

Healthcare Costs: End-of-Life and Palliative Care

Mary Beth Morrissey and Bruce Jennings

Introduction

“Summary Report on Healthcare Costs: Legal Issues, Barriers and Solutions” (Davino et al., 2009) clearly indicates that health care costs must be brought under control and that laws and legal practices are a significant factor, both in contributing to the cost problem and in helping to solve it. In this paper we focus on the end-of-life and palliative care part of the health system, its financing and delivery systems. Many single out this part of the health care system and attribute its rising costs to utilization that takes place in the last two years of life, or less. Indeed, medical services are often intensive and expensive for chronically and terminally ill patients; much of their care takes place in multi-site care settings, including hospitals and even intensive care units. What are the barriers to developing end-of-life care decision making that is high quality, cost effective, and in keeping with the wishes and values of dying patients, their families and caregivers? What are possible solutions to eliminating these barriers? Medical care near the end of life is particularly fraught with strong emotions, and resistance to understanding its complexities is strong. It is also ethically important to protect dying persons, who surely are among the most vulnerable members of society, from both inappropriate overtreatment and undertreatment. Balancing values of efficiency and health care justice (Sulmasy, 2003) by employing a social ecology of health model in end-of-life decision making may be the biggest challenge posed by spiraling health care costs (Morrissey & Jennings, 2006). The decisions we make are decisions that affect individuals in relation to their families, caregivers, communities, the assets and resources of their communities, and the public health.

It is difficult to talk about this as a society, but talk about it we must. Our viewpoint is in keeping with a conclusion reached in a recent report from the Dartmouth Institute for Health Policy and Clinical Practice: “The nation needs a crash program to transform the management of chronic illness [i.e. treatment during the last two years of life] to a rational system where what happens to patients is based primarily on illness severity, medical evidence, and the patient’s wishes, and where resource allocation and Medicare spending can be guided more and more by knowledge of what is needed to produce cost-effective, high-quality care” (Wennberg et al., 2008: 17). We believe that our system can reduce expenditures near the end of life and improve quality of care at the same time. Improving communication in treatment decision making holds a key, as does improving access to appropriate hospice and palliative care. Changes in the law can facilitate both of these objectives.

Do We Spend Too Much on End-of-Life Care?

One estimate puts end-of-life care spending at 10 to 12 percent of total healthcare spending in the US (Simmons, 2004). The federal Medicare program is the primary financing vehicle for end-of-life care in the United States for the aged (Hartman et al., 2008). Approximately 30% of Medicare program benefits are spent on care at the end of life (Zhang et al, 2009). The average expenditure on a Medicare beneficiary during the last year of life is six (6) times higher than the average per capita expenditure earlier in a beneficiary’s lifespan; this ratio has been fairly constant for two decades (Raveis, 2006; Simmons, 2004). With slower economic growth in this decade, and forecasts based on baby-boomers enrolling in the Medicare program in the next decades, it is expected that the financial burden of end-of-life care that will fall on public program financing and on families through 2050 will continue to grow (Banthin et al., 2008; Hartman et al., 2008; Sisko et al., 2009).

Wennberg and colleagues (2008) and others (Yasaitis et al., 2009) have presented compelling research that variations in regional spending patterns on end-of-life care show no evidence of benefit from higher levels of spending. For example, in the most supply-sensitive regions of the country, terminally ill patients on average had 60 physician visits in the last 6 months of life, compared to 15 visits in the lowest supply-sensitive regions of the country. Similarly, the chronically ill spent 6.1 days on average in the hospital in the last 2 years of life in the least sensitive region, compared to 21.9 hospital days in the most sensitive region. As a way of accounting for findings that local factors influence physicians' discretionary decision making in high-spending regions, Sirovich et al. (2008) identify local practice influence on clinical judgment as having more of a significant role in physicians' decision making than adherence to clinical practice guidelines.

Challenges to the Dartmouth Atlas research "more is less" theory that higher spending does not correlate with higher quality of care have been raised by Cooper and others. Cooper makes a claim that Medicare spending is not a proxy for total health care spending and that higher Medicare spending in certain regions of the country may point to certain socioeconomic trends and social ecology factors that would be consistent with lower quality indicators. Social capital may also be a consideration (Cooper, 2008)

According to Landrum et al. (2008), spending more may not always be inappropriate based upon distinctions drawn among types of care that are characterized as recommended, discretionary or not recommended. These distinctions would seem to parallel to some extent beneficial, marginally beneficial, and non-beneficial levels of care. The discussion developed by Landrum and colleagues around these concepts leads to ethical questions about the value of spending. In addition to supply drivers, local practice environment, clinical practice guidelines, and levels of care, Edmund Pellegrino (2009) reminds us that physician integrity cannot be overlooked. Like Landrum and colleagues, Pellegrino returns to a discussion of values, reminding us that conscience and meaning are important factors in the behavior of physicians and patients alike. Medicine is more than "economic incentives," "cost-drivers," and commodities.

Barriers to Cost Containment in End-of-Life Care

Legal Barriers

In recent history, the federal government has seen an expansion of its power to regulate health care under its constitutional spending, commerce and taxing powers (Jost, 2009). The Medicare Hospice Benefit (MHB) was enacted in 1982 and was hailed during the Reagan years as a major breakthrough in end-of-life care (Byock, 2001). Hospice has been a successful program (Mahoney, 1998; Lorenz et al., 2004; Taylor et al., 2007). The National Hospice and Palliative Care Organization (NHPCO) reports that in 2007, 1.4 million people with a life-limiting illness received care from the nation's 4,700 hospice providers, with average length of service increasing to 67.4 days from 59.8 days in 2006 (NHPCO, 2008). However, after well over two decades of experience, in 2009 the MHB stands as a legal barrier to health care reform, integration and collaboration across the health systems. At the time the legislation was crafted and in the early years of implementation of the benefit, there was concern about cost-effectiveness (Vladeck, 1984; Mahoney, 1998). As a result, there were restrictions built into the MHB that today severely constrain expansion of access to hospice and palliative care services. A 2008 survey of chronically ill adults conducted by the Commonwealth Fund in eight countries including the U.S. shows that the U.S. leads other nations in cost-related access problems and in

poor care coordination (Schoen et al, 2008). With the burgeoning aging demographic and longer life expectancies that have transformed the health care landscape, the challenge now for the federal government is to regulate health care by creating opportunities for investment in a public health infrastructure that supports patient-centered, high quality and cost-effective care for populations (Gostin et al., 2004).

In order to become eligible for the MHB, regulations require that an individual be certified as having a life expectancy of six (6) months or less if the illness runs its normal course. The second restriction is that, while on the MHB, regular Medicare coverage is suspended and providers will only be reimbursed for services that have a palliative intent. Normally this means that to be on hospice, the individual must forgo and additional “curative” medical treatments. Although certain hospices are now adopting and implementing “open access” policies which permit certain curative treatments, such as chemotherapy, at the same time as comfort care, this is not the general rule. Oncology is a good example of a medical specialty where there may be perverse incentives driving physician practice and increasing costs. The research evidence is that there may be a need for increasing collaboration between hospice and oncology in defining the goals of care for patients at the end of life (Harrington & Smith, 2008).

While hospices are governed by state licensure requirements and federal Medicare conditions of participation, other providers of palliative care services are not so strictly regulated. Moreover, there still is no clearly defined financing mechanism for palliative care services that are not provided by a certified hospice and not covered by the MHB, although palliative physicians do now have a Medicare billing code. Hospices may on their own, or through contractual arrangements with other entities, provide non-licensed palliative care services to patients who do not meet the criteria for hospice eligibility, or who do not elect coverage under the MHB. Such arrangements need to be structured properly to assure that they meet the necessary requirements under applicable safe harbors that may protect them against the federal anti-kickback laws. (See full Health Care Costs Report).

There is a growing body of evidence that hospice and palliative care services are cost-effective in various health care settings including hospitals and nursing homes (Morrison et al., 2008; Taylor et al., 2007; Connor, 2007-2008). A study conducted in 2002 under the auspices of the National Hospice and Palliative Care Organization (NHPCO), the Hospice Association of America, and the Center to Advance Palliative Care, demonstrates the broad support among hospices nationally for collaborating with hospitals in providing palliative care services to those individuals who do not have the traditional hospice benefit. This study also delineates some of the significant barriers to such collaboration including lack of reimbursement, and legal and regulatory constraints (Sutton Final Report, 2002).

Meaningful health cost reconfiguration in end-of-life care will involve collaboration among providers to establish a continuum of palliative care that not only permits, but incentivizes earlier access to critical services for the chronically ill in the last two years of life. Hospice is a subset of the palliative care continuum of services (Jennings, 2003) and should be fully integrated into the healthcare delivery systems with hospitals, nursing homes, and other providers, physicians and health professionals. If such delivery system integration is to occur on a larger scale, there are several bodies of laws and regulations that may interfere with legal and regulatory reform aimed at fostering provider innovation and efficiency in and across the health systems including but not limited to:

- Federal self-referral laws (42 USC §1395nn(a) (2000));
- Federal antikickback laws (42 USC §1320A-7b(b) (2000 and Supp V 2005));

- Federal Health Insurance Portability and Accountability Act of 1996 (HIPAA); and
- State self-referral, corporate practice of medicine, licensing, insurance, certificate of need, and privacy laws.

Consideration should be given to amending laws at the federal level, and revising or instituting new safe harbors against self-referral, antikickback laws to remove obstacles to more closely allied relationships between providers who are committed to shared patient-centered goals in end-of-life care; the scope of antitrust and tax-exempt organization laws applicable to proposed collaboration, care coordination and integration activity should also be examined (Jost, 2009; Fuchs, 2009; Jost & Emanuel, 2008). Jost and Emanuel (2008) suggest the formation of a Commission for Innovation in Delivery Systems that would provide “one-stop” reviews. While sweeping change cannot be implemented immediately, these recommendations do deserve urgent attention as the legal and regulatory structure itself is responsible for a portion of the healthcare cost escalation. At a minimum, immediate attention should be given to examining the impediments to health research created by the HIPAA privacy rule discussed in a recent report of the Institute of Medicine (Institute of Medicine, 2009; Gostin & Nass, 2009).

Access to Palliative Care

Development of a national palliative care model through legal reform, education and research is key to cost containment in end of life care. An ethic of care that is palliative is by definition, person- and family-centered, interdisciplinary, and aimed at improving pain and symptom management, care coordination, physician-patient communication, and encouraging conversations with loved ones about the goals of care, values and treatment preferences (Fins, 2006; Morrison & Meier, 2004).

The National Consensus Project for Quality Palliative Care defines the goals of palliative care as follows:

...to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. (National Consensus Project, 2004, p. 6).

Improving care at the end of life for those who have life-limiting illness or who are suffering by increasing access to meaningful palliative care services is an important public health mandate (Jennings, 2003). Many factors have contributed to the development of this public health mandate including the aging demographic (U.S. Census Bureau, 2008), the epidemiology of disease with the growing prevalence of chronic illness, and the burdens on family caregivers (World Health Organization, 2004; Raveis, 2004). The last ten years have seen a marked growth in palliative care programs in the United States, especially hospital-based programs (Morrison et al, 2008; Connor, 2007-2008; Morrison et al, 2005), and good evidence that hospitals are achieving cost savings and improvements in care outcomes by introducing palliative care teams (Morrison et al, 2008; Morrison et al., 2005; Smith et al., 2003). This growth in hospital-based palliative care is crucial to improving access and relieving pain and suffering at the end of life for the frail elderly, many of whom are receiving acute care services during the last year of life (Zhang et al., 2009; Morrison et al., 2005).

Recommendations for increasing access to hospice and palliative care include:

1. Establishing appropriate reimbursement and financing mechanisms for hospital-based palliative care consultation and services;
2. Expanding Medicare eligibility criteria for hospice benefits away from the criterion of patient's prognostic life-expectancy and toward more medically suitable utilization, benefit eligibility, and provider reimbursement standards (Casarett, 2007);
3. Making the transition between palliative care and hospice care more seamless and continuous between health care settings;
4. Expanding access and delivery of hospice and palliative care to chronically and terminally ill persons residing in long-term care facilities (Center to Advance Palliative Care, 2007);
5. Providing support for the development and dissemination of i) clinical practice guidelines such as the Clinical Practice Guidelines for Quality Palliative Care; ii) paradigms such as the Physician Orders for Life-Sustaining Treatment (POLST) paradigm that originated in Oregon and has been shown to be effective in hospice settings (Hickman et al., 2009); and iii) preference-sensitive decision aids to assist in patient choice (Connor et al., 2007-2008).
5. Funding and developing research that will inform policy decisions, policy analysis and implementation, and guide investments in public health infrastructure.
6. Developing educational programs to "reintroduce" hospice and palliative care to the public in light of their new capabilities, flexibility, and accessibility (Jennings, et al. 2003).

Cultural and Attitudinal Barriers

Particularly in end-of-life care, it is virtually impossible to draw a bright line between legal, and ethical and social value considerations. Legislators and judges feel the same pressures, value conflicts and emotions that dying persons, their families, and health care providers do. Federal and state case law, as well as statutory law, has set up a standard for end-of-life medical decision making that focuses strongly on the preferences and rights of dying patients, notably when it comes to forgoing life-sustaining medical interventions. Therefore, the execution and use of advance directives is extremely important. But we have an informal system that nearly as strongly accedes to patients or to surrogate decisionmakers and family members who desire to continue aggressive and expensive life-sustaining treatments. The law can be changed to counteract this, but the key will still be attitudinal and behavior change at the bedside. End-of-life care planning and decision making is fundamentally relational (Morrissey & Jennings, 2006). Why is it so hard to opt for a treatment plan directed toward palliative care goals, quality of life and comfort, instead of aggressive treatment goals?

Understanding. One barrier to changing attitudes is poor and incomplete or inaccurate information and communication. Patients and families are attuned to medical "miracles" by the popular culture and media. Providers often give inconsistent and conflicting information concerning prognosis and treatment options, sometimes due to genuine medical uncertainty, other times due to a reticence about giving bad news and depriving people of hope. Physicians must learn to recognize when such reticence is no longer appropriate and is indeed harmful. Patients and families need honest assessments and they need to be allowed to move from hoping for a cure to hoping for comfort and good palliative care. Any stigma attached to hospice and palliative care will be mitigated by accurate information about the effectiveness and benefits of the services these programs provide. Less inappropriately aggressive treatment, and better

utilization of hospice and palliative care services will result from more honest and timely communication at the bedside.

Cultural difference and meaning. We live in an increasingly pluralistic society. Cultural differences and racially or ethnically based discrepancies in health care access make communication in end-of-life care more difficult due to differences of values and meaning concerning illness and death and due to suspicion and mistrust based on past social discrimination. Special services and culturally competent efforts must be taken to ensure good communication and decision making are available to all in end of life care.

Does cost-worthiness in end of life care reside in the eye of the beholder? It must be acknowledged that we will never find the Goldilocks point—the “just right” mean between overutilization and underutilization of expensive life-sustaining treatments in end-of-life care. The reason for this has to do with the inherently subjective aspects of weighing probabilities and assessing quality of life. There is no science or standardization for that. There will always be a certain amount of utilization of expensive life-sustaining treatment and monitoring that is open to reasonable disagreement. This is the domain of “marginally beneficial” treatment. It poses probably the single greatest ethical dilemma in relationship to cost containment in end of life care.

There may in fact be no principled ethical solution to the problem of how to value “marginally beneficial” end of life treatment at the legal or policy level. Ultimately it will be a political determination. In the years ahead we will have to ponder the following question: If the patient’s choices and request are well informed, (a very big if, to be sure) should society provide financial support for medical treatments near the end of life that have some perceived benefit, but may fall well short of cure and recovery, or substantial prolongation of life? Such an accommodation to diverse beliefs and preferences at the end of life will cost some money. But are the financial savings to be gained by denying such choices worth overriding personal patient values, religious meaning, and family relationships in these cases?

Conclusion

We believe that every person is intrinsically worthy and is entitled to quality health care that will prevent premature death and relieve pain and suffering. We also believe that resources are limited and that there is no absolute right to medical treatments. In some instances, such treatments may have no evidence based warrant and may actually heighten suffering, not only for patients, but for patients’ families and caregivers. However, we do make a strong case for expanding access to, and yes, perhaps recognizing a right to palliative care that relieves the pain and suffering of every human being who is chronically ill or at the end of life. This may be the most cost-effective approach to legal and regulatory health reform.

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