The hard question we face, then, is not how we can afford this system's expense. It is how we can build a health-care system that will actually help dying patients achieve what's most important to them at the end of their lives. – Atul Gawande (2010)

This special issue of Nursing Economic$ is focused on one of the most complex, morally critical health care practice and policy issues that nurses must face and advocate for: individual choice for end-of-life care. As the Supreme Court examines the constitutionality of the Patient Protection and Affordable Care Act (known by some as ObamaCare), many nurses are contemplating the future of national health care policy. While the Supreme Court’s decision will have great influence over the access, cost, and quality of treatment individuals receive, individuals can still make important decisions about end-of-life planning that can help themselves and their society. This national focus provides us with the opportunity to make the controversial topic of planning end-of-life care part of the larger health care conversation. The specialization and fragmentation of health care delivery directs health care professionals to focus on parts of care rather than the whole patient and his or her family. Nurses must hold timely conversations, especially with the chronically ill, to ensure their care is well coordinated and aligned to their preferences and choices.

We Need the Conversation

There are very important reasons for making end-of-life planning part of this larger conversation. As baby boomers live longer, they place unmatched demands on the health care system. At the same time, rising costs threaten Medicare just as millions of boomers are turning to it for health insurance coverage. Adding to this difficult situation is the reality that the prevalence of catastrophic diseases that once killed swiftly (e.g., pneumonia, cholera, massive heart attacks) have been replaced by chronic and, often, degenerative diseases (e.g., advanced cancers, diabetes, lung disease, Alzheimer’s), leading to a slow death for most. Technology has enabled the life of patients to be sustained well past their ability to make decisions. Finally, while the demand for palliative care is increasing as part of treatment, differences in pain management across health facilities can make dying in an intensive care unit or being in the care of hospice very distinct experiences. Of the 1.5 million Americans who die of a chronic illness each year, more than 70% are admitted to a hospital during the last 6 months of life. Recent studies also show that most people living with a serious illness experience inadequately treated symptoms, fragmented care, poor communication with their doctors, and enormous strains on their family caregivers (Meire & Morrison, 2011).

Barriers to the Conversation

Despite this increasingly everyday reality, people don’t want to talk about dying. We live in a society that denies or avoids discussing death. According to public polls, we certainly don’t talk about it, at least when it comes to making decisions that will ensure the implementation of our wishes for how we die. This is increasingly distressing as by 2030, roughly half of the projected 8.5 million Americans over the age of 85 are expected to suffer from some form of dementia. This age group is also more likely to be divorced and childless compared with their parents, thus there may be no family advocate (Jacoby, 2012).

While the U.S. public doesn’t like to talk about
death and dying, they will answer questions generalized to society. Findings from national polls taken over the years have shown them to be largely in favor of physician-assisted suicide. A recent Angus Reid Public Opinion (ProCon.org, 2010) found 60% supported the legalization of euthanasia (good death) and 70% in supported euthanasia for people who request it to ease their pain and suffering. Those opposed to euthanasia argue that it sends a message that the lives of the sick or disabled are less valuable and they would be most vulnerable. The need to clearly define what is meant when using the word euthanasia is critical. Physician-assisted suicide is defined as: “When a physician provides either equipment or medication, or informs the patient of the most efficacious use of already available means, for the purpose of assisting the patient to end his or her own life” (Dyer, 2006a, ¶ 3). Voluntary active euthanasia is defined as “when, at the request of the patient, a physician administers a medication or treatment, the intent of which is to end the patient’s life” (Dyer, 2006b, ¶ 1). To make the choice of euthanasia (good death), it must be voluntary euthanasia. Oregon and Washington legalized this type of euthanasia and call it assisted dying.

But can individuals truly decide when to die? A 2010 national survey of 10,000 U.S. physicians found that only 46% of respondents agreed physician-assisted suicide should be allowed in some cases (Kane, 2010). Like most Americans, doctors would prefer not to discuss the topic. With the American Medical Association firmly against assisted dying, the medical establishment remains a house divided. The American Nurses Association’s (ANA) Position Paper (2010) on the nurse’s roles and responsibilities in providing end of life care also states that assisting in euthanasia is not permissible. Based on anecdotal information and some small surveys, nurses are also divided over the question of euthanasia. However, the ANA does state that nurses are to serve as advocates and resources for patients and their families. End-of-life patient counseling and education are to be encouraged systematically through rigorous practice standards and appropriate reimbursement.

Unfortunately, while death may be certain, often the timing is not – a question of when the time comes rather than if, needs to be addressed with “when and how” questions. Individuals are faced not only with the difficulties of how to plan for care at the end of life, but also with the struggle to know when to give up the battle. These overlapping contexts add to the barriers as well as the complexity of end-of-life conversations. These conversations are critically important and can enable each person to decide to communicate his or her individual goals, including what constitutes quality of life, and how he or she wants to die (Gawande, 2010). Greater numbers of nurses educated in end-of-life care will be needed if we are to make this topic “discussable" and a standard part of patient care. However, another barrier to the end-of-life care conversations for both patients and health professionals is fear of a slippery slope.

Slippery Slopes?

The health reform bill originally included a provision to compensate doctors for talking to patients about end-of-life choices. Congress removed that language after critics charged such conversations could lead to sanctioning euthanasia or creating death panels to decide which patients would live or die. End-of-life policy efforts that include euthanasia reflect the political distortion that goes into blocking change in health care. Orfali (2010) argues that fear, uncertainty, and doubt is used by opponents of assisted dying to frighten people. Using the term death panels is an example of this rhetorical strategy and one that effectively works against the legalization of assisted dying. To challenge the veracity of the slippery slope arguments, Orfali (2010) presents studies of assisted dying in Oregon, the Netherlands, and Switzerland. The studies reveal no slippery slope toward mass euthanasia nor any evidence that the elderly, the disabled, or the poor are being pressured into assisted dying. Based on these findings, Orfali (2010) advocates the legalization of physician-assisted dying modeled after Oregon’s “Death with Dignity Act.”

There is an ongoing conflict between pro-life and right-to-die forces but the visibility of the fight is only intermittent. The last well-known engagement occurred almost 7 years ago, after the death of Terri Schiavo in 2005. Since then, the issue has seemed relatively calm, belying the continuing turmoil in hospitals and court rooms over what, exactly, marks the end of life. With such successful discursive strategies for frightening the public, it is not surprising death remains a taboo topic for polite conversation. The review of research by Orfali (2010) highlights how death needs to be addressed as a rational conversation topic – a reality that affects all of us and need not be frightening.

Current State Policy Agendas

End-of-life care legislation efforts exemplify the long journey it takes to change policy and practice. Successful milestones have been met and yet some key goals remain elusive. An excellent review of these efforts can be found in the Robert Wood Johnson Foundation’s retrospective Series “Improving Care at the End of Life” (Patrizi, Thompson, & Spector, 2011). To offer assisted dying effectively, it must be integrated into the practice of medicine. Thus far, the integration has been largely piecemeal as the U.S. Supreme Court ruled there is no constitutional right to die and the decision to legalize euthanasia must be done at the state level. Every state must have this discussion and then put it to a vote. Some states (e.g., Oregon)
had this conversation and lifted the prohibition.

In the 2006 landmark case *Gonzalez v. Oregon*, the U.S. Supreme Court reaffirmed its position, by a 6-3 decision, in support of Oregon. Currently the only two states with Death with Dignity laws are Oregon and Washington. However, end-of-life issues are at least on the policy agendas of some state legislatures. This year eight states proposed end-of-life legislation. It falls into three basic categories: (a) Death with Dignity legislation, modeled on the Oregon and Washington laws (Vermont, Hawaii, and Massachusetts); (b) bans which would outlaw Death with Dignity from being practiced, like the ones in Idaho, Montana, and Wyoming; and (c) end-of-life options notification and honoring patients’ end-of-life designations – perhaps the broadest category. Arizona has a bill pending modeled on the New York and California palliative care acts. A bill in Idaho would amend a law passed last year to ensure advance directives are honored. Maryland is working toward a standardized form for individuals to specify their wishes for life-sustaining treatments and end-of-life care similar to the Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in many states (Death with Dignity National Center, 2012).

**Cost and Quality Conversations**

As noted, end-of-life care composes a large proportion of services funded by Medicare. Partially as a result of this expenditure, the level, types, and intensity of such care have driven substantial amounts of research over the past 25 years. Some of the interest in this area has come from the observation that costs can be contained by targeting aggressive and expensive care at the end of life. Research has also found problems with end-of-life care, leading analysts to conclude that existing patterns of care do not meet the needs and preferences of terminally ill patients. More research is needed. For instance, policy changes, such as making hospice a benefit, has led to the rapid increase in its use. However, evidence of its impact on costs in the last year of life, while exhibiting some variability, indicates only a slight overall decrease in costs (Riley & Lubitz, 2010). Despite changes in the delivery of medical care over the past 28 years, Medicare expenditures have not changed substantially. This likely indicates the quality of end-of-life care issue can still be addressed without increasing costs significantly and that it may in fact contribute to innovative pathways to reducing costs. While costs have remained stable, the quality of care has improved with the integration of palliative care as part of treatment in chronic conditions.

There is solid research suggesting the use of palliative care as part of treatment to extend quality of life can extend the length of life. Palliative care also holds significant value in providing relief from suffering at the end of life (Temel et al., 2010). The demand for palliative care is growing as the public begins to understand that it is not the same as hospice care. Today, hospice care is considered one type of palliative care. Another important function of palliative care is the opportunity it provides to help people define their long-range goals. Many patients who receive it are not expected to die anytime soon. However, when making the shift from treatment directed toward cure to treatment for comfort the conversation has already been started.

The National Institute of Nursing Research (NINR) has also supported and informed policy changes to improve the quality of end-of-life care. The director of the National Institutes of Health designated NINR as the lead institute for end-of-life research in 1997. This has led to NINR-supported investigators to advance the science of palliative care and end-of-life care. The research to develop the POLST form, mentioned earlier, was developed through NINR funding. Standard communication guidelines have also been developed to assist health professionals to hold these important conversations with patients and their families (NINR, 2011).

**Nurses Must Advocate for Patients**

As nurses, we participate in providing social justice through the delivery of health care. While much of what we do supports healthier lifestyles and healing, we must also acknowledge that for an increasing number of our patients, life may have become irreversibly painful and unwanted. For these people, the trauma associated with disease and the restrictive nature of age transforms continued living into a daily exercise of pain and humiliation. Nurses have acute sensitivity to the dilemmas faced by dying patients and their families. Our empathy and know-how in such cases dictates that we make an effort to relieve such suffering.

But moving this belief into practice is complex and requires policy support at both the state and organization levels. Nurses must identify or develop the professional expertise to hold conversations with patients and their families. We are neither victims (just following the doctor’s orders) nor executioners (members of death panels). Nurses know advance directives are not part of “death panels” but pertain to treatment preferences and the designation of a surrogate decision-maker in the event a person is unable to make medical decisions on his or her own behalf. Advanced directives are one of the tools we can use to hold conversations with patients regarding their choices of end-of-life care. They are used to address the spectrum of choices from those who want aggressive treatment to ensure the deployment of every tool available in modern medicine to those individuals who want to avoid unwanted treatments. Easing suffering will require assessments of the changing terrain of end-of-life care and the populations receiving that
care. Dialogues can bridge the interest of patients, providers, and policymakers and ultimately legislation that reinforces ethical end-of-life care and ensures a voice for those who will be most affected.

REFERENCES


