The promotion of quality of life for dying individuals and their survivors is integral to the achievement of the Healthy People 2010 goal of increasing the quality and years of healthy life. With death from chronic terminal illness common, individuals and families frequently experience the negative consequences of terminal decline for long periods of time, and our healthcare system often does not adequately address these consequences. In this article we discuss ongoing efforts and programs to promote higher quality of life for dying individuals and their families/significant others, and we propose an expanded public health paradigm that recognizes the birth-to-death need for public health surveillance, education, and intervention.

The major achievements in the U.S. Public Health system from 1900–1999 highlight the importance of activities that prevent illness and disability and premature mortality and promote health (Morbidity and Mortality Weekly Report, 1999). These activities have resulted in improved quality of life and longer life expectancies and thus can be said to have contributed to human flourishing, which is at the core the goal of medicine and public health. But what about the specific challenges to quality of life in the last years of life? Because Americans are dying at older ages and avoiding premature deaths from infectious diseases and other conditions, they are now dying from chronic terminal illnesses, which frequently are characterized by a long and uncertain path toward death. This path is often fraught with difficulties for dying individuals and their families, ranging from physical and emotional distress to financial ruin. It is imperative that healthcare providers, communities, state and local public health departments, and other government entities promote high-quality end-of-life care so that the negative consequences of living with and dying from chronic terminal illness can be prevented. From a public health perspective, monitoring the quality of end-of-life care in communities by looking at care and outcomes and promoting improvement of this care can result in higher quality of life for dying individuals and in more years of healthy life for community populations.

**THE POPULATION IMPERATIVE AND CONSEQUENCES**

While death is of course a universal experience, death is more likely to occur among people in older age groups, with chronic disease and...
frailty the likely cause of death. In 2000, three-quarters of all deaths in the United States were of people 65 years of age and older, and one-third of these deaths were from (chronic) heart disease (National Center for Health Statistics, 2003). Nearly a quarter of nontraumatic deaths in 2001 occurred in nursing homes. Hospitals (and their emergency rooms) were the site of death for 49.5 percent among this group, homes in the community (including residential care and assisted living) for 23.2 percent, and other locations were the site of death for 3.9 percent of decedents older than 65 (Brown University Center for Gerontology and Health Care Research, 2004). Connor (1999) estimates that 66 percent of all deaths are from conditions with prior periods of medical treatments or dependency.

There is no one definition of a good death, but high levels of patient symptom distress and caregiver burden have been identified by consumers as characteristics of “bad dying” (Steinhauser et al., 2000). Thus, the high prevalence of physical symptoms associated with chronic terminal illness and the increased severity of many symptoms as death nears result in management of physical symptoms being of foremost concern in end-of-life care. In fact, higher assessments of quality of life have been shown to be associated with fewer symptoms or with a lesser severity of symptoms (Portenoy et al., 1994). However, research has also shown quality of life for dying people and the needs of their significant others to be aligned with what patients, families, and providers deem important; quality of life encompasses more than the health-related domains and also is related to emotional, social, and spiritual consequences of terminal illness, as well as the survivor's experience of the illness (Steinhauser et al., 2000).

While Steinhauser and colleagues (2000) found that patients, families, and physicians agreed that consequences such as pain and symptom management and preparation for death (and achieving a sense of completion) are important to improving end-of-life care, other factors such as not being a burden and coming to peace with God were considered important by patients (but not by physicians). Once the distressing consequences of illness are addressed, clinicians say, patients and families, including caregivers, are better able to experience the personal opportunities for growth that can come with the close of life.

Specialized Care

Palliative care (including hospice care—a specialized form of palliative care) can meet the diverse needs of terminally ill individuals and their families. The goal of palliative care is to provide “effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s)” (National Consensus Project for Quality Palliative Care, 2004). Currently, more than 1,500 physicians are certified by the American Board of Hospice and Palliative Medicine, with subspecialty status by the American Board of Medical Specialties considered likely. Palliative care certification for nurses is available through the National Board for Certification of Hospice and Palliative Nurses.

However, formal programs incorporating palliative care principles and practices outside of hospice, while increasing, are just beginning to be fully integrated into U.S. healthcare provision. Integration has been slow because no discrete government funding is earmarked for provision of comprehensive palliative care (and congressional observers say it is unlikely that such reimbursement will soon be forthcoming), with the Medicare hospice benefit, state Medicaid hospice benefits, and special disease-related waiver programs being the only sources of government funding for related care.

So, funding for palliative care programs comes largely from existing payment streams. For example, many hospitals have integrated hospice and palliative care programs into their ongoing operations (and many of those wise enough to provide palliative services directly or with hospice partners have recognized cost savings with this integration even though no additional payment for provision of palliative care services outside of hospice is secured).

The use of hospice care, unlike palliative care outside of hospice, is widespread. Hospice care considers the patient and family as the treatment unit in an approach that is best described as “condition management,” distinguishing it
from the narrower focus of disease management. Given the often high prevalence and severity of symptoms as a patient's terminal disease progresses, hospice staff must have advanced assessment and diagnostic and treatment skills. However, they must also possess the competencies to address the human consequences of disease. For example, while congestive heart failure requires skilled assessment and treatment skills for associated shortness of breath and other physical symptoms, the other adverse consequences of this terminal condition must also be addressed. These include a patient's concern about the family's finite resources or a significant other's concern about losing a companion and caretaker and are the province of trained social work and bereavement counseling staff.

In 2002, some 25 percent of all Medicare beneficiaries who died from any cause received hospice care prior to death of beneficiaries in Medicare managed care plans, 34 percent received hospice (MedPac, 2004). Also, while 25 percent of non-Hispanic whites used hospice, 18 percent of African American, 20 percent of Hispanic, and 15 percent of Asian decedents used hospice (MedPac, 2004).

Of course, not all individuals who die are Medicare beneficiaries, and many deaths are sudden and not from chronic conditions. Estimates indicate that hospices potentially provided care for approximately 43 percent of people dying from chronic diseases in 2003. While 43 percent is a greater hospice enrollment rate than is generally thought to be the case (based on consideration of total mortality numbers), there is still a recognized need for increased access to hospice care. For example, in 2003 many people who accessed hospice did so in the last weeks or days of life, as evidenced by a median hospice length of stay of 22 days (National Hospice and Palliative Care Organization, 2004).

Such diverse communities as Fort Myers, Florida, Lexington, Kentucky, and Grand Junction, Colorado, have responded to consumer demand for a service that assists with the consequences of illness, resulting in hospices serving 40 percent to 59 percent of the communities' total decedents and 67 percent to 95 percent of all people dying from cancer across settings. Still, in many communities hospice care is underutilized, in part, because of healthcare systems that revere high technology and too often do not adequately consider the quality of life of patients and their survivors when pursuing goals of prolonged survival. Another reason is lack of knowledge about hospice and its scope of care and support beyond physical symptom management. Another is Medicare hospice eligibility guidelines. However, providers who are familiar with hospice eligibility criteria and understand the wide range of needs addressed by hospice and palliative care can potentially reverse the trend of short hospice stays as well as increase the proportion of individuals and families referred to hospice and palliative care.

Generally, hospice care improves family satisfaction with care, reduces the occurrence of invasive treatments and hospitalizations, and results in better management of pain (e.g. Miller, Mor, and Teno, 2003). In a recent national study, families of decedents who died in their homes with hospice care, versus in other care settings or in their homes without hospice care, reported lower rates of unmet needs, higher satisfaction with care, and fewer concerns with the adequacy of communication (Teno et al., 2004).

In addition to the quality benefits of hospice care, its provision does not appear to be associated with significant increases in government expenditures for Medicare beneficiaries, even though government savings or additional costs vary by patient diagnoses (Miller et al., 2004; Campbell et al., 2004) as well as by some patient characteristics such as race. For example, greater government savings are observed for African American versus non-Hispanic white nursing home residents who receive hospice (Gozalo et al., 2003). Yet undetermined are the healthcare costs and potential savings associated with the reduced illness and mortality rates of survivors whose family and caregivers received hospice care.

It is notable that hospice care is viewed and practiced by many as the "Medicare hospice benefit," which is restricted to people with physician-certified terminal prognoses of six months or less (if the disease runs its normal course) and requires patients and families to forgo any
### Table 1

**Comparative Public Health Valuation of Hospice/Palliative Care Provision to People Experiencing Terminal Decline Versus Flu Shot and Liver Transplant**

<table>
<thead>
<tr>
<th></th>
<th>Flu Shot</th>
<th>Liver Transplant</th>
<th>Hospice/Palliative Care (Directed to Patient and Family Unit)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prevalence of Potential Adverse Outcomes</strong></td>
<td>Estimated 10–20% of Americans annually get the flu</td>
<td>&lt;0.1% of population needs and is eligible to benefit from liver transplant</td>
<td>Estimated 66% of all people dying experience a terminal decline</td>
</tr>
<tr>
<td><strong>Magnitude of Need for Individual</strong></td>
<td>Depends on risk</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td><strong>Prospect of Success, of Individual Impact</strong></td>
<td>50–75% (depends on age)</td>
<td>50%</td>
<td>&gt;90%</td>
</tr>
<tr>
<td><strong>Likely Alternatives to Intervention and Likely Outcome(s) of Alternative</strong></td>
<td>Treat symptoms • Experience lesser degree of symptoms • Higher probability of death for high-risk groups</td>
<td>None • Death</td>
<td>Traditional medical care • Lower probability of having key preferences met and condition-adjusted desired clinical outcomes obtained</td>
</tr>
<tr>
<td><strong>Cost</strong></td>
<td>Very low</td>
<td>Very high</td>
<td>Low to moderate</td>
</tr>
<tr>
<td><strong>Public Health Impact</strong></td>
<td>High • “Community immunity” (for high-risk groups) • Cost savings</td>
<td>Low • New knowledge is created that is generalizable to other aspects of medical science</td>
<td>High • Reduction of caregiver strain and stress, resulting in lowered incidence of morbidity and longer life expectancy of caregivers and some patients. • Community solidarity is upheld as dignity for individuals is preserved. • Cost savings, futile expensive medical care and treatments are avoided, and potentially lower healthcare costs for survivors</td>
</tr>
</tbody>
</table>

**Source:** Sulmasy, 2003.

Curative care and relinquish other Medicare Part A benefits (for their terminal illness). However, nearly half of U.S. hospices report offering palliative care services outside of the Medicare and Medicaid hospice benefits. Palliative care outside of the Medicare hospice benefit is often
provided by these hospices as a specialty consultant practice or home-health-agency service, or in partnership with hospitals. Specialized palliative care outside of the hospice benefit is also available. Absent regulations, palliative care is not constrained by the six-month prognosis eligibility requirements or by the need for patients and families to forgo curative treatment (and thus acknowledge terminal illness). Providers interested in gaining access to such palliative care services for their patients and families are therefore encouraged to query their local hospices to determine if palliative care services beyond the Medicare hospice benefit are provided. If a hospice does not provide such services, it is probable that the hospice staff can provide referral information.

However, providers should be aware that although both hospice and nonhospice forms of palliative care are generally believed to encompass the management of symptoms as well as psychological, social, and spiritual problems, there is currently no licensure or quality surveillance of nonhospice provision of palliative care to guarantee uniformity of service provision or compliance with recently established national palliative care guidelines (National Consensus Project for Quality Palliative Care, 2004). Therefore, the extent of services and support available through nonhospice palliative care providers should be confirmed to be sure the care and support desired for patients and families are available.

Despite the above efforts, in order to meet the public health needs of communities, much work remains to be done to integrate hospice and other palliative care more comprehensively into U.S. healthcare. There is a need to move palliative care services “upstream” (i.e., farther from death), to promote specialized palliative medicine education for all healthcare professionals and to integrate monitoring and educational activities addressing end-of-life issues into the ongoing public health activities now occurring at state and local levels.

Efforts should be especially targeted to address the palliative care needs of those who have chronic terminal illnesses for which the terminal decline spans long time periods and who, therefore, may not be eligible for hospice care even though their needs are great. Also, care and services should be targeted to individuals and families less likely or able to enroll in Medicare hospice, such as African Americans and Hispanics and those who for a number of reasons are without access to specialists certified in hospice or palliative care. Especially needed are innovative partnerships and systems in hospitals and nursing homes to extend the availability of hospice and palliative care into these settings, where large proportions of vulnerable older adults spend their last days, weeks, months, and years of life.

We now face a looming volume of unprecedented needs, from an aging population and, at the same time, a dwindling healthcare labor pool and inadequate economic resources to fully meet future healthcare needs. At such a time, a public health focus on promoting high-quality end-of-life care is a promising approach both to promoting well-being and to preventing unnecessary healthcare spending. Nevertheless, even though the quality of end-of-life care affects the quality of life for virtually every American (both as caregiver and care recipient), we still lack widespread consensus that improving the end of life is a worthy public health focus. However, some have previously advocated for this focus (Rao, Anderson, and Smith, 2002; Jennings et al., 2003).

A CALL TO ACTION

Considering that the experience of death is indeed universal and that a high proportion of deaths occur from chronic conditions, a public health approach to improving the experience of death from chronic terminal illness for the dying person and for caregivers and family indeed appears warranted. The potential public health value of such an approach is explored in Table 1, which compares the costs and potential public health impact of high-quality end-of-life care (defined here as care provided by hospice and palliative care specialists), on the one hand, to the costs and impact of flu immunization programs and liver transplants, on the other (Sulmasy, 2003; Jennings et al., 2003). This comparison considers the estimate that 66 percent of all people die of chronic conditions. As shown, while both flu immunization and specialized hospice
and other palliative care directed to the patient-family unit have very low to low-to-moderate costs (respectively), the potential public health impact of both is high. The reasonableness of developing public policies and programs to promote the delivery of specialized end-of-life care to Americans is apparent.

In conjunction with the above, adoption of a birth-to-death public health paradigm is recommended to identify and address the public health needs of individuals, families, and communities. Such a paradigm would address a sort of continuum of public health needs—from those of pregnant women (prenatal care) to those of survivors (bereavement support for families). A birth-to-death paradigm approaches public health from a twenty-first-century perspective in which health is not simply the absence of disease and where dying and health meaningfully coexist. A birth-to-death paradigm makes explicit the need for public health efforts to span all age groups and diseases, from infectious to chronic disease and debility; additionally, the paradigm focuses interventions at the level of the individual, family, and community or population, not just the patient. A

Top Five Priority Recommendations for State Health Department Action

1. Identify a chronic disease point person within the state health department to coordinate/liaison end-of-life activities with relevant issues (e.g., aging, cancer).
2. Collect, analyze and share data about end of life through state surveys such as the Behavioral Risk Factor Surveillance System (BRFSS).
3. Incorporate end-of-life care into state comprehensive cancer control plans.
4. Educate the public about the availability of hospice and palliative care.
5. Educate the public about the importance of advance directives and health care proxies.

CONCLUSION

The baby boom population is fast approaching its Medicare years with unprecedented life expectancies. To adequately address the needs of this population, it is essential for growth in the use of palliative care to occur, and for such growth to be promoted by healthcare providers, public health professionals, and government entities. Alternatives to futile or otherwise undesired medical interventions must be made widely available by hospices and other palliative care providers so that the progressively more aged and frail population of older adults in the U.S. can live optimally in life’s final phases. Provision of such care to these individuals and their families has the potential not only to improve quality outcomes in the final phase of life and to reduce caregiver morbidity and premature mortality, but also to result in dollar savings for healthcare providers and for Medicare and Medicaid (with a resultant greater availability of government dollars for other public health priorities).

None of us is immune to death, but we can be protected from the adverse consequences of living with chronic terminal illness, or the burden of prolonged caregiving. This article has highlighted the significance of preventing these adverse consequences and has identified efforts under way to improve the quality of end-of-life care through the evolution of hospice and palliative care, and has proposed an expanded public health paradigm from birth to death. Through the efforts of healthcare providers, communities, and state and local health departments and other government entities, healthier days, months, and years of life can be achieved for individuals living with chronic terminal illness and their families.

Susan C. Miller, Ph.D., is associate professor of community health (research), Center for Gerontol-
ogy and Health Care Research, Brown University School of Medicine, Providence, RI. True Ryndes, A.M.P, M.P.H., is president and CEO, National Hospice Work Group, and vice president, Public Policy and Advocacy, San Diego Hospice and Palliative Care, San Diego, Calif.

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