

## ARTICLES

# Palliative and End-of-Life Care: Policy Analysis

Anne M. Reb, MS, NP

**Purpose/Objectives:** To present an overview of policy issues affecting hospice and palliative care focusing on the nursing home and hospital settings and to discuss factors affecting end-of-life care, policy initiatives, recent legislation, and nursing implications.

**Data Sources:** Published articles; technical, advisory, and research reports (from government, professional, and private organizations); newsletters; textbooks; meeting minutes; online references; and legislative documents.

**Data Synthesis:** Improvements are needed in end-of-life care, especially with regard to access, delivery, and financing of such services. Legal, organizational, and reimbursement policies, as well as healthcare professional education, have been identified as areas that need improvement. The nursing shortage and variable reimbursement policies for nursing services have a significant impact on access to quality end-of-life care, especially for underserved populations.

**Conclusions:** A need exists for further research, including demonstration projects to test new ways to deliver and integrate hospice and palliative care throughout the illness continuum. Education and research are needed regarding symptom management, communication and decision making, caregiver support, and other end-of-life issues. Nursing interventions, palliative care networks, and other models that promote a coordinated approach to care delivery have been shown to decrease costs and improve quality of care.

**Implications for Nursing:** Nurses play a key role in advancing improvements in palliative and end-of-life care through their involvement in educational, quality improvement, research, and legislative initiatives. Nursing activities in these areas may contribute to improved access, lower costs, and improved quality of care in advanced illness.

### Key Points . . .

- Access to palliative and end-of-life care is threatened by the nursing shortage, reimbursement barriers to nursing practice, and various social, organizational, and economic policies.
- Key goals include the integration of palliative care throughout the course of illness and earlier referrals to palliative and hospice services.
- Clinical nurse specialists (CNSs) and other advanced practice nurses are key to providing continuing education to practicing nurses regarding palliative and end-of-life care.
- The shortage of CNSs and the conversion of many of these positions to case managers calls for targeted recruitment and incentive programs to support this role.

and hospital settings. Because of the variety of factors affecting end-of-life care, selected issues are addressed in a framework of access, cost, and quality: (a) factors limiting access to hospice and palliative care in nursing homes, hospitals, and homecare settings; (b) impact of the payment system on provision of services and access to care; (c) need for guidelines, standards, and quality measures to evaluate end-of-life care; and (d) federal and private initiatives including nursing activities. An overview of state policy initiatives and recent federal legislation will be examined as well as nursing implications with regard to practice, education, research, and health policy.

### Problem

In 1997, the Institute of Medicine (IOM) sponsored an influential, evidence-based study to make recommendations for improving care at the end of life (Field & Cassel, 1997). Although committee members recognized improvements in practices being advanced by the field of palliative care, they found that problems persisted, including (a) inadequate pain and symptom management despite the availability of effective

With the aging of the baby boomers, the number of older people living with chronic conditions will increase and the need for palliative and support services throughout the illness continuum and at the end of life will be greater. Recent studies and advisory reports suggest that the healthcare system provides inadequate care for the dying (Field & Cassel, 1997; Foley & Gelband, 2001; Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment [SUPPORT] Principle Investigators, 1995). A main problem includes underdiagnosis and undertreatment of patients with significant distress, including pain and psychosocial concerns (Bernabei et al., 1998; Foley & Gelband). These concerns, as well the debate over physician-assisted suicide, have heightened awareness of the need to improve quality of care at the end of life (Rudberg, Teno, & Lynn, 1997). This article will address policy issues regarding hospice and palliative care with emphasis on nursing homes

*Anne M. Reb, MS, NP, is a clinical instructor in the College of Nursing at the University of Maryland in Baltimore and a doctoral candidate at the Catholic University of America in Washington, DC. (Submitted November 2001. Accepted for publication May 1, 2002).*

Digital Object Identifier: 10.1188/03.ONF.35-50