Serving Patients Who May Die Soon and Their Families
The Role of Hospice and Other Services

Joanne Lynn, MD, MS

Patients who may die soon and their families may benefit from the services provided by hospice care. However, many patients may not be ready to embrace all aspects of hospice care: they may wish to continue some forms of curative treatment, they may not be ready to conclude that death is imminent, and their prognosis may not be clearly 6 months or less. In this article, using actual interviews with a patient who may die soon and his family, Dr Lynn discusses these issues and approaches to care.

The Patient's Story
Mr M and his partner Ms L were interviewed together by a Perspectives editor on March 8 and 29, 2000. Mr M's physician, Dr D, was interviewed by a Perspectives editor on May 15, 2000.

MR M: What's happened is just terrible. All of a sudden I got sick and couldn't take care of myself... I'm horrified by this whole thing. Being ill is just a feeling of being lost. A quagmire. Your life has no beginning or end. It's just, "You're dying."

Only 47 years old, Mr M lives with advanced rectal carcinoma. Twenty-three years ago, he had radiation and chemotherapy for abdominal Hodgkin disease. Eight years ago, he underwent potentially curative surgery for rectal carcinoma. Mr M performs with a professional symphony orchestra. Although estranged from his family of origin, he has been in a committed relationship with a woman artist for 5 years, and they have a 2-year-old son. Three years ago, he developed a bulky pelvic mass—a recurrent rectal carcinoma.

Initially he did well, but during this past year his condition has slowly worsened—pain, partial small-bowel obstructions, urinary retention and infections, fecal incontinence, weight loss, delirium, and fatigue. His partner, Ms L, describes "losing him slowly." The couple's relationship is strained, partly because Ms L must work, raise a child, and live life as a healthy person, while arranging or providing direct services for her increasingly disabled partner. A paid attendant around-the-clock has recently supplemented volunteer help from friends. In addition to Medi-

See also Patient Page.

The case story of a 47-year-old man with advanced rectal carcinoma illustrates the professional services and care system strategies available to help clinicians serve patients coming to the end of life. For this patient, who understands his prognosis, primary care physician services include (1) prevention and relief of symptoms, (2) assessment of each treatment before and during implementation, (3) ensuring that the patient designates a surrogate decision-maker and makes advance plans, and (4) preparation of patient and family for the time near death. Good care may entail enduring unavoidably difficult times with patients and their families.

Enrollment in a hospice program requires that decision-makers confront the prognosis and their uncertainties about it, consider the desirability of other services, recognize variations among available hospice programs, address financial issues, and weigh the distress of patients and loved ones at being labeled as "dying." Hospice provides competent, continuous, and reasonably comprehensive care, but it has some constraints.

Function and symptoms for those living with serious chronic illness at the end of life generally follow 1 of 3 trajectories: (a) a short period of obvious decline at the end, which is typical of cancer; (b) long-term disability, with periodic exacerbations, and unpredictable timing of death, which characterizes dying with chronic organ system failure; or (c) self-care deficits and a slowly dwindling course to death, which usually results from frailty or dementia. Effective and reliable care for persons coming to the end of life will require changes in the organization and financing of care to match these trajectories, as well as compassionate and skillful clinicians.

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caid coverage for hospitalizations, physicians, medications, treatments, and some home care, the couple pays $2300 per week out-of-pocket for additional home care.

Author Affiliation and Corresponding Author and Reprints are listed at the end of this article.

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Mr M is realistic about his prognosis but wants to live as long as possible. He resists the label “dying.” Twice, he enrolled for hospice care; twice, he promptly disenrolled.

An interdisciplinary palliative care team (funded mostly by philanthropy) has helped Mr M with pain control and with arranging services. He has had a skilled and responsive primary care physician throughout the past 2 years. He takes only opioids for pain, transfusions to counter rectal bleeding, and laxatives or antibiotics as needed.

**Perspectives**

**MR M:** My life has been one of great promise, but not on a grand scale. Life is so grand and so glorious, and yet so sad. Things just aren’t okay. I’m incontinent. I’m kind of a mess.

**MS L:** He’s frustrated. He’s stuck. The hard thing about living for a long time with very serious disease is that you incrementally lose your faculties and your capabilities.

**Dr D:** About 6 months ago, I had a conversation with Mr M about prognosis. On a cognitive level, he had been told that his cancer was incurable and ultimately terminal, but I don’t think he had an emotional grasp of this. By a few months later, it required a lot more work on my part to coordinate things for him.

Mr M has endured much and yet has forged a life he considers worthwhile. He will likely live a while longer, with worsening disability, increasingly impaired cognition, and greater dependence on others. He worries about his partner and child and resents that he must leave them. He bitterly observes the loss of the tenuous financial security they had achieved. He worries about whether he has “left a mark.” While life will be short and difficult, he still sees it as precious.

**Preparing for the End: Decision Making and Medical Issues**

Mr M and Ms L each face overwhelming challenges and need both empathy and concrete services. Mr M’s physician and care team must help them confront at least 4 issues.

First, Mr M’s caregivers must seek to prevent and relieve distressing symptoms. The patient and family must be able to count on competent, continuous, and effective treatment to ensure comfort and preserve function whenever possible. This patient and his partner live with considerable emotional turmoil, but his physical discomforts are well controlled, as they should be.

Second, Dr D must repeatedly weigh the merits of every treatment. Most people want more than just a longer life; they want the end of life to be meaningful, comfortable, and supportive to loved ones. When living longer becomes less important to the patient, forgoing life-sustaining treatments often becomes appropriate, and the patient and family should be involved in weighing the merits of various goals of care. Mr M’s transfusions and antibiotics probably will become inappropriate. Patients and families generally trust their care team to guide them in these specific treatment issues. This requires excellent communication, a sensitive understanding of the patient’s life, and a realistic assessment of the capabilities, limits, and costs of health care. Third, the patient, family, and care team have to plan ahead for likely emergencies. Planning in advance should prevent emergency hospitalizations, resuscitations, or frantic responses to death at home. Since this couple has no legal status and Mr M will likely have periods of diminished mental clarity before death, he should consider granting Ms L a formal durable power of attorney for health care (some states refer to this as a “health care proxy”). The patient should also undertake appropriate estate and funeral planning. Otherwise, Ms L may face uncomfortable dealings with Mr M’s long estranged natural family.

Fourth, the care team should prepare Mr M and his family for the time very near to death, including education regarding signs that death is imminent and has occurred. Hospice programs provide handouts that describe the common signs that death is imminent. The family should know that they can stay with the body after death, if they want. Specific advance planning for the time just before and after death reduces stress and bad judgments and also helps the patient and family to acknowledge the reality of impending death.

**Family Concerns**

**MS L:** At the hospital they take very good care of him. But the idea is that when he comes home I’m going to run an institution. That’s crazy. The social workers who come here say, “It would be great if your community could come in.” But we’re talking about someone who’s been seriously sick for 8 years. We have an amazing community, but what are they going to do? Pay the $2300 a week it’s costing us?

Families face not only the intense emotional burden of losing a loved one, but also the expense of end-of-life care. Costs of medications, personal assistance, institutional care, and lost wages are quite substantial and often are not covered by insurance, except that hospice benefits usually cover medications and some personal assistance. One third of families of seriously ill, hospitalized, well-insured patients report a major financial change such as loss of most income or having to move because of the costs of illness.

Impoverishment of their families worries many patients. Sometimes legal and financial planning really help, and physicians should consider recommending it early in the course of fatal illness. If he had assets before becoming ill, Mr M probably could have protected some funds in a trust for his partner and child, especially if he had started when he first had rectal cancer (or even later, when it recurred). In addition, this course might have accelerated his eligibility for Medicaid.

This young family and their friends will be forever altered by the experience of a slowly progressive, lethal illness. Family caregivers often enlarge their spiritual lives in the experience of providing physical care. Journalist Robert J. Samuelson reported on the difficult death of a friend’s father, noting that “it reminds us that successful dying, like successful childrearing, depends on family.” In contrast to the gratification
some people articulate, Ms L acknowledges her changing role from partner to caregiver with some resentment.

Ms L: And why am I, who's also going through this, having to be his advocate? What that ends up doing is putting me in a role that no longer includes our emotional connection.

Ms L finds it overwhelming to balance managing the home, providing hands-on care, raising a child, working, and supporting her partner. A hospice or palliative care program could provide respite care, counseling, financial advice, volunteer help, and compassion. With that help, perhaps her relationship with Mr M could have time to deepen and their shared experience could be more meaningful.

The bond between Mr M and his child is also important. Many patients facing death while their children are young want to create remembrances for later: videos or letters for special occasions, or a box of mementos with explanations of why each has a special meaning for the dying person.

Good care at the end of life requires continuity in caregiving. The patient who has the same physician from the onset of serious illness through death has a substantial advantage in advance planning, family support, and in shaping services to real needs and priorities. Mr M's primary care physician has undertaken this role. Most health care, though, is increasingly fragmented. While hospitalists and hospital-based palliative care teams will improve some aspects of care, very sick patients cannot readily develop new relationships and trust with an ongoing stream of providers. Being asked about "do not resuscitate" orders several times each day, for example, can make hospitalized patients feel that no one is in charge and that the professional caregivers do not talk with one another. Continuity is important to dying patients, and it also allows clinicians the satisfaction of caring for the whole person and family, rather than just feeling defeated by a disease.

Dr D: Despite the tensions that have formed over time, Mr M is one of those patients that make you think, "This is why I went into medicine. This is what it feels like to be a doctor." The whole process is very rewarding.

Challenges in End-of-Life Care

Even with good care, not everyone will live well near death. Caregivers should be able to promise Mr M pain relief and assistance with hands-on care, but the health care system cannot realistically aim to relieve his sense of degradation and tragedy. Dying is often difficult and tragic despite good care. Bearing witness to the humanity of those nearing the end of life, and accompanying them on their journeys, are essential parts of serving the dying.

Seriously ill patients, their families, and their physicians are often inexperienced in practical aspects of serious illness, such as making timely use of appropriate services. Experts in care coordination, such as geriatric care managers, palliative care teams in hospitals, and local hospice and home care personnel, can help connect patients with services that are often unfamiliar to physicians (eg, home care, hospice programs, nursing homes, and palliative care units). Just as specialists help deliver other state-of-the-art medical interventions, end-of-life specialists often provide critical expertise in palliative care and symptom relief.

Using a Hospice Program

Hospice programs provide comprehensive, mostly home-based care to dying patients who consent to a hospice plan of care. Although initiated only a quarter century ago, US hospice programs provided services to 700,000 patients and their families in 1999, about one quarter of all deaths. More than half of Medicare recipients who die with cancer now use hospice, though the median hospice length of stay is less than 3 weeks.

Under Medicare (and with many commercial plans for younger patients), a hospice program may only enroll patients whose life expectancies are 6 months or less, provided that the patient also consents to forgo "curative" treatments and accept care only from hospice for the fatal illness. In the United States, 63% of Medicare patients in hospice have cancer, and the Medicare program covers more than 75% of hospice payments.

Hospice programs aim to serve patients where they live, whether at home or in nursing facilities. The hospice interdisciplinary team includes at least a physician, nurse, and social worker, and usually physical and occupational therapists, counselors, chaplains, and nutritionists. While nearly half of Medicare patients die in hospitals, only rarely do hospice patients die there. Hospice providers have been supportive of discontinuing life-sustaining treatments and of providing terminal sedation, but in my experience, hospice teams generally have opposed efforts to legitimize physician-assisted suicide. Hospice under Medicare covers prescription drugs, oxygen, aids, volunteer and respite companions, spiritual counseling, advance planning, and support and bereavement resources for family.

Anyone involved with a potential hospice patient—physician, family member, social worker, chaplain, or patients themselves—can contact a hospice program, which will offer to visit the patient and family; explain the services, costs, and insurance coverage; and, if appropriate, enroll the patient. The attending physician must attest that the patient is expected, in the usual course of events, to die within 6 months. However, predicting the patient's life span is far from straightforward. Remarkably, Medicare and other insurance plans provide no guidance as to whether the physician should aim to attest that "most patients in this condition would die within 6 months," or that "virtually all patients in this condition would die within 6 months." For non-small-cell lung cancer, the choice among possible definitions may not make much difference: almost all patients who are ready to forgo "long shot" treatments aimed at remission and who need comprehensive home care will generally fit any of the possible definitions. In chronic obstructive lung disease, however, only a very few outpatients are so clearly near death that they would meet a "virtually cer-
tain to die in 6 months" criterion, while many would meet a "more likely than not" standard.

In 1996, in an effort to assist clinicians and regulators in determining which patients could be enrolled in hospice, the National Hospice and Palliative Care Organization published medical guidelines for hospice enrollment in non-cancer diagnoses (Box).18 Local Medical Review Policies (implemented by Medicare intermediaries in each region of the country) and individual case interpretations have modified these guidelines, particularly by mandating some of the optional elements. In addition, hospices have adjusted their own enrollment criteria to limit risks of denied payments or allegations of fraud. Medicare has offered to work with hospice providers to discern better ways to implement this threshold,19 but currently hospices vary substantially in their interpretations of eligibility.

Primary care physicians and seriously ill patients should consider hospice enrollment as early as patients might qualify, so that they and their families might benefit from timely, comprehensive supportive services. They should be informed that if the prognosis brightens after enrollment, the hospice might have to disenroll the patient, but there is neither any financial penalty nor any barrier to reenrollment in the future.

Primary care physicians can, and usually should, continue to care for hospice patients. Physicians continue to bill Medicare Part B for hospice patients. The overall plan of care requires accord among the interdisciplinary team members, the patient, and the family. Physicians, patients, and family members gain coherent and comprehensive home care; in return, the physician ordinarily relinquishes some autonomy in working with the team.

In my experience, hospices generally have good reputations, and testimonials from families and patients are common. A few studies have implied that hospice care might cost less, but these are dated and had inadequate comparison groups.20-22 Even if hospice generally does not save money, hospice programs do focus more substantially on medications and personal support than on hospital services, and this probably serves patients better. As hospice use has expanded, the average length of stay in hospice has become shorter. The median length of stay in Medicare hospice declined from 26 days in 1994 to 19 days in 1998, and the median in some states (eg, Tennessee) is less than 2 weeks.23 In general, patients cannot fully benefit from very short stays, since becoming familiar with new staff and implementing treatment plans takes time. Although all days are paid at the same rate, the first few and last few days require more services. Thus, short stays also threaten hospice programs' financial viability.24

Most people's lives, like Mr M's, have a variety of potentially conflicting priorities—wanting both more life and more comfort, for example. The mental model underlying the Medicare hospice benefit assumes that hospice patients will no longer hope for a cure or for prolonged survival, having transitioned to hoping only for meaningfulness and comfort. However, most patients nearing the end of life want and need both disease-modifying and comfort-enhancing treatments simultaneously.25 Building on the misleading "transition" model, people around the dying patient have come to expect that, rather than medical treatments, the dying patient's needs will focus on symptom management, family needs, and spiritual concerns. It is my observation that, in the United States, institutions such as hospice, developed for those who are dying assume that dying persons take to their beds, reflect on life's meaning, and proceed to die "on time." A dying person is not expected to run a business, make long-term investments, or do something frivolous, even when these activities are otherwise quite appropriate and satisfying. The cultural stereotype ensures that many patients resist being labeled as "dying" or accepting hospice care, even while they acknowledge a very limited prognosis.

End-of-Life Care Options

Just as eligibility criteria for hospices differ, so do their individual styles differ. Ms L's experience with one hospice program made her reluctant to embrace their services.

MS L: I had a name for the hospice folks when they first arrived. I called them valets to the grim reaper. No. We're going to take our time. Why would we park at their door? We want to get there through life, not by being red-carpeted into death.

Hospices differ markedly both in clinical practices and in style.26 Mr M and Ms L were repelled by their vision of hospice providers. They might have reacted more positively to another hospice with a different philosophy, a staff whose personalities were more attuned to sensitivities, and a set of services better fitted to their needs, including supporting hope for prolonged survival.

Hospice programs are often reluctant to implement treatments other than symptom management. In part, this reflects their need to prioritize within constrained resources. The hospice program's vision, leadership, staff, population served, and philanthropic resources shape those choices.

Medicare and other insurance plans reimburse hospice programs at a rate of about $100 per patient per day.27,28 Some raise enough charitable donations and enroll enough low-cost patients to operate with rather inconsequential restrictions. Others will not enroll patients who live alone, or who desire costly treatments. For example, many hospices cannot afford gemcitabine, blood transfusions, low-molecular-weight heparin, vancomycin,29 or parenteral nutrition, or of providing one 8-hour shift of aide care, because these approximate or exceed the total per diem hospice payment. In some areas or for some patients, other home care benefits (private insurance, Medicaid, or Veterans' Health Care) may actually provide better coverage for a particular patient, especially for those wanting costly treatments.

Should Mr M Use Hospice?

MS L: What we need is a comprehensive care team, but we need it not only in the institution, we need it in life.
National Hospice and Palliative Care Organization

General Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases
(adapted from National Hospice Organization, 1996, updated to reflect common current practices)

The patient should meet all of the following criteria:

1. The patient’s condition is life limiting, and the patient and/or family know this
2. The patient and/or family have elected treatment goals directed toward relief of symptoms, rather than the underlying disease
3. The patient has either of the following:
   A. Documented clinical progression of the disease, which may include:
      1. Progression of the primary disease process as listed in the disease-specific criteria, as documented by serial physician assessment, laboratory, radiologic, or other studies
      2. Multiple emergency department visits or inpatient hospitalizations over the prior 6 months
      3. For homebound patients receiving home health services, nursing assessment may document decline
      4. For patients who do not qualify under 1, 2, or 3, a recent decline in functional status should be documented; clinical judgment is required
   B. Documented recent impaired nutritional status related to the terminal process:
      1. Unintentional, progressive weight loss of >10% over the prior 6 months
      2. Serum albumin <25 g/L may be a helpful prognostic indicator, but should not be used in isolation from other factors above

Highlights of Guidelines for Specific Diseases

Heart Disease:
1. Intractable or frequently recurrent symptomatic heart failure, or intractable angina pectoris with heart failure
2. Pericarditis should already be optimally treated with diuretics and vasodilators
3. Other factors contributing to a poor prognosis: symptomatic arrhythmias, history of cardiac arrest and resuscitation or syncope, cardiogenic brain embolism, or concomitant human immunodeficiency virus disease

Pulmonary disease:
1. Severe chronic lung disease, documented by dyspnea at rest, fatigue, decreased functional ability, or increased exacerbation
2. Cor pulmonale or right heart failure
3. Hypoxemia at rest on supplemental oxygen
4. Hypercapnia (pCO2 >50 mm Hg)
5. Other factors contributing to a poor prognosis: unintentional continuing weight loss of >10% body weight over the preceding 6 months; resting tachycardia greater than 100/min

Dementia:
1. Severe dementia: unable to ambulate without assistance and unable to communicate meaningfully
2. Presence of medical complications: aspiration pneumonia, sepsis, intractable decubitus ulcers
3. Other factors contributing to a poor prognosis: unable to dress without assistance, unable to bathe properly, urinary and fecal incontinence

Human Immunodeficiency Virus disease:
1. CD4+ count <25 cells/µL
2. Viral load >100,000 copies/mL
3. Life-threatening concomitant conditions
4. Other factors contributing to a poor prognosis: chronic persistent diarrhea for 1 year; persistent serum albumin <25 g/L; concomitant substance abuse; age >50 years; decisions to forgo human immunodeficiency virus disease treatment; and symptomatic heart failure

Liver disease, advanced cirrhosis:
1. Both serum albumin <25 g/L, and either international normalized ratio >1.5 on no anticoagulants, or prothrombin time prolonged >5 seconds over control
2. At least 1 of the following: intractable ascites or hepatic encephalopathy, spontaneous bacterial peritonitis, hepatorenal syndrome, recurrent variceal bleeding
3. Other factors contributing to a poor prognosis: progressive malnutrition, muscle wasting, continued active alcoholism, hepatocellular carcinoma, and hepatitis B surface antigen positivity

Renal disease:
1. Creatinine clearance <0.17 mL/s (10 mL/min) and serum creatinine greater than 707.2 µmol/L (8.0 mg/dl)
2. End stage renal disease discontinuing dialysis, or dialysis-eligible but refusing, and therefore with uremia, oliguria, intractable hyperkalemia, uremic pericarditis, hepatorenal syndrome, and/or intractable fluid overload
3. Other factors contributing to a poor prognosis: mechanical ventilation, malignancy of other organ systems, chronic lung disease, advanced cardiac disease, advanced liver disease, sepsis, immunosuppression/acquired immunodeficiency syndrome, albumin <25 g/L, cachexia, platelet count <25 x 10^9/L, age >75 years, disseminated intravascular coagulation, gastrointestinal bleeding

Acute stroke and coma:
1. Coma or persistent vegetative state, beyond 3 days’ duration, or
2. In postanoxic state, coma or severe obtundation, accompanied by severe myoclonus, persisting beyond 3 days past the anoxic event, or
3. Comatose patients with any 4 of the following on day 3 of coma (97% mortality by 3 months): abnormal brain stem response, absent verbal response, absent withdrawal response to pain, serum creatinine >132.6 µmol/L (1.5 mg/dl), age >70 years, or
4. Dye absent before even to prevent the patient from receiving foods and fluids necessary to sustain life (patient not using artificial nutrition/hydration)

Chronic, after stroke:
1. Poor functional status, as evidenced by Karnofsky score of <50%, with evidence of recent decline
2. Medical complications related to debility and progressive clinical decline, such as: aspiration pneumonia, upper urinary tract infection, sepsis, refractory stage 3-4 decubitus ulcers, or fever recurrent after antibiotics
3. Also weigh: post-stroke severe dementia; age >70 years; poor nutritional status

Adapted with permission from: National Hospice Organization. Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases; 1996.

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Mr M refused hospice, then enrolled and disenrolled twice. Although his partner reasonably points to his need for comprehensive care, the decision to accept hospice care can be complex. Currently, hospice offers Mr M his only way to get comprehensive, coordinated, supportive services at home. Hospice finds the nurses and aides, provides in-home assessment of problems, treats complications such as infections and bowel obstruction, and generally keeps the patient comfortable and in command. Hospice also provides counseling to help Mr M and his family cope through his dying and their bereavement. Hospice providers respect patient and family preferences, so they tend to be open to alternative and complementary treatments and to religious expression. By law in Medicare, and usually also with younger patients, at least 80% of the hospice program’s patient days must be at home, so the emphasis is strongly on staying at home to the end.

Mr M may reevaluate his situation as he becomes more disabled. Because his insurance covers comprehensive services at home only if he is in hospice, he might be forced to enroll. While Mr M and his family should get this comprehensive assistance, the hospice program that they found offensive should not be their only option.

One alternative might be to use a nursing facility or an inpatient hospice at the end of his life. Even if purchased privately (with no insurance), those services would cost no more than what his family now pays, since the national average for inpatient long-term care is approximately $42,000 per year. Most likely, Medicaid would pay for nursing home care. Although giving up the comfort of home, the couple would be relieved of the considerable burden of dealing with attendants. Nursing home residence, if available, is sometimes quite helpful, either for a few days of respite for the family caregiver or for the patient’s final weeks.

Developing a New Model of Care
An overview of health care services for the population illuminates why care at the end of life can be such a challenge. At any one time, most people are healthy, needing only preventive services and rapid rescue from acute illnesses. The usual system of health care serves this group well, with ready availability of emergency transport, diagnostic testing, and surgery. A second group of people function fairly normally but have chronic conditions that require ongoing attention, eg, diabetes, mild heart failure, sensory deficits, and arthritis. This group needs self-care education and rehabilitation, in addition to primary prevention and acute care. Usually toward the end of life, most people join a third, smaller group—those with serious, progressive illnesses that interfere with their usual activities and generally worsen until death.

The healthy and the mildly chronically ill want prevention and cure. Those with disabling, progressive, eventually fatal chronic illness have much broader priorities. For example, when patients are very sick, they want to be comfortable, retain control and dignity, leave a legacy, live longer, and bring closure to their lives. This group particularly needs continuity, advance care planning, reliability across multiple provider organizations, family and caregiver support, spiritual counsel, symptom control, and other elements of palliative care. President Clinton’s Patients’ Bill of Rights protected those with “serious and complex illness,” which is roughly the same category.

Function and symptoms for those living with serious chronic illness at the end of life generally follow 1 of 3 trajectories (Figure). The first trajectory dominates our cultural imagery—those with “terminal cancer.” Cancer patients have a more predictable course and can perform activities of daily living until quite late. Most weight loss and self-care disability occurs in their last 2 months. This trajectory meshes with hospice, which provides comprehensive services for the last weeks or months. However, as Mr M’s case shows, various constraints on hospice can limit its acceptability and delay its use.

Those dying mainly of chronic organ system failures tend to follow a second trajectory. With conditions like heart failure, obstructive lung disease, and cirrhosis, patients usually are quite ill for many months or even years, with occasional dramatic exacerbations. Each episode might cause death, but the patient usually survives many episodes. Since no one says otherwise, patients and families expect to survive each exacerbation. Nevertheless, the severity of the exacerbation and the patient’s dwindling reserves eventually intersect, and death results. The timing of death remains uncertain until very late in the course of the disease. For patients with advanced heart failure, for example, death most often comes within 1 day of

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**Figure.** General Trajectories of Function and Well-being Over Time in Eventually Fatal Chronic Illnesses

![Diagram](https://www.jama.com/images/figure.png)

A: Cancer

B: Organ System Failure

C: Dementia/Frailty

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their having been estimated to have at least a 50% chance of living 6 months. Services for patients dying with chronic medical illness are generally covered by health insurance, except for prescription drugs. The patient's physiology almost never dictates an abrupt change from “cure” to “care.” Instead, aggressive and palliative treatments will be mixed, with advance care planning occurring alongside emergency medical services, dyspnea relief alongside pacemaker placement, and family support alongside resuscitation.

The increasing numbers of persons with progressive disability follow a third trajectory. People with strokes, dementia, and frailty of old age need long-term help with the activities of daily living. These patients often dwindle in weight and functional reserve and succumb to minor infections or diminished function. Most of the expenses for this care are borne privately or, for the poor and those impoverished by long survival with dependency, by Medicaid. With payments coming from private assets, Medicare and other health insurance, and Medicaid, the first strategy of each payer seems to be to offload liabilities onto another payer. Comprehensive and coordinated services are unusual and hard to sustain.

**What Could a Better Care System Deliver?**

Our care system was built for a bygone era, when people mostly died from unintentional injury, infections, and myocardial infarction. Patients can count on emergency resuscitation virtually anywhere, anytime, but continuity and comprehensiveness of care are scarce. Building on national guidelines, 2 breakthrough collaboratives involving 83 provider organizations generated a list of the promises that a good care system should make to patients who face serious, eventually fatal illnesses:

1. Proven medical treatments;
2. Treatment that ensures comfort and avoids overwhelming symptoms;
3. Continuity, coordination, and comprehensiveness;
4. Advance planning so that complications are anticipated and optimum treatment is ready to be implemented, rather than emergency efforts;
5. Customized care, reflecting patient preferences;
6. Thoughtful use of patient and family resources (financial, emotional, and practical); and
7. Assistance to make the best of every day.

Mr M urgently needs a care system that could deliver on any of these promises. Hospice can often come close, but the rest of the available health care organizations were never designed to ensure reliable, high-quality care in his situation at home. Thus, Mr M's physician must patch together a workable array of services as the patient's situation changes. This will require creativity and persistence, and the difficulty entailed should motivate all professionals who provide end-of-life care to enlist others in efforts to reform care delivery so that reliably good care becomes routine.

Provider organizations that serve the very sick—whether hospitals, physician groups, hospice or home care teams, or nursing facilities—can make major improvements in their own practices including enhanced performance in such arenas as pain control, advance care planning, coordinated and comprehensive care for heart failure, and easing bereavement. All provider organizations that serve the same group of patients also need to integrate services to be able to make promises that dying patients can count on. No one can promise pain relief, for example, unless all provider organizations in the area will effectively treat the patient's pain. No one can promise advance care planning unless all organizations in the area honor the plans.

**Mr M: Hospice is for people who are obviously at the very end, and can't help themselves. That's sad. But for a person who can do some things but not others, hospice might not be right. There should be a whole new thing made for people who fall under that category.**

Mr M sees clearly the gap in services between acute care and hospice. Many patients with eventually fatal chronic illnesses do not qualify for hospice because their prognosis is uncertain or because aggressive treatments might still offer real gains. They do not qualify for Medicare home care because they are not homebound or do not have a “skilled need.” Yet, they are too sick for self care. At this phase of life, patients need the continuity, interdisciplinary approach, and focus on symptoms and family that are hallmarks of hospice, even though they could live for many months and might still benefit from certain hospital-based treatments.

Quality improvement teams working on end-of-life care have found that comprehensive end-of-life services are best triggered by recognition that the patient is “sick enough that dying this year would not be a surprise.” Rather than targeting the patients who “will die” within 6 months, programs for end-of-life care should target those who “reasonably might die.” This population will need aggressive, disease-modifying treatment at times, as well as symptom prevention and relief. For most patients, no point marks a dramatic transition from “cure” to “care.”

"MEdiCaring" offers one approach to learning how to finance and deliver care for those with eventually fatal chronic illnesses, by deliberately matching payment coverage with the appropriate service array. Key elements would be targeting services to those who are “sick enough to die” (rather than those with a 6-month prognosis), building continuity and reliability into provider arrangements that cross settings (home, hospital, nursing home), and providing payments in a way that allows substantial flexibility to providers of front-line care. These reforms will require the guidance of data from pilot and demonstration programs, as well as the vision and commitment of concerned practitioners.

**CONCLUSION**

Mr M, Ms L, Dr D, and their friends and caregivers all face substantial challenges as Mr M's life comes to a close. The arrangements made for care delivery in the United States...
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do not serve his situation well. Just as is true for Mr M, fatal illnesses now occupy a substantial portion of most people’s lives. We have no cure, and not much rehabilitation, for any of the 5 major conditions that mark the end of most lives: cancer, stroke, heart disease, lung disease, and dementia. Living with serious illness through to death can be an extraordinarily important phase of life for patient and loved ones, but only if the dying person is comfortable, assured of the resources needed for daily living, and respected. We need to build the skills, attitudes, and patterns of care that allow us to make promises of good care to dying patients.

Author Affiliation: Center to Improve Care of the Dying, RAND, Arlington, Va. Corresponding Author and Reprints: Joanne Lynn, MD, MS, Director, Center to Improve Care of the Dying, RAND, 1200 S Hayes St, Arlington, VA 22202-5050 (e-mail: jlynn@medicaing.org).

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Other Resources: For a list of relevant Web sites and other resources, see the JAMA Web site at http://jama.ama-assn.org/cgi/content/full/287/7/abj/600002.html.

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REFERENCES


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Resources

Web Sites

American Academy of Hospice and Palliative Medicine
http://www.aahpm.org
Information and conferences from the national association representing physicians and other professionals involved in palliative care.

American Alliance of Cancer Pain Initiatives
http://www.aacpi.org
Materials to support efforts to reduce pain, both through changes in practitioner behavior and in regulatory matters.

Americans for Better Care of the Dying
http://www.abcd-caring.org
Information on public policy and a newsletter mainly addressing quality improvement initiatives by provider organizations.

ACP-ASIM End-of-Life Care Consensus Panel
http://www.acponline.org/ethics/eolc.htm
Consensus statements in journal articles on critical arenas of medical practice, including terminal sedation, pain management, and communication.

Center to Advance Palliative Care
http://www.capcsm.org
Providing support to hospitals and nursing homes that want to establish palliative care units or services.

Education for Physicians on End-of-life Care
http://www.EPEC.net
Provides printable professional education documents, conference information, speakers and trainers, and ongoing communication tools.

The End-of-life Physician Education Resource Center
http://www.eperc.mcw.edu
 Provides online peer-reviewed information about instructional and evaluation materials (eg, lectures, small-group exercises, slide sets, videotapes, self-study guides, assessment tools) focused on end of life.

Growth House, Inc
http://www.growthhouse.org
The net's major information clearinghouse for palliative care and end-of-life care, with referral to other sites, streamlined search engines, and resources on-line.

The Inter-Institutional Collaborating Network on End-of-life Care (IICN)
http://www.growthhouse.org/iicn.html
The net's leading online community for health care professionals involved with end-of-life care, with access to >70 mailing lists from 20 major organizations through a single interface.

Last Acts
http://www.lastacts.org
A call-to-action campaign to improve care at the end of life and provides an array of information for the public.

National Hospice and Palliative Care Organization
http://www.nhpco.org
Trade organization for provider organizations doing hospice and palliative care; offers materials, meetings, and referral.

RAND/HII Initiative to Improve Quality at the End of Life
http://www.medicaring.org
Provides support for quality improvement through training, conferences, consultations, tailored projects for networks, and referrals to other resources.

Supportive Care of the Dying
http://www.careofdying.org
Collaboration of Catholic health systems that has created resources to support improvement activities, including a newsletter and assessment tools.

Books and Texts


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Downloaded from www.jama.com at Yale University, on August 29, 2006


