network has developed guidelines for patients who have advanced incurable cancer, and the National Consensus Project for Quality Palliative Care, a collaborative effort of five national palliative care organizations, has similar guidelines for patients who have advanced chronic illnesses. These guidelines encompass many of the recommendations detailed in this article, and the National Consensus Project guidelines also include recommendations regarding the spiritual, religious, and existential aspects of care; cultural aspects of care; and care of patients whose death is imminent. Although the guidelines of the National Comprehensive Cancer Network are targeted to patients with terminal cancer, many patients who have early stages of the disease or uncertain prognoses or who are undergoing active curative or life-prolonging therapies can benefit from the organization’s recommendations. The application of those recommendations should not be restricted to patients with a limited life expectancy.
Table 3. Summary of Medicare Coverage for Common Services Required by Patients with Serious and Chronic Illnesses.

<table>
<thead>
<tr>
<th>Service</th>
<th>Medicare Part A†</th>
<th>Coverage</th>
<th>Out-of-Pocket Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulance</td>
<td></td>
<td>Transportation only to a hospital or skilled nursing facility and only if transportation in any other type of vehicle endangers health</td>
<td>20% of Medicare-approved amounts</td>
</tr>
<tr>
<td>Custodial care</td>
<td></td>
<td>No coverage for custodial care if this is the only care needed</td>
<td>100%</td>
</tr>
<tr>
<td>Home health care</td>
<td></td>
<td>Skilled nursing care in the home for treatment of an acute illness if at least one of the following is needed: intermittent skilled nursing care, physical or speech therapy, or continuing occupational therapy and if the patient is unable to leave the house except with major effort</td>
<td>None; if the patient has only Part B coverage, services are covered by Part B</td>
</tr>
<tr>
<td>Hospice</td>
<td></td>
<td>Eligibility: life expectancy of 6 mo or less if disease follows its usual course and willingness to relinquish Medicare-reimbursed services focused on prolongation of life or cure; coverage includes physician and nursing services, durable medical equipment and supplies, medications for pain or symptom control, home health aide and homemaker services (4 hr/day on average), physical and occupational therapy, short-stay hospitalizations and respite care, social work services, and bereavement services; regular Medicare covers services not related to hospice diagnosis; room and board are covered only for respite care and short hospital stays, not for nursing home or residential hospice stays</td>
<td>None for regular hospice services; copayment of up to $5 for outpatient prescription drugs; 5% of Medicare-approved amount for inpatient respite care</td>
</tr>
<tr>
<td>Hospital inpatient care</td>
<td></td>
<td>General hospital services with semiprivate room</td>
<td>For each benefit period, deductible of $812 for days 1–60, $203/day for days 61–90, and $406/day for days 91–150; benefit period begins on hospital day 1 and ends when hospital or skilled nursing care has not been received for 60 consecutive days</td>
</tr>
<tr>
<td>Skilled nursing facility or rehabilitation</td>
<td></td>
<td>If patient has Part A benefit days remaining after hospitalization; qualified hospital stay (inpatient stay of 3 consecutive days and entry into a skilled nursing facility within 30 days of discharge); need for a skilled service to treat a medical condition that was treated in the hospital or started while getting Medicare-covered skilled nursing care; no coverage for nursing home custodial care</td>
<td>For each benefit period, none for days 1–20, $101.50/day for days 21–100, and 100%/day for day 101</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service</th>
<th>Medicare Part B†</th>
<th>Coverage</th>
<th>Out-of-Pocket Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulance</td>
<td></td>
<td>Transportation only to a hospital or skilled nursing facility and only if transportation in any other type of vehicle endangers health</td>
<td>20% of Medicare-approved amounts</td>
</tr>
<tr>
<td>Custodial care</td>
<td></td>
<td>No coverage for custodial care if this is the only care needed</td>
<td>100%</td>
</tr>
<tr>
<td>Durable medical equipment</td>
<td></td>
<td>‘Air-fluidized’ beds, canes, commode chairs, crutches, home oxygen and equipment (with qualifications), hospital beds, nebulizers, patient lifts, suction pumps, walkers, and wheelchairs</td>
<td>Variable after $100 deductible</td>
</tr>
<tr>
<td>Office visits to doctors</td>
<td></td>
<td>No coverage for routine physical and gynecologic examinations</td>
<td>20% of Medicare-approved rates</td>
</tr>
<tr>
<td>Outpatient mental health services</td>
<td></td>
<td>Office visits to physicians, clinical social workers, psychologists, nurse specialists, and physician assistants</td>
<td>50% of Medicare-approved rates</td>
</tr>
<tr>
<td>Nonphysician health care services</td>
<td></td>
<td>Office visits to clinical social workers, psychologists, physician assistants, and nurse practitioners (for medically necessary services)</td>
<td>20% of Medicare-approved rates</td>
</tr>
<tr>
<td>Prescription drugs</td>
<td></td>
<td>Limited coverage for erythropoietin only in end-stage renal disease, injectable drugs, limited oral cancer medications, limited oral antiemetics (if a Medicare-covered cancer drug), some infusion therapies (if considered reasonable and necessary). A Medicare discount card is currently available for other prescription drugs and a $600 credit is available for qualifying low-income individuals. In 2005, a Medicare prescription-drug plan will become available. In 2004, 75 to 90 percent for most prescriptions. In 2005, a $35 monthly premium and a $250 deductible; 25 percent of pharmacy costs between $250 and $2,250 in drug spending, 100 percent of costs between $2,250 and $3,600, and 5 percent of costs over $3,600</td>
<td>In 2004, 75 to 90 percent for most prescriptions. In 2005, a $35 monthly premium and a $250 deductible; 25 percent of pharmacy costs between $250 and $2,250 in drug spending, 100 percent of costs between $2,250 and $3,600, and 5 percent of costs over $3,600</td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td>No coverage for transportation to physicians’ offices, laboratory tests, outpatient physical therapy, or ambulette (van) services</td>
<td>100%</td>
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</tbody>
</table>

† Under Part A, the patient pays no premium if the patient or the patient’s spouse has paid Medicare taxes while working for 40 or more quarters.
‡ Under Part B, the patient pays for optional coverage with a premium of $58.70 per month.
The aim of palliative care is to relieve suffering and improve the quality of life for patients with advanced illnesses and their families. It is based on an interdisciplinary approach that is offered simultaneously with other appropriate medical treatments and involves close attention to the emotional, spiritual, and practical needs and goals of patients and of the people who are close to them. The patient who is described in the vignette, who has multiple chronic and serious medical conditions but is not actively dying, is ideally suited to receive high-quality palliative care. Specifically, we suggest the following approach. The patient’s symptoms should be assessed and treated, as discussed in Table 1. If available, consultation with a palliative care team should be strongly considered to help with evaluating and managing his symptoms. Once the patient is comfortable, a discussion about realistic goals should be held, with particular attention given to clarifying the patient’s opinion about an acceptable quality of life, identifying conditions under which the patient would consider life not worth living, establishing attainable short- and long-term goals, and designating a health care proxy. We recommend that this discussion be summarized in a treatment directive and that a health-care-proxy form be completed. Once goals are clarified, appropriate treatment and discharge planning can begin.

In the case described in the vignette, for example, the treatment goal might be to focus on the patient’s comfort and on caring for him at home, and the appropriate treatments might be spoon-feeding rather than placement of a PEG tube, diuretics and bisphosphonates, avoidance of hospitalization, and a trial of physical and occupational therapy with the aim of regaining function. The patient’s discharge services will depend on the goals, the patient’s insurance coverage and financial resources, and available home care services. Since a hospice program will support these goals, a referral to hospice should be considered. If hospice is not an option (e.g., because of limited home care hours or uncertainty about the prognosis), the patient should be referred to a case-management program, PACE, or a certified home care agency. The family’s ability to afford medications should be evaluated, and alternative sources (such as mail-order drug plans or state-sponsored prescription plans for low-income elderly people) or less costly medications should be considered. Before discharge, a home-safety and home-needs evaluation should be performed either by an occupational therapist or through a structured interview with the patient’s caregiver. An assessment of support requirements for the caregiver should be conducted to ensure that the personal care needs of the patient and the patient’s family are met. Referral to a social worker can help identify community alternatives and determine Medicaid eligibility. Finally, a regular system of communication should be established between the treating physician and the home care team.

Dr. Morrison is a Paul Beeson Faculty Scholar in Aging Research, an Open Society Institute Project on Death in America Faculty Scholar, and the recipient of a Mid-Career Investigator Award in Patient-Oriented Research (K24AG022345) from the National Institute on Aging. Dr. Meier is an Open Society Institute Project on Death in America Faculty Scholar, the recipient of an Academic Career Leadership Award (K07AG00903) from the National Institute on Aging, and the director of the Center to Advance Palliative Care, a program office of the Robert Wood Johnson Foundation.

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