



PALLIATIVE CARE WITH OLDER ADULTS

SECTION 3: POLICY ISSUES RELATED TO AGING AND PALLIATIVE CARE

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Synopsis

Palliative care, defined broadly as a holistic approach to care for patients with progressive and advanced disease with limited prospects for long-term survival (World Health Organization, 2008), confronts a number of formidable policy obstacles and challenges to its development in the U.S. Included among them are inadequate access, fragmented delivery systems, inadequate financing mechanisms, limited professional education, and the shortage of health care providers that is endemic throughout the U.S. health care system (Institute of Medicine, 2001; Reb, 2003). In the brief analysis that follows, two of the dominant policy issues in palliative care are highlighted. The first is the problematic approach to palliative care in the U.S. that, for historical reasons, forces an often harsh choice between curative health care and health care that is narrowly limited to comfort and “death with dignity.” This dichotomous orientation toward palliative care contrasts with that of other countries (e.g., Australia, Canada, New Zealand, the United Kingdom), which approach palliative care as more of a holistic continuum with permeable boundaries between curative and purely supportive care. The second policy issue brought into focus concerns the economic viability of more progressive approaches to palliative care, in particular the need to promote research that identifies the most cost-effective approaches to palliative care.

The Dichotomous Orientation of Palliative Care Services in the U.S.

A Brief History of the U.S. Hospice Care Paradigm

- ◆ Throughout most of the 20th century, health care in the U.S. focused almost exclusively on the cure of diseases, such that the dying process was not considered part of the health care mission.

Until the last few decades of the 1900s, the U.S. health care system was dominated by a curative paradigm, which treated the dying process as a failure of medicine, as opposed to embracing care of the dying as an essential mission of medicine and an integral component of the health care system. As a result, aggressive and futile curative

interventions too often were pursued to harmful and dehumanizing extremes, and the dying were often relegated to the stigmatized category of “lost causes” that medicine had nothing further to offer (National Hospice and Palliative Care Organization, 2008). *The hospice movement*, which had its beginnings in England with the work of British **social worker and physician** Sicily Saunders in the late 1960s, was propelled into American public consciousness and policy during the 1970s both by the research and writings of American psychiatrist Dr. Elisabeth Kubler-Ross (*On Death and Dying*, 1969) and through the transformative partnership between Saunders and Florence Wald of the Yale University School of Nursing (Almgren, 2007; National Hospice and Palliative Care Organization, 2008). Ultimately, Congress institutionalized hospice care through a series of legislative modifications to the Medicare program, culminating with *the establishment of a Medicare hospice benefit in 1986*. The Medicare hospice benefit in turn established the basic template for hospice benefits throughout the health care system, including the private health insurance industry, hospice programs funded by state Medicaid programs, and the Veterans Administration system. Although the specific hospice program benefits vary by the form of insurance coverage, the typical array of hospice benefits follow the Medicare model, which includes physicians’ services, intermittent home nursing care, medical supplies, outpatient drugs, home health aide services, social work, professional therapies (physical, occupational, and speech), short-term inpatient care for respite/symptom management, and spiritual counseling. To be eligible for hospice benefits in the typical program, the recipient must be diagnosed by a physician as terminally ill within a specified period (conventionally 6 months), and must voluntarily accept hospice care benefits as an alternative to standard health insurance benefits—including and most specifically those benefits that involve “curative treatment” (Almgren, 2007).

Square Pegs and Round Holes: The Hospice Care Paradigm and the Indeterminate Nature of Palliative Care

- ◆ Palliative care philosophy, which does not have strict borders between curative and supportive care, does not fit easily into the mainstream hospice care paradigm in the U.S., which presumes fixed limits on survival time and rigid boundaries between curative and supportive care.

Although the introduction of hospice care into the mainstream of American health care over the past few decades has been a great leap forward, the hospice paradigm of palliative care has also institutionalized a regrettable dichotomy between palliative care with an indeterminate course and duration, and the “hospice” approach to care for the dying that is predicated on a fixed limit of survival and eligibility for palliative care benefits.

In contrast, palliative care in its conventional definition does not rigidly dichotomize the choice between curative and supportive care and normalizes the

coexistence of potentially fatal disease processes with hope and uncertainty. The World Health Organization's definition of palliative care, while it pertains to care that is not intended to postpone death or provide cure for disease, entails a holistic approach to care that both helps patients live as actively as possible until death and also "can be provided in conjunction with other therapies that are intended to prolong life" (World Health Organization, 2008). Thus palliative care, as a concept and general philosophy of care, acknowledges that people can live a very long time in the penumbra between the pursuit of curative or at least ameliorative treatment and the acceptance of death—particularly the many elderly that are burdened with multiple chronic and potentially fatal conditions with largely indeterminate trajectories.

Reconciling Palliative Care Policy with Clinical Reality: The Origin of Medical "Term Limits"

- ◆ Palliative care policy in the U.S. is centered on the same restrictive eligibility criteria used for hospice.

The primary policy challenge of palliative care policy during the final three decades of the last century entailed the development of a system of care for the dying that was accessible to persons of all ages and income levels—not just the Medicare eligible older adult population (Morrison, 2005; National Hospice and Palliative Care Organization, 2008). The organizing paradigm for palliative care policy, however, remained entrenched in the more restrictive and deterministic hospice model of palliative care that is centered on two (previously mentioned) eligibility criteria that are nearly universal to all hospice programs:

- 1) A prognosis of death within 6 months.
- 2) The voluntary abandonment of curative interventions.

Although to some extent these restrictive eligibility criteria align with a philosophy of care that is centered on "death with dignity," it is also true that both criteria were introduced as a way of promoting the financial sustainability of the Medicare hospice care benefit. These financially driven criteria ultimately became institutionalized as hospice benefits were expanded into the employer-based insurance industry and state Medicaid programs. The end result is a system of palliative care in the U.S. that confuses health care financing assumptions with clinical efficacy (Passik et al., 2004; Scitovsky, 1994).

We are now confronted by a new policy challenge in palliative care, one that entails the development of services and financing structures that can better accommodate the clinical complexities of the final stages of life. That is, for example, a system of care that can at once accommodate the patient with late stage chronic obstructive pulmonary disease (who may be 2 months or 2 years from death), as well as the cancer patient who

desires palliative care mixed with naturopathic curative medicine as a way of holding out hope (Fitzsimons et al., 2007; Kramer & Auer, 2005).

Reconciling Palliative Care Policy with Clinical Reality: Family and Caregiver Needs versus Provider Service Structures

- ◆ There is often a mismatch between the standard set of services provided by palliative care provider organizations and the actual needs of the dying and their caregivers.

Although health care provider organizations can often operate more efficiently to the extent that services can be standardized, research has shown that there is enormous diversity in the needs of caregivers for specific forms of support (both professional and non-professional), and that needs change as the illness progresses (Osse, Vernooij-Dassen, Schade, & Grol, 2006; Proot et al., 2004). The implications of these kinds of findings, from a policy standpoint, are that palliative care delivery and financing schemes must accommodate individualized approaches to patient care and frequent periodic reassessment of changing needs (Davies & Higginson, 2004).

The Promotion of Palliative Care Services

- ◆ An intuitively logical strategy for the promotion of palliative care into the mainstream entails the integration of specialized palliative care services within existing hospice programs.

This approach has several advantages, among them:

- 1) building on the significant areas of overlap between the holistic orientation and clinical expertise of clinicians,
- 2) utilizing the provider connections and credibility established by the hospice organization,
- 3) where possible, avoiding unnecessary duplication of clinical and support services,
- 4) reducing or eliminating destructive competition between palliative care and hospice care provider organizations, and
- 5) providing for a true continuum of care from diagnosis to death (Byock, 2000).

However, some early evidence suggests that there are formidable barriers to surmount, arising from the assumption of costs associated with more complex patients, e.g., higher drug costs, higher utilization of outpatient and emergency services, and physician visits (Passik et al., 2004). In effect, hospice care organizations are at risk for having to subsidize palliative care services from hospice benefit dollars—an unsustainable strategy over any length of time (Passik et al., 2004). Yet, cost and clinical outcome findings are more favorable among studies that evaluate the cost-effectiveness of

hospital-based consultation models of palliative care, which may be in a better position to ameliorate the most egregious instances of high cost/poor outcome care (Cowan, 2001). Hospital-based consultation models, though they may differ from one another in some respects, commonly entail the use of physicians, nurses, and social workers with specialized training in palliative care as consultants to more traditionally trained health care providers. While the traditional providers continue to retain primary responsibility for care of the patient, the palliative care consultants provide essential expertise in all aspects of palliative care. In the long run, a seamless continuum of care is best promoted by a financing structure that is integrated with clinical services, as in capitated (HMO) financing or a universal social insurance fund (Almgren, 2007).

The Economics of Palliative Care

Evidence Pertaining to the Cost Effectiveness of Hospice Care

- ◆ Despite the extensive literature on the cost-effectiveness of hospice care relative to curative-oriented conventional care, a clear consensus on findings has been difficult to sustain due to the lack of consistency in methodological approaches (Robinson & Pham, 1996; Scitovsky, 1994).

The most definitive review of the various studies assessing the cost-effectiveness of hospice care relative to conventional care that occurred after the Medicare hospice benefit had become widely utilized concluded that the cost-savings attributable to the benefit was 25-40% during the last month of life, but only 10-17% during the last 6 months of life (Emanuel, 1996). Studies that have been produced during the most recent decade have provided more mixed evidence, some suggesting significant cost savings (Pyenson, Connor, Fitch, & Kinzbrunner, 2004) and others actually finding increased expenditures depending on such factors as age and diagnosis (Campbell, Lynn, Louis, & Shugarman, 2004). Yet, the most current comprehensive study, based on a comparison of 1,819 hospice decedents with a rigorously matched 3,638 control sample, finds that hospice use reduced Medicare program expenditures over the last year of life by an average of \$2309 per hospice care recipient, although the maximum cost savings achieved varies significantly by the primary health condition leading to death (Taylor, Ostermann, Van, Tulskyc, & Steinhauserc, 2007). Significant also, from a policy standpoint, is this study's findings that in 70% of cases, earlier introduction of hospice care would have resulted in increased savings. Despite some remaining ambiguity as to whether hospice care consistently yields a higher quality of care at equal or less cost across all diagnostic and age groupings, the overall evidence suggests Robinson and Pham (1996) are correct in asserting that the original goals of at least the Medicare program's hospice benefit have been met: "a choice is available that responds to the

needs and concerns of many dying people and their families, at no additional cost to the taxpayer” (p. 417).

Evidence Pertaining to the Cost Effectiveness of Palliative Care

- ◆ An evidence base for the cost-effectiveness of palliative care is lacking; large-scale multisite studies are needed.

The literature on the cost-effectiveness of palliative care approaches that fall outside of the more restrictive hospice model is far less developed than that of the cost-effectiveness of conventional hospice care. The most recent comprehensive review of this literature, published in *the Journal of the American Medical Association* in spring 2008, found only 22 studies that met the inclusion of randomized controlled trials of specialized palliative care interventions included outcome measures for quality of life, satisfaction with care, or economic cost. While the evidence for higher levels of family satisfaction with care was favorable across most studies, the evidence concerning other benefits, including cost savings relative to conventional care, was scant and inconclusive (Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008). To many advocates of patients and families in the advanced stages of incurable health conditions, the case for the development of specialized palliative care services is self-evident. However, major policy advancements promoting the mainstreaming of palliative care await more evidence from large-scale multisite studies that use well-defined palliative care interventions and comparable outcomes across a range of patient and family system characteristics (Morrison, 2005).

In sum, although the evidence pertaining to the cost-effectiveness of palliative care is as yet scant, the clinically based arguments for a move away from the more restrictive “hospice vs. curative treatment” are compelling. At least in these terms, the grounds for investments in research that identify the most clinically efficacious and cost-effective models of palliative care have been sufficiently established. In absence of such research investments, specifically large-scale studies that link clinical efficacy with cost-efficiency, it may be that innovations in palliative care that are less tied to considerations of cost will still emerge—only to wither away in the face of shrinking health care dollars.

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- Passik, S., Ruggles, C., Brown, G., Snapp, J., Swinford, S., Gutgsell, T., et al. (2004). Is there a model for demonstrating a beneficial financial impact of initiating a palliative care program by an existing hospice program? *Palliative Support Care*, 2(4), 419-423.
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Curriculum Resources



Suggested Readings:

- Davies, E., & Higginson, I. (Eds.), (2004). *Better palliative care for older people*. World Health Organization for Europe. Copenhagen Denmark. Available for download at: <http://www.eapcnet.org/download/forProjects/Elderly/BetterPC.Older%20People.pdf>

This monograph is a comprehensive primer on the population aging and palliative care needs as a public health problem throughout the aging societies of Europe, with obvious parallel implications for the U.S. Because it is written primarily for a more general audience of policy-makers rather than specialists, it is parsimonious and cogent. The monograph is divided into six parts that address 1) the implications of population aging for palliative care needs and why these are a public health priority, 2) a descriptive summary of the needs and rights of older people and their families, 3) a summary of the evidence pertaining to the widespread underassessment and treatment of older peoples' problems and their lack of access to palliative care, 4) a synopsis of the evidence for effective palliative care solutions (e.g., better pain relief, improvements in home care services), 5) a review discussing the key challenges for academic researchers and policy-makers in the governmental and nongovernmental sectors of society, and 6) specific recommendations to improve care in ways that promote the security and dignity of older people in the final stages of life. Although too lengthy for an assigned reading, certainly segments of the report on specific issues are a rich source of learning. In addition, this monograph serves as an excellent source for lecture material.

- Passik, S., Ruggles, C., Brown, G., Snapp, J., Swinford, S., Gutgsell, T., et al. (2004). Is there a model for demonstrating a beneficial financial impact of initiating a palliative care program by an existing hospice program? *Palliative Support Care*, 2(4), 419-423.

This relatively short article summarizes the findings from the research literature on alternative approaches to the integration of palliative care with conventional hospice programs. Its primary value is that it highlights, through analysis of hospice and palliative care utilization data, the kinds of challenges confronted in trying to promote new innovations in palliative care within the current system of health care finance in the U.S. The findings do not suggest that hospice programs, under the current hospice care financing mechanisms available through Medicare, can offset the introduction of palliative care services earlier in the course of a final illness through cost savings realized by less intensive use of services and supplies over time. Instead, the findings suggest that the cost savings that may be essential to the fiscal viability of palliative care services must come from the curative side of health care—that is, those curative interventions that provide the least benefits in either prolonging life or increasing its quality.

- Morrison, R. S. (2005). Health care system factors affecting end-of-life care. *Journal of Palliative Medicine*, 8(Suppl 1), S79-87.

Although a number of articles summarize the state of the palliative care field in the U.S., this article is highly recommended as an assigned reading of choice for a social work in health care course. The article

is succinct, yet provides the essential background structure of the health care system and financing as pertains to palliative care, with depth, clarity, and precision. Of particular value to readers who are not well versed in the structure of the health care system and how palliative care differs from the more dominant “cure or care” hospice care model, the article provides easily interpreted graphics that aide conceptual understanding. After establishing the policy context of palliative care, the article then provides an excellent review of the recent research on palliative care, with particular emphasis on the evidence of beneficial outcomes for patients and caregivers relative to cost.

- Reb, A. (2003). Palliative and end-of-life care: policy analysis. *Oncology Nursing Forum*, 30(1), 35-50.

Although written from the disciplinary perspective of nursing, this article provides a well organized and fairly exhaustive review of the palliative care literature as pertains to policy issues. While some readers may be put off somewhat by the extend to which the focus on policy issues is relatively specific to the concerns of the nursing profession, the brunt of the policy analysis provided speaks to all disciplines involved in the development and delivery of more humane and cost-effective approaches to palliative care. The author’s background research for this article included not only the published literature, but also a variety of policy briefs, advisory panel meeting minutes, monographs, and research reports from government, professional, and private organizations involved in the shaping of palliative care policy. Perhaps the most valuable contribution of this article is the author’s cogent synthesis of the state and federal policy initiatives, through the early years of the current decade, that are determining the structure and direction of national palliative care policy. Finally, the references cited for this article are of great assistance to students and faculty interested in pursuing more in-depth analysis of specific domains of palliative care policy.



Web Resources:

- Project on Death in America Homepage. Open Society Institute.
http://www.soros.org/resources/articles_publications/publications/report_20041122

The “Project on Death in America” (PDIA), an initiative funded by the Soros Foundation’s Open Society Institute, invested 45 million dollars between 1994 and 2003 to transform the cultural context of death, dying, and bereavement in America, and to advance improved care for the dying through knowledge development and policy advocacy. The PDIA Web site is polished and comprehensive, with links to policy briefs and full-length publications on the ethical, clinical, and economic aspects of palliative care in the U.S. and internationally. It serves as a great resource for students and faculty interested in any aspect of palliative care and the state of death and dying in the U.S. In particular, the PDIA Web site is an excellent resource for students who have little background in palliative care, either clinically or in terms of policy issues.

**Class Exercise:**

Australia, Canada, New Zealand and the United Kingdom have all adopted approaches to end of life care that blend palliative care and curative medicine in ways that are specific to the needs of individual patients and their caregivers. In contrast, the U.S. employs a dichotomous approach to end of life care that imposes a rigid dividing line between curative health care and health care that is oriented to symptom control and the psychosocial supports reserved for final stages of illness.

- 1) Identify what you believe to be the top three impediments to the development of a more integrated approach to palliative care in the U.S.
- 2) Explain your reasoning.
- 3) Choose one of the impediments and suggest what might be a policy strategy for overcoming it.