Executive Summary

An eight-point action plan is proposed for lowering costs associated with end-of-life health care in the United States, as well as improving the quality of life experienced by patients and their families.

This action plan was derived from an analysis of the six articles presented in this special issue of Nursing Economic$.

The two major features of this action plan are: (a) expansion of hospice and palliative care, as well as (b) increased use of advance directives.

Additionally, as pre-conditions for the effective operation of this action plan, the political, cultural, and legislative contexts that merit attention are discussed.

Finally, arguments as to the desirability, feasibility, and sustainability of this action plan are offered.

The preceding six articles presented in this special issue of Nursing Economic$ illustrate with uncommon clarity the nature and scope of the end-of-life cost problems facing the U.S. health care system. They tactfully navigate the sensitive and often contentious subject of death, while acknowledging that it must be addressed by patients, by their families, and ultimately by all Americans, if we are to efficiently and expertly dodge the catastrophic effects of the “perfect cost storm” that several of the authors reference. The storm — rising health care costs, particularly at the end-of-life, and the aging baby-boomer generation — is just beginning to lap at our shores; predictably soon it will be a tsunami. Taking the necessary actions to deal with the nexus of the Cost and the Dignity of Death issues will require making difficult decisions about the extent and types of care delivered, as well as the mode of health care delivery offered in the United States. The authors of the articles that you have just read provide convincing evidence for why and how these decisions should now be made. To give a sense of the most salient points that each of the preceding authors make, we will next summarize them. Following our summaries, we will offer an eight-point action plan that policymakers and lobbyists would do well to consider to avoid the impending tsunami that inaction will surely invite.

Lessons Learned from Papers Addressing the Question, How Can We Afford to Die?

In “End of Life Care in the United States: Current Reality and Future Promise — A Policy Review,” Lisa A. Giovanni, BSN, RN, details the end-of-life reforms, or lack thereof, in the 2010 Patient Protection and Affordable Care Act and the inherent potential of the 1991 Patient Self-Determination Act, specifically as it pertains to advance directives and their ability to curtail end-of-life health care costs. Stressing “that the unique needs of the terminally ill remain poorly addressed,” she explains the benefits of hospice and palliative care and advance directives, and suggests their integration, bringing forward their individual benefits but also anticipating the synergy created by folding these initiatives together. Giovanni also raises an alert that must be considered — that of dis-
parity in access and funding for these cost-controlling measures.

Marlene McHugh, DNP, DCC, FNP-BC; Joan Arnold, PhD, RN; and Penelope R. Buschman, MS, RN, PMHCNS-BC, FAAN, in their article, “Nurses Leading the Response to the Crisis of Palliative Care for Vulnerable Populations,” posit that nurses are innately qualified to provide palliative care. They poetically suggest that the qualities and duties of palliative care compose the essence of nursing and that all nurses can be palliative care generalists, whereas nurses with more specialized, advance knowledge in the field can lead the implementation and expansion of palliative care. Beyond simply encouraging the expansion of palliative care, McHugh and co-authors argue palliative care must be expanded to vulnerable populations, as these populations are especially in need of palliative care and should have easy access to it. The authors go on to detail recent innovations in encouraging and expanding palliative care in the United States and recommend all nurses should be aware of these initiatives. Ultimately, the authors want patients, not settings, to dictate the quality and type of care received at end-of-life. They conclude with a hopeful vision of the future: “all nursing care is palliative care” and adopting this viewpoint “can transform health with nurses taking the lead.”

In “Death Is Not an Option – How You Die Is: Reflections from a Career in Oncology Nursing,” Brenda M. Nevidjon, MSN, RN, FAAN, and Deborah Mayer, PhD, RN, AOCN, FAAN, describe the fears associated with dying that they have witnessed in decades of practice in oncology nursing and which they also support with evidence. Nevidjon and Mayer also address the costs associated with dying and ask the profound question, “Life at what cost?” By denying that death is an inevitable reality, we make it impossible to discuss our end-of-life care rationally. Nevidjon and Mayer provide resources and cite examples of successes in beginning this conversation, but assert that providers have not gone far enough. Ultimately, they suggest that to answer this question, providers must begin the end-of-life conversation in their own homes.

Deborah Witt Sherman, PhD, CRNP, ANP-BC, ACHPN, FAAN, and Jooyoung Cheon, MS, RN, in “Palliative Care: The Paradigm of Care Responsive to the Demands for Health Care Reform in America,” go beyond asserting that something must be done to curtail costs and improve the quality of end-of-life care and identify a remedy: palliative care. Sherman and Cheon offer convincing evidence that palliative care is poised to become a “universally available approach” to health care, which addresses both the quality of life needs of patients and families as well as the costs of delivering end-of-life treatment and services. Although they address the differences between hospice and palliative care, they focus quite intently on palliative care because of its broader potential (it can be coupled with curative treatments and it can be used to ease the suffering associated with long-term, not just end-of-life, diseases) and because of its proven cost-saving and quality-improving characteristics. The logical extension of their idea is that costs at the end of life, which seems to be the most contentious aspect of “controlling” health care costs in general, can be routinely subsumed in the palliative care domain and so controlled. In addition to documenting the positive aspects of palliative care, Sherman and Cheon offer convincing evidence that advance practice nurses, as a result of their educational training, proficiency in practice, and professional commitment, are and should continue to be the integral players in the rapid and continued expansion of palliative care nationally and internationally.
We propose this action plan because, at some point, systemic change will happen.

1. All individuals over 18 years old should have advance directives long before they find themselves at the “seventh age”: the end of life. Nurses, physicians, and other health care providers should be required to follow these advance directives. Many of the authors who have contributed to this special issue suggest and demonstrate advance directives have significant cost-cutting potential, but recognize that even when patients do complete them, they are not always honored. The contributing authors posit ways to increase completion and use of advance directives. These suggestions, which we believe to be the essentials in scripting effective advance directives, are: (a) reimbursement policies should compensate health care providers for helping their patients to complete advance directives, (b) advance directives should be discussed and created in the context of an individual’s community, and (c) cost sensitivity should be discussed transparently as part of the intended effect of the advance directives.

2. Hospice and palliative care (as defined in the “Introduction” to this special issue) must be available for all patients treated at hospitals or using services that are supported in part by any municipal/local, state, or federal-derived revenue. Derived revenue is any tax revenue that accrues by way of the taxing/redistribution authority following the accounting principles as laid out in Statement No. 34 of the Governmental Accounting Standards Board.

3. The decision to provide a patient with hospice and/or palliative care will be determined by the patient, his or her family, case manager, and nurses and physicians of the organization where the patient is receiving care. All the while, the patient’s advance directive must be kept in mind and adhered to in accordance with the patient’s wishes. This is, of course, where the cost sensitivity of the advance directive will play a major role in dealing with the nexus of the Cost and Dignity of Death issues.

4. Traditional reimbursement sources will bear the cost of providing individuals with hospice and palliative care; specifically, private insurance with no/low deductibles or co-pays and a combination of municipal, state, and federal sources. Reimbursement agreements should be as simple as possible, following the usual concept of equitable redistributions. This may sound daunting; however, simple rules such as “telescoping” where one first exhausts private insurance, then municipal, then state, and finally federal may make the funding and reimbursement processes simpler and more equitable. We also propose that an individual’s personal wealth should not be exhausted before municipal, state, or federal sources are used.

5. To increase the availability of hospice and palliative care facilities, for which there will be a sharp increase in demand due to the aging baby-boomer generation as well as the fact the central feature of our action plan requires the expansion of such facilities, legislators and other elected officials should consider incentivizing or sub-

hensions surrounding creating and implementing advance directives are lessened. As evidence for this, the authors cite numerous studies showing early adoption and sensitive cultural creation of advance directives makes these documents more effective. Ultimately, the potency of the authors’ argument is that if scripted properly, based on individual, family, and community beliefs and norms, advance directives can contribute to a dignified end-of-life strategy consistent with the community discourse an individual is engaged in over his or her lifetime. This may finally allow the health care delivery system to move away from providing heroic and ineffective end-of-life treatments and toward a more palliative approach.

These six works competently address the myriad issues warranting consideration in the development of an action plan, which addresses the question, “How can we afford to die?” These articles have many common arguments and fit together nicely; that is to say, our proposed action plan basically wrote itself.

The Action Plan

Following are the eight central points of our action plan derived from a synthesis of the research summarized in this special issue. We fully recognize the complicated systemic-dynamic change necessary to achieve our action plan will require pilot testing, redesign refinements, further pilot testing, a full-scale launch, and then periodic monitoring and evaluation. We propose this action plan because, at some point, systemic change will happen; we want these change efforts to be pro-active – driven by design rather than re-active – not spawned by panic. After outlining our proposed action plan, we will discuss its desirability, feasibility, and sustainability.

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6. Social networking should be used by health care organizations and local, state, and federal governments to promote choosing hospice or palliative care over heroic, and often futile, end-of-life treatments. Successfully increasing the use of hospice and palliative care is contingent upon convincing individuals and their caregivers to choose these less-expensive and quality-of-life improving options, as well as detailing them in their advance directives. As Wholihan and Pace recommend, a way to encourage individuals to include hospice care in their advance directives is through extensive and intensive community dialogue and communication. Additionally, fully using social networking in this regard may also be beneficial. This is the powerful communication tool, made famous by Mark Zuckerberg’s Facebook, and should not to be dismissed as a fad. Although we were unable to find scholarly sources connecting social networking and improved health outcomes or increased engagement in health care decision making, some studies indicate social networking may increase civic and social engagement (Pasek, More, & Romer, 2009; Valenzuela, Park, & Kee, 2009). Make no mistake: everything is contingent upon developing sensible advance directives.

7. A greater number of nurse faculty at U.S. colleges and universities will be required to meet the increased demand by nurses who need advance training and education in hospice and palliative care. Nurses can, and traditionally, have played a major role in hospice or palliative care; expanding hospice or palliative care will necessitate an increase of the numbers of specialized nurses (American Association of Colleges of Nursing, 2005).

8. We recommend that Tilden and colleagues’ list of punitive reimbursement policies (penalties for hospital re-admission, value-based and pay-for-performance plans, and other payment reforms that emphasize quality and penalize systems that deliver poor care), as well as possible incentives, be linked to documented patient outcomes and be audited by the Government Accounting Office (GAO). We recommend the GAO audit the expansion of hospice and palliative care because of the unbiased, analytical role it has played in objectively evaluating U.S. legislation and governmental actions. GAO-audited and approved services would be reimbursed. Un-audited or unnecessary/non-recommended treatments would not be reimbursed under this proposed system, unless the treatment was in accordance with a patient’s advance directive. This “unless-caveat” regarding the advance directives needs to be considered carefully; if many patients have advance directives that make positive, cost-conscious systemic change impossible, most of the other efforts discussed as part of our action plan will go for naught.

Other Important Contextual Issues

- The GAO audit will include an assessment of the benefits of a specific treatment or service relative to its cost for a particular patient population under examination. The audit will focus on a series of questions. For example, “How was the treatment or service delivered given the alternatives?” or “What were the benefits of the treatment relative to its cost?” The answers to such questions will be considered relative to reasoned a priori expectations for the group within which the particular patient falls. That is to say: Context matters in assessing the effects of medical treatment plans.

- As an additional control as well as enrichment of the development of the patient treatment plan, nurses should be integrated into the treatment team decision making group on hospice and palliative care units. Nurses, as a result of their training and experience, can make significant contributions in developing hospice and palliative treatment plans. Specifically, we suggest hospice and palliative care treatment plans are signed by both a trained hospice or palliative care nurse and the patient’s physician. This additional documenting voice is just a simple way of recording the opinion of another health care professional as part of the treatment plan. Over time, such dual recording will likely improve the quality of care.

- It is clear that increasing hospice and palliative care use and advance directives will require the creation of many systemic support initiatives; as a result, we recommend that our action plan be the purview
One should see this special issue as a catalyst for developing ways to deal with the difficulties of negotiating end-of-life care.

Features of the Eight-Point Action Plan

Let us now consider the features of this action plan. Following we discuss the desirability, feasibility, and sustainability of the action plan presented here.

Desirability. We believe expanding and incentivizing hospice and palliative care and respecting advance directives, which are central aspects of the eight-point action plan, is desirable because of their inherent effectiveness and efficiency. Specifically, effectiveness is addressed because patients’ advance directives will dictate the progression of their care, thus potentially avoiding heroic, ineffective, and unwarranted end-of-life treatments. Additionally, the action plan will be efficient by curtailing costs by adhering to the GAO-audited reimbursement procedures as set forth in action plan item eight.

Feasibility. The expansion of hospice and palliative care would not be feasible, from a cost or dignity perspective, if the execution of the eight-point action plan worked against the legal, religious, moral, or financial fabric of American social and cultural norms and expectations. Engaging communities in discussions of health, recommending cost-sensitive advance directives, using discharge planning in hospitals, suggesting hospice or palliative care at the end-of-life alternatives, and financing health care through insurance and audited distributive measures have all long been used by those trying to curtail health care costs in the United States. Expanding and incentivizing hospice and palliative care is only a modest re-organization of these aspects of the U.S. health care delivery system, the action plan of which will realign these systemic features to conserve resources and preserve individual end-of-life dignity.

Sustainability. Sustainability is the most difficult-to-predict aspect of the eight-point action plan. Expanding and incentivizing the use of hospice and palliative care with an eye to conserving scarce resources will, by definition, move the U.S. health care delivery system in the sustainability direction. Simply put: Economies affected by cost-sensitive incentives will translate into more resources being available to cover needed services. However, the Patient Protection and Affordable Care Act of 2010 (the first health legislation in decades seeking to directly help millions of uninsured Americans) will undoubtedly put greater financial pressure on the current reimbursement system, as many more millions of citizens obtain access to health care. This increased pressure may compromise the gains made in affecting economies through the eight-point action plan. Here is where experimentation, monitoring, and redesign will be needed to maintain the hospice and palliative care initiatives as features of the U.S. health care delivery system. This of course may call into question the distribution of resources of all of the federal programs from the Department of Defense to the Department of Health and Human Services as in the Zero-Based Budget context.

Concluding Comments

A recent poll from the California Health Foundation notes there is a great disparity between what people say they want (to die a natural death at home) and what actually occurs. Eighty-two percent of respondents reported “that it was important to have end-of-life wishes in writing,” and yet less than 25% had done so (Wood, 2012). Ultimately, this special issue begs the question: Given our political and economic realities of 2012, can we realistically imagine positive, cost-reducing changes in the way we deliver health care in the United States? To realize the expansion of our hospice and palliative care action plan, many details must be worked out. For example, how will the incentives listed by Tilden and co-authors be employed given the GAO audit? And how will the appointment process to the independent decision making group be organized and monitored? Of course this is normal; one should not read this special issue of Nursing Economics$ and think, “Well, I see problems here and there,” and then stop thinking. One should see this special issue as a catalyst for developing ways to deal with the difficulties of negotiating end-of-life care. In this regard we appreciate the “spirit” of Peter Neumann’s (2012) editorial where he introduces the central issue that defined this spe-
Physicians have a responsibility to practice effective and efficient health care and to use health care resources responsibly. Parsimonious care that utilizes the most efficient means to effectively diagnose a condition and treat a patient respects the need to use resources wisely and to help ensure that resources are equitably available (p. 585).

With this as the logical backdrop, Neumann systematically considers the difficulties in “doing what is needed” and keeping everyone satisfied and also controlling the resources needed to affect the needed delivery. He offers the following as guidance to begin the discussion needed to avoid the impending storm:

The challenge is how to have a more honest conversation. A candid discussion could set expectations, inform policy debates, and help the country prioritize uses for resources within and outside the health care sector. There seems to be little evidence, however, that such a conversation will take place, at least in the public sphere. There is no political advantage in talking realistically about our problems. The election-year rhetoric will continue to emphasize prevention, quality, and health information technology. On the campaign trail, the speculating will be about fraud and abuse, the evils of rationing, and the need to improve our way to sustainability. That is why the new ACP guidelines are so valuable. Their focus on responsibility, their direct acknowledgment of the need to consider constraints, their recognition that less care may be better care, and their call for individual physicians to use resources wisely are rare and welcome. The ACP should be applauded for its engagement of costs. Is “parsimonious” the right word? Perhaps there are better ones, but “frugal,” “prudent,” “thrift,” “cost-conscious,” and others would also raise objections. Whatever we call this necessary quality, the conversation could use a dose of reality. Calling it parsimonious is a reasonable start (p. 586).

To close this important Nursing Economic$ special issue, let us have the courage to be proactive, evaluate the impact of our actions, make modifications, and continue to learn and evolve the health care delivery system to produce a responsive and responsible way to address the problems that we have gotten ourselves into. As Pogo so wisely quipped: “We have met the enemy and he is us.” Let’s prove him wrong.

REFERENCES


ADDITIONAL READINGS