

ARTICLES

Palliative and End-of-Life Care: Policy Analysis

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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

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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

treatments; (b) legal, organizational, and economic obstacles that interfere with quality end-of-life care; (c) inadequate education and training of healthcare professionals with regard to end-of-life care; and (d) inadequate knowledge to support the consistent use of evidence-based practice at the end of life.

In 2001, IOM and the National Research Council issued a report targeting specific areas for improving care for people at the end of life (Foley & Gelband, 2001). Although the report focused on people with cancer, many of the recommendations also could benefit people dying from other chronic conditions. The report identified problems regarding the separation of palliative and hospice care from life-prolonging treatments. The report stated that, in most cases, the lack of integration of these approaches deterred access to palliative and hospice services and forced people to choose between curative therapy and comfort care. The low level of public investment in research and training was another barrier that was identified (Foley & Gelband).

Definitions

The World Health Organization (1990) defined palliative care as the active total care of patients whose disease is not responsive to curative treatment, including control of pain, other symptoms, and psychological, social, and spiritual problems. Although palliative care may include services delivered by hospice, palliative care may be offered at any point during an illness, whereas reimbursement for hospice services usually is limited to the final six months of life (Zerzan, Stearns, & Hanson, 2000). Hospice refers to a specific, programmatic model for delivering palliative and end-of-life care. In the United States, hospices are organized as programs that assume case management for all care related to advanced illness, including family support (Byock, 1998).

Nursing Homes

In 1989, the rules for the Medicare hospice benefit were updated to include long-term care institutions. The Omnibus Budget Reconciliation Act allowed reimbursement for hospice services for nursing home residents receiving both Medicare and Medicaid. Despite the expanded eligibility, access to hospice care in this setting remains limited. Although nursing homes increasingly are providing hospice services, 70% of nursing homes have no hospice patients (Petrisek & Mor, 1999). This situation may be improving according to a Medicare Payment Advisory Commission (MedPAC) report (2002b) that evaluated hospice use from 1992–2000. This report indicated increased growth in hospice use in people living in nursing homes and rural areas as well as in people with noncancer diagnoses. Some reasons for limited access included the six-month prognostic criterion for hospice eligibility, federal policy emphasizing rehabilitation, and reimbursement incentives for procedural skills and restorative care. Access to care varies by region and may be more influenced by the facility or locality instead of patient preferences (Zerzan et al., 2000). One study demonstrated that nursing homes with 5% or more residents receiving hospice services were more likely to be located in urban counties and operate in more competitive markets with more for-profit, free-standing hospices (Petrisek & Mor). The significant variation in hospice beneficiaries among states suggested that reimbursement rates and insurance coverage may influence hospice enrollment patterns in different states (Petrisek & Mor).

Eligibility Requirements

One factor limiting access to hospice is that Medicare requires physicians to certify that patients have six months or less to live. The uncertainty in estimating this prognosis affects the willingness of hospices to accept patients whose conditions may improve (Foley & Gelband, 2001). The estimation of prognosis is difficult, especially with illnesses other than cancer (Alliance for Health Reform, 2001; Fox et al., 1999; Lynn, 2002a). Thus, nursing home residents particularly are affected by this regulation because they die more often of heart disease and stroke than cancer. Despite guidelines by the National Hospice Organization to help document prognosis, determining the prognosis for people with dementia or other chronic illnesses still is difficult. Thus, many nursing home residents may be excluded from this benefit (Zerzan et al., 2000).

Regulatory and Financial Barriers

The current payment structure does not provide incentives for palliative and hospice care in nursing homes. For example, Medicare provides higher reimbursement for procedural nursing skills and rehabilitation following hospitalization compared with support services and symptom management. One proposed strategy is to fund cost-effectiveness studies of hospice or palliative services in nursing homes and modify reimbursement structures to cover palliative services (Zerzan et al., 2000).

Fears related to regulatory oversight also may limit access to hospice. As part of a 1995 investigation, the Office of Inspector General (OIG) investigated potential areas of fraud and abuse in services funded by the Centers for Medicare and Medicaid Services (CMS). OIG targeted hospice providers with longer lengths of stay, more noncancer diagnoses, and larger numbers of nursing home enrollees. Although investigators cited many examples of abuse, critics of this investigation countered that OIG's methodology was flawed, especially with regard to its conservative definition of the six-month eligibility criterion. Overall, these inspections resulted in a deterrent of expansion of hospice care in nursing homes (Zerzan et al., 2000). As a result of these investigations, healthcare providers may be reluctant to refer patients to hospice for fear of punitive measures (Walsh & Gordon, 2001). The passage of the Medicare, Medicaid, and State Children's Health Improvement Program Benefits Improvement Act of 2000 began to address some of these concerns. This legislation acknowledges the uncertainty in determining prognosis by clarifying that certification of terminal illness be based on physicians' clinical judgment regarding the normal course of illness (Consolidated Appropriations Act, 2001).

Hospitals

Despite the fact that a large number of deaths occur in hospitals and other institutions, most palliative-care experts have focused research on the hospice model of home care. SUPPORT documented shortcomings in end-of-life care for hospitalized patients, including patient-physician communications, time spent in an intensive care unit, reported pain, and other outcomes. Although an intervention was designed to improve these outcomes, no significant improvements occurred in the outcome variables (SUPPORT Principle Investigators, 1995). However, this study was pivotal in stimulating further research and other efforts to improve palliative care in hospitals and other settings (Cassel, Ludden, & Moon, 2000).

Reimbursement Barriers

Most insurance plans do not cover services needed for quality end-of-life care (Raphael, Ahrens, & Fowler, 2001). For most individuals who die in hospitals, no explicit reimbursement exists for palliative services (Capello, Meier, & Cassel, 1998) and very limited reimbursement is available for palliative services outside the hospice benefit (Metzger & Kaplan, 2001). For example, reimbursement for psychosocial care is limited, even in major cancer centers (Foley & Gelband, 2001). In addition, reports suggested that the Medicare physician payment system may not adequately recognize the resources needed for quality palliative care (Alliance for Health Reform, 2001; Field & Cassel, 1997). In addition, the system also may lack appropriate payment categories. Although evaluation and management codes are used primarily for billing, they do not account for special services needed for certain patients (e.g., the frail elderly) (Field & Cassel). This problem is exacerbated by a Medicare payment policy that encourages a short length of stay in hospitals, further limiting the ability to provide palliative services (Cassel et al., 2000; Meier, Morrison, & Cassel, 1997). The impact of reimbursement policies and cost-containment efforts on health care, policy issues, and nursing practice is significant as described in various research studies.

Research in Hospitals and Home Care

In response to concerns related to financing issues, CMS initiated a study using a new International Classification of Diseases code to estimate the use and costs of palliative care in hospitals (MedPAC, 1998). Unfortunately, use of the code was limited for a variety of reasons, including a lack of financial incentives and a comprehensive educational plan (Capello et al., 1998). As a result, CMS was unable to adequately assess costs of in-hospital palliative care. However, studies by the Milbank Memorial Fund and the Robert Wood Johnson (RWJ) Foundation are attempting to measure these costs (Cassel et al., 2000).

Perceptions study: The Milbank Memorial Fund sponsored a study to explore the perceptions of healthcare leaders about end-of-life financing, barriers to quality end-of-life care, and policy options (Cassel et al., 2000). The study found that some administrators were concerned about the lack of financial resources and retroactive reimbursement denials for palliative care by insurance companies. With regard to policy options, leaders agreed that quality measures should be developed to provide evidence-based standards for hospital accreditation. Further, most leaders in this study supported the development of a diagnosis-related group code and the creation of a palliative care specialty to reduce financial barriers related to billing. A step in this direction is the establishment of a new specialty code for pain management, effective in January 2002. This code facilitates data collection related to pain services and the establishment of new billing codes for pain management (American Academy of Pain Medicine, 2001; Milder & Crowell, 2002d).

Nursing practice in hospitals: Financial policies and cost-containment efforts affect nursing practice and the quality of care delivered. In a study in 2000, 108 nurses working primarily in hospital settings were surveyed regarding their perceptions of changes in the healthcare system with respect to care delivery. The majority of nurses reported increased workloads, decreased resources, and decreased quality of patient

care. Many nurses reported increased insurance company control over patient care (Bowen, Lyons, & Young, 2000). Healthcare restructuring has resulted in increased numbers of assistive care providers and decreased numbers of nurses providing direct care (Mooney, 2000). Many clinical nurse specialist (CNS) positions have been cut or converted to the role of case manager. CNSs in oncology and other specialties traditionally have been the main resource for nursing staff development in the past. Although the impact of the loss of these positions on nursing knowledge is not known, nursing competency in end-of-life care likely will be affected. Hospitals now are recognizing the need for CNS experts to maintain quality care in the current healthcare environment. However, student interest in this role may take several years to renew (Mooney, 2000).

Transition to home setting: Cost-containment policies that limit hospital and nursing home use are shifting care to the home setting (Ferrell, Virani, & Grant, 1998). As a result, research studies are needed to facilitate improved transition from the healthcare setting to the home setting (National Institute of Nursing Research [NINR], 1998). Nurses in hospitals or other settings play an important role in facilitating communication with patients and caregivers during these transitions. Mooney (2000) described the use of computer technology as a potential strategy for improving communication and symptom management in a cost-effective manner. For example, oncology nurses could monitor patient symptoms by the use of computer-initiated phone calls that would enter symptom severity and other patient concerns directly into a database. The computer system could alert nurses as to which patients need further intervention.

Nursing practice in home care: Home healthcare agencies have experienced economic difficulties as a result of cost-containment measures that began with the implementation of the interim payment system in 1997. As a result, about one-third of homecare agencies have closed and about one million fewer Medicare beneficiaries have coverage compared to 1997 (National Association for Home Care [NAHC], 2002a). A 2001 study evaluated the use and payments for Medicare home health services using Health Care Financing Administration (HCFA) claims data from a 1% sample of Medicare fee-for-service beneficiaries. This study found significantly greater than average declines in home health visits for females and people aged 85 and older. Further, user rates declined the most for those in rural areas and those with state Medicaid buy-in (McCall, Komisar, Petersons, & Moore, 2001). Beneficiaries who are very sick, have complex medical illnesses, or live in rural areas have been especially disadvantaged (NAHC, 2002b). The decline in home health use has resulted in changes in service mix, including a reduction in skilled nursing visits, decrease in length of visits, and shift toward more medically oriented visits (McCall et al.; Turk, Parmley, Ames, & Schumacher, 2000).

The trend of earlier discharges from hospitals has placed greater burdens on homecare nurses and family caregivers. For example, discharge planners from one public hospital were concerned that home health agencies were discharging patients too soon and increasing family burden under the interim payment system (Huskamp, Buntin, Wang, & Newhouse, 2001). Homecare nurses have an even greater role in managing pain and other symptoms and often act as independent practitioners in managing such symptoms (Glajchen & Bookbinder, 2001).

However, many nurses who transition to homecare nursing often have minimal experience in palliative care. For example, recent studies found deficiencies in homecare nurses' knowledge of pain management principles (Ferrell, Borneman, & Juarez, 1998; Glajchen & Bookbinder). The increased burden on family caregivers, as well as caregiver knowledge deficits, also have been identified as barriers to quality palliative care. These factors, in addition to the increased use of assistive care providers in place of RNs, have limited the amount of time that nurses can spend in educating patients and caregivers about palliative care (Ferrell, Borneman, et al.; Ferrell, Virani, et al., 1998).

Hospice in Various Settings

Payment System and Common Problems of Advanced Illness

Although the use of hospice has increased rapidly, a recent report suggests that older people and people receiving palliative chemotherapy, radiation, or surgery have difficulty accessing hospice care (MedPAC, 2002b). Patients with advanced cancer or other illnesses often experience multiple symptoms, physical complications, and psychosocial needs (Walsh, 1998). Pain is a common symptom in advanced cancer, HIV, and other debilitating illnesses. Other common symptoms include dyspnea, nausea, weakness, fatigue, anxiety, and delirium (Byock, 1998; Ingham, 2000). The hospice benefit may not provide adequate coverage for common problems of advanced illness. Medicare pays a fixed daily amount for hospice based on four broad categories of care with no adjustment for case mix. Although the rates have been updated for inflation, they probably are not consistent with the costs that hospices incur in providing services (MedPAC, 2002b). Because the hospice payment system is designed to limit costs, the fixed rates and caps on payments for inpatient care may adversely affect the services provided. For example, the per diem rate for routine home care may discourage use of costly pain medications, extensive counseling services, or high-technology equipment such as infusion pumps (Field & Cassel, 1997; Huskamp et al., 2001; Lynn, Wilkinson, & Etheredge, 2001b). Hospices also may underuse valuable treatments, such as include palliative radiation therapy for bone metastasis and certain expensive antiemetic agents for financial reasons. In some cases, hospices may need to deny care or accept charges for complications over which they have no control (Huskamp et al.; Walsh).

Financial and Quality of Care Implications

The financial risk for patients who require expensive treatments can threaten rural or small hospice programs (Byock, 1998). According to a recent report, the proportion of patients who die within one week of admission to hospice has increased (MedPAC, 2002b). The short length of stay frequently seen in hospice care reflects a pattern of late referrals, often resulting in a negative financial impact. For example, the cost of services is greater during the initial entry period and the last few days of hospice care but generally is offset by more stable days between these periods (Foley & Gelband, 2001; Huskamp et al., 2001). Late referrals also may compromise quality of care because adequate time is not available to implement the comprehensive services that define the hospice philosophy (Walsh, 1998).

Demonstration projects: The National Cancer Policy Board (NCPB) recommended that CMS fund demonstration projects that integrate palliative care throughout the course of illness. Some small-scale projects are ongoing in selected cancer centers (Foley & Gelband, 2001). For example, the RWJ Foundation is funding demonstration projects in Michigan, New Hampshire, Ohio, and California to test models of cancer care that provide palliative care services to people receiving anticancer treatments. Early data from some of these projects suggested improved documentation of pain as well as increased hospice referrals and length of stay (Foley & Gelband). The Hospice Improvement Program Act (H.R. 3492/S. 1425) was reintroduced in the 107th Congress. This bill included provisions for demonstration projects that would increase access to hospice care for Medicare beneficiaries.

Nursing research: Various factors may influence the timing of hospice referrals, including the difficulty in estimating prognosis for many chronic illnesses, as well as system and reimbursement policies. Integrating palliative care services throughout the illness continuum may help to facilitate earlier transitions to hospice. The American Academy of Nursing's Palliative and End-of-Life Care Expert Panel (2001) has identified the need to integrate palliative care skills throughout the nursing care of people with acute and chronic illnesses. Enhancing knowledge about advanced care planning and communication skills also may help to facilitate decision making and earlier referrals to palliative and hospice care. In a study of nurses practicing in acute care settings (i.e., medical, cardiology, pulmonary, and oncology), the majority of nurses reported using palliative care practices. However, nursing knowledge about hospice eligibility criteria and communication with patients and families about prognosis and hospice were limited (Bradley et al., 2001). In a subsequent letter to the editor, Ferrell and Grant (2001) noted the importance of examining these findings in the context of the scope of the nursing role, communication factors, and integrating palliative care across settings.

A 2001 study described the interpersonal interactions of SUPPORT nurses with patients and families (Murphy, Price, Stevens, Lynn, & Kathryn, 2001). Nurses in this study provided emotional support and information about the disease process and expected outcomes. The nurses identified barriers to effective communication, such as inadequate preparation in grief theory and pain interventions and the lack of integration of the SUPPORT nurses' role into the healthcare team. Another observation was related to the "readiness" of patients and families to accept prognoses and engage in decision making. "The nurses did not seem to believe that they could directly . . . bring patients or families to a state of readiness" (Murphy et al., p. 242), although analysis of narratives suggested that effective communication did foster readiness. Another study explored the beliefs and experiences of 852 critical care nurses regarding end of life care. Approximately one-third of nurses identified the need for better guidance in addressing this area. The researchers described needs for improvement in the areas of collaboration between nurses and physicians and participation of nurses in the decision-making processes. Many nurses expressed concern about barriers that limited their role in end-of-life decision making such as differences in professional norms between physicians and nurses as well as in status (Asch, Shea, Jedrzejewski, & Bosk, 1997).

These studies suggested a need for further research to understand and facilitate nursing communications regarding end-of-life decisions.

Quality Measures

Practice guidelines and quality indicators for palliative care are in the early stages of development (Foley & Gelband, 2001). The Agency for Healthcare Research and Quality and the National Comprehensive Cancer Network have developed guidelines for pain control at the end of life, and guidelines for other symptoms are in progress (Foley & Gelband). The development of clinically meaningful quality measures to evaluate care is essential to improving care (Rudberg et al., 1997). An initial research focus is to develop and validate measurement tools that are consistent with professional guidelines and current research (Teno, 2001). Groups such as the American Geriatrics Society (Cassel et al., 2000; Rudberg et al.), the National Hospice and Palliative Care Organization (NHPCO) and National Hospice Work Group (NHPCO, 2002), the Department of Veterans Affairs (VA), and groups supported by the RWJ Foundation are working on such measures (MedPAC, 1999). For example, NHPCO and the National Hospice Work Group organized an interdisciplinary outcomes forum to develop measures for evaluating the efficacy of end-of-life care. Nursing leaders including True Ryndes, ANP, MPH, Chris Cody, RNC, MSN, and others were instrumental in working on this initiative (Ryndes et al., 2000).

Managed Care Research

In a study focusing on managed care systems, Hoffmann (1998) interviewed 39 senior medical directors of Blue Cross Blue Shield Medicare insurance plans regarding the problems of pain management and palliative care and obstacles the directors face when designing plans to address these issues. A significant finding was the lack of a consistent approach regarding pain treatment and coverage guidelines, especially those discussing chronic pain. One concern expressed by medical directors was the difficulty in identifying pain experts and quality pain centers, which may influence referral patterns and coverage decisions. In evaluating quality, the medical directors generally relied on certification or accreditation. However, credentialing of pain specialists and centers may be confusing or inadequate in some cases. Hoffmann recommended that provider organizations develop more quality-based standards for certification of pain centers, including evidence of competence of participating providers.

In 2001, NCPB recommended that the National Cancer Institute designate certain cancer centers and community centers as centers of excellence in symptom and palliative care. Activities of these centers should include the evaluation of practice guidelines, pilot-testing quality indicators to assess end-of-life care, and initiatives to increase access to care for minority and other underserved populations (Foley & Gelband, 2001). Such designations may help to standardize criteria for excellence in end-of-life care.

Nursing Certification

Certification is important in setting standards of quality care and documenting clinical expertise acquired through education and clinical experience (Last Acts, 2002; Turk et al., 2000). Third-party payors may consider certification as a

means to demonstrate expertise and a factor that may influence reimbursement decisions. For example, nurse practitioners (NPs) must be certified by a national certifying body and hold a state license to become Medicare providers and receive reimbursement for services (Buppert, 2002). The Hospice and Palliative Nurses Association (HPNA) offers a generalist certification examination that is nationally recognized. In addition, the American Nurses Credentialing Center, New York University, and the National Board for Certification of Hospice and Palliative Nurses conducted a role delineation study in preparation for the development of an advanced practice palliative care certification examination (M. Smolenski, personal communication, December 11, 2002; American Nurses Credentialing Center, 2002). A certification examination for advanced practice nurses will be available in May 2003 (HPNA, 2002). Certification examinations also are offered for various nursing specialties including homecare nursing (Turk et al.). Certification in oncology nursing is available at the general, pediatric, and advanced practice levels (Mooney, 2000).

Standards

Formal documents and standards should be used to benchmark processes and outcomes of care. Some groups have made efforts to define quality-of-care standards, including Last Acts, the American Nurses Association, the American Association of Colleges of Nursing (AACN), HPNA, and other groups. As part of a grant funded by RWJ Foundation, nursing leaders are working with other healthcare professionals to develop a national consensus document for best practices in palliative care (D. Sherman, personal communication, March 21, 2002). This group is currently in the planning stages of writing this document (D. Sherman, personal communication, November 22, 2002). With regard to educational initiatives, AACN has developed competencies and curricular guidelines for end-of-life nursing care for undergraduate nursing students (AACN, 2002b). Another example is HPNA and the National Board for Certification of Hospice and Palliative Nurses' recent completion of standards and competencies of palliative and hospice nursing practice for advanced practice nurses (APNs) (D. Sherman, personal communication, April 5, 2002).

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has mandated standards for pain assessment and management for hospitals, nursing homes, and other facilities (Foley & Gelband, 2001). Because JCAHO accreditation is essential for healthcare institutions, the implementation of these standards represents a major advance with regard to private standard setting (Metzger & Kaplan, 2001). Once quality of care is evaluated, this information should be communicated to the public and the healthcare community (Byock, 1998). For example, CMS announced a plan to publish quality data online, leading to "report cards" for certain health facilities (Milder & Crowell, 2001c).

Federal and Private Initiatives

Federal

Federal sources and private foundations are funding research and education initiatives in palliative medicine. Some federal initiatives are authorized by the Assisted Suicide Funding Restriction Act of 1997 and include research, training, and demonstration projects to reduce restrictions on access to hospice (U.S. General Accounting Office, 1998). The

VA has developed a faculty scholars program in palliative care and an initiative for recording pain as the “fifth vital sign” in VA hospitals (Foley & Gelband, 2001).

NINR is the lead National Institutes of Health (NIH) institute addressing palliative and end-of-life research. NINR convenes periodic working groups such as workshops on end-of-life research in older people and end-of-life issues in genetic illnesses (Grady, 2002b). NINR has been involved in several initiatives and has identified research needs in this area (see Table 1).

NINR’s “Symptoms in Terminal Illness” workshop was followed by a program announcement requesting multi-

disciplinary research addressing symptoms at the end of life (*Improving Care at the End of Life*, 1999). Another program announcement was issued in August 2000 requesting clinical studies related to symptoms, communication issues, clinical decision making, and caregiver support (NINR, 2001a). In 2001, NIH and the National Cancer Institute sponsored a conference on symptom management that focused on pain, depression, and fatigue (NIH, 2002). The conference panel recommended symptom research in the areas of methodology, treatment, quality of care, and policy initiatives (see Table 1 and Figure 1). The NIH End-of-Life Research Group was

Table 1. National Institute of Nursing Research Activities in End-of-Life Care Research

Initiative	Focus	Research Needs
Symptom Management Workshop	<ul style="list-style-type: none"> State of knowledge regarding common symptoms of terminal illness Pain, dyspnea, cognitive disturbance, cachexia Multidisciplinary research to address constellation of symptoms at end of life 	<ul style="list-style-type: none"> Symptom clusters: Symptoms are interrelated and should be studied as symptom groups. Epidemiology: Incidence, combinations of symptoms Basic and clinical research: Mechanisms and interactions of symptoms; multifactorial interventions: behavioral and pharmacologic Methodology: New and improved tests and tools to assess symptoms and monitor intervention effectiveness
Capitol Hill Briefing on Pain Management	<ul style="list-style-type: none"> Gender differences in response to pain medications Pain mechanisms and gender differences related to metastasis and surgery 	<ul style="list-style-type: none"> Pain and symptom management in various population groups Similarities and differences in pain experience, including genetic, cultural, age, and gender considerations Interaction between biology and behavior and influence on how pain is experienced
Capitol Hill Briefing on End-of-Life Care	<ul style="list-style-type: none"> Families report that loved ones experience more pain and distress than perceived by healthcare providers. Problems of discontinuity in care and lapses in health services Many with inadequate health insurance lack access to quality palliative care Need for low-technology home care with nurse practitioner managing end-of-life symptoms 	<ul style="list-style-type: none"> Pain management Family caregiver needs and strategies Improved transition from the hospital to home setting Education strategies about end-of-life issues for public and healthcare providers
Capitol Hill Briefing on Quality of Life (QOL) for Patients With Chronic Illness	<ul style="list-style-type: none"> QOL studies in people with HIV; interventions to improve QOL and promote adherence to antiretroviral therapy Nursing and advanced practice nursing interventions showing improved QOL outcomes for patients with cancer in home care; positive influences on caregiver bereavement 	<ul style="list-style-type: none"> Impact of treatment regimens on QOL in people with HIV Interventions to improve QOL in people with HIV Ways that nurses can incorporate advanced practice nursing expertise more effectively in practice setting Including caregiver in discharge plans to ensure smooth transition from hospital to home care
The End of Our Lives—Guiding the Research Agenda Conference (Convened by the National Institutes of Health End-of-Life Interest Group)	<ul style="list-style-type: none"> Technologic interventions in end-of-life care Palliative care Ethical concerns Ethnic and cultural factors in end-of-life research 	<ul style="list-style-type: none"> Psychological interventions to reduce distress; spiritual care Caregiver needs Decision making, advance directives; enhancing communication with patients and families Needs and preferences of minorities
Research in Informal Caregiving: State of Science Workgroup Meeting	<ul style="list-style-type: none"> Review of research in informal caregiving Potential research in chronic illness, aging, technology, cognitive impairment, cultural and ethnic groups, caregiver support, measurement issues 	<ul style="list-style-type: none"> Population-based research on caregiver prevalence and variability of caregiving experience Interventions to improve caregiver knowledge, skills, and support Caregiver burden; impact of responsibilities on caregiver health; interventions to improve caregiver health
Symptom Management in Cancer: Pain, Depression, and Fatigue (State-of-the-Science Conference Statement)	<ul style="list-style-type: none"> Methods for symptom assessment Use of brief assessment tools for evidence-based treatments Strategies to improve symptom management and reduce barriers 	<ul style="list-style-type: none"> Common biological mechanisms New treatments and combinations of pharmacologic and nonpharmacologic treatments Quality improvement studies and treatment guidelines

Note. Based on information from National Institute of Nursing Research, 1997, 1998, 1999, 2000, 2001d; National Institutes of Health, 1997, 2002.

- Increased funding for symptom research at the National Institutes of Health, including public and private partnerships
- Regulatory issues regarding opioid prescriptions
- Adequacy of reimbursement and insurance coverage for symptom management
- Demonstration projects in clinical settings
- Education in symptom management for healthcare professionals
- Continued involvement of cancer advocacy organizations to facilitate policy changes to improve access to care

Figure 1. Directions for Future Policy Research

Note. Based on information from the National Institutes of Health, 2002; Nurse Reinvestment Act, 2002.

established to promote interdisciplinary research on end-of-life issues and to improve coordination of research efforts in this area (NINR, 2001a; Rushton & Sabatier, 2001). NINR is also a major sponsor of an IOM study to evaluate issues faced by dying children and their families (Field & Berhman, 2002; NINR, 2001a).

Private

Private foundations have played a leading role in promoting improvements in end-of-life care (Foley & Gelband, 2001). The RWJ Foundation created Last Acts, an initiative to improve the communication and exchange of information regarding palliative care practices. Last Acts created committees addressing guidelines, outcomes, provider education, and other issues (MedPAC, 1998). The RWJ Foundation funds projects such as the End-of-Life Nursing Education Consortium (ELNEC) Project and Education for Physicians on End-of-Life Care. The ELNEC project consists of national training programs to prepare nurse faculty members to provide end-of-life education for students and practicing nurses. The curriculum was developed under the guidance of Betty Ferrell, PhD, and Marcia Grant, RN, DNS, in collaboration with other end-of-life care experts. The ELNEC project addresses undergraduate and graduate education, continuing education, and pediatric palliative nursing. ELNEC, in collaboration with the Oncology Nursing Society (ONS), has an oncology-specific grant that currently is under review (B. Ferrell, personal communication, November 20, 2002). ELNEC also sponsors courses for continuing education and staff development nurses who provide education to nurses practicing in various settings (AACN, 2002a).

The RWJ Foundation also funds the Promoting Excellence in End-of-Life Care national program. In 2002, Senators Max Baucus and Charles Grassley collaborated with this group by cosponsoring a policy forum for legislators and government officials on trends in end-of-life care financing. The briefing addressed successful local demonstration projects providing end-of-life care with regard to financing and efficiency issues. A key theme was the need to implement larger, regional demonstration projects to validate these findings. Key policymakers supported the need to develop such projects to administer palliative care services in a cost-effective manner (Milder & Crowell, 2002f; Promoting Excellence in End-of-Life Care, 2002).

In July 2001, Promoting Excellence in End-of-Life Care convened a group of APNs practicing in palliative care settings to identify successful practice models, barriers, and future strategies to promote this role. A recently released monograph de-

scribed the APN's role in various innovative practice settings that promote continuity and improved access to care (Emnett, Byock, & Twohig, 2002). For example, the Supportive Care program at Memorial Sloan-Kettering Cancer Center (MSKCC) in New York, NY, extends the inpatient palliative care service to the home setting. APNs, with support from the MSKCC Pain and Palliative Care Service, provide palliative care to patients at home primarily through telephone support and coordination with the community homecare team (Emnett et al.). Recommendations for advancing the APN role in palliative care were conveyed in a position statement accompanying this monograph (Dahlin, Campbell, & McCorkle, 2002).

The Project on Death in America (PDIA) sponsors a faculty scholars program to prepare nursing leaders to implement projects in their specialty groups (Foley & Gelband, 2001; Rushton & Sabatier, 2001). The Nursing Leadership Consortium on End-of-Life Care, funded by PDIA, was established to develop a coordinated nursing effort to improve end-of-life care. Priorities included developing nursing standards and practice guidelines and establishing a network among nursing organizations to focus on end-of-life care. Other priorities included incorporation of end-of-life care in educational models, development of a research agenda and outcomes criteria, and support for policy changes to increase access to palliative services (American Association of Critical-Care Nurses, 1999).

Other nursing groups involved in efforts to improve end-of-life care include the Nursing Leadership Academy in End-of-Life Care and the American Academy of Nursing. The Nursing Leadership Academy was created by the Institute for Johns Hopkins Nursing and funded by PDIA. Participants include leaders from 22 national nursing organizations that are developing plans to advance palliative and end-of-life care in their organizations (PDIA, 2000). For example, the American College of NPs (ACNP) End-of-Life Task Force has developed an action plan and position statement on end-of-life and palliative care as part of its involvement in this group (Henderson, 2000). Other accomplishments included the publication of 18 articles in nursing journals and six national nursing conferences that addressed palliative and end-of-life care (Rushton, Sabatier, & Spencer, 2002). The American Academy of Nursing's Palliative and End-of-Life Care Expert Panel was established to develop public policy priorities regarding practice, research, and education. The panel's agenda includes developing principles of quality end-of-life care, supporting educational efforts, and improving communication with regard to advance directives and other aspects of advance care planning (American Academy of Nursing's Palliative and End-of-Life Care Expert Panel, 2001).

State Agenda

Task Forces and Attorney General Initiatives

Issues regarding palliative care, pain management, do-not-resuscitate orders, healthcare advance directives, and physician-assisted suicide have dominated the policy agenda regarding end-of-life care in recent years (Sabatino, 2000a). Some states have adopted intractable pain statutes with the goal of reducing fear of liability for aggressive pain management practices using opioids. However, controversy exists regarding whether legislating such guidelines will improve clinical practice. Thus, several states have established task forces or commissions to study a broader range of legislative options. A leader in this

initiative is the New York State Task Force on Life and the Law (Sabatino, 2000a). Attorney General initiatives have been implemented in states such as Maryland, New York, and Nevada (Sabatino, 1998). In November 2002, Last Acts released a report card that analyzed state policies that regard end-of-life care. State policies were rated based on criteria such as advance directives, hospice use, pain, hospital palliative care services, and other measures. The data suggested that the quality of end-of-life care varies widely, some aspects of care are better in certain states, and “in general, care for dying Americans is no better than mediocre” (Last Acts, 2002, p. 47). Readers are referred to the American Bar Association (ABA) Commission report and the ABA Web site for summaries of recent legislation enacted on the state level (Sabatino, 2000b, 2001).

Community-State Partnerships

Community-State Partnerships to Improve End-of-Life Care is a national program sponsored by the RWJ Foundation that awards grants to state and community groups to improve end-of-life care. The grants support the work of state-based groups to identify problems and foster public support for policies to improve end-of-life care. For example, the Michigan Partnership is implementing model projects such as a health-care professional education project, a nurse facilities project to create practice guidelines in nursing homes, and a community resource development project for consumers (Last Acts, 2000). The Maine Consortium for Palliative Care and Hospice reports to the Maine legislature about state trends regarding end-of-life care (Metzger & Kaplan, 2001).

Federal Agenda

Recent Hearings

The 106th Congress focused more attention on end-of-life issues compared with all prior Congresses. In addition to a House hearing, the Senate held hearings on nursing home initiatives, long-term care, and pain management. The Senate Special Committee on Aging held hearings on barriers to hospice care and issues surrounding end-of-life care (Last Acts, 2001; *The End of Life*, 2000). The House and Senate Judiciary Committees also held hearings on the Pain Relief Promotion Act, which opposed physician-assisted suicide (Last Acts, 2001). In the 107th Congress, the Senate Special Committee on Aging held a series of 13 hearings focusing on the long-term care system. The Committee examined the difficulties in financing long-term care for baby boomers and the need for reform of the financing system (Milder & Crowell, 2001e, 2002e, 2002g; Senate Special Committee on Aging, 2002). Hearings also were held on disease management with the goal of coordinating care, improving outcomes, and reducing costs of chronic disease in the Medicare program (*Disease Management and Care Coordination*, 2002; Milder & Crowell, 2002a, 2002c). The Senate Health, Education, Labor, and Pensions Committee’s Subcommittee on Aging also held a hearing on the accomplishments and future goals of the National Family Caregiver Support Program (Milder & Crowell, 2002b).

Legislation: 106th Congress

Congress has passed legislation dealing with end-of-life care, including the Healthcare Research and Quality Act of

1999, the Consolidated Appropriations Act of 2001, and the Older Americans Act Amendments of 2000 (see Table 2). Although Congress also considered a number of bills that were not voted on in the 106th Congress, these bills acknowledge the efforts to prioritize palliative and end-of-life care through legislative initiatives (see Table 3).

Legislation: 107th Congress

Various bills addressing palliative care were introduced in the 107th Congress. The bills addressed issues such as caregiver support, hospice improvements, pain, advance directives, and coordination of chronic illness care (Lynn, 2002b) (see Table 4). The Conquering Pain Act (H.R. 2156/S. 1024), the Hospice Improvement Program Act (H.R. 3492/S. 1425), and the Advanced Planning and Compassionate Care Act (S. 2857) were reintroduced in the 107th Congress. The Hospice Improvement Program Act would establish hospice demonstration projects and facilitate access to care provided by NPs. For example, this bill specifies that NPs can admit Medicare patients to hospice and provides direct payment for NP services related to hospice care (J. Towers, personal communication, April 5, 2002). The current statute specifies that only physicians can admit patients to hospice.

The Nurse Reinvestment Act (P.L. 107-205) addresses the nursing shortage and was passed by Congress in 2002. The act authorizes grants for various recruitment and retention strategies to promote the nursing profession (see Figure 2). Under this law, various health facilities, including hospices, home health agencies, skilled nursing facilities, and others are eligible for grants to improve nursing education and retention (NHPCO, 2002). The original Nurse Reinvestment bill was developed by members of Congress with input from various nursing organizations, including the American Nurses Association and the Americans for Nursing Shortage Relief (I. Halpern, personal communication, March 29, 2002). This law and similar legislation are important because a shortage of educated nurses limits access to quality end-of-life care, especially in underserved areas (ONS, 2002b).

Other bills introduced in the 107th Congress included the Access to Cancer Therapies Act (H.R. 1624/S. 913), Quality of Care for Individuals With Cancer Act (S. 2965), Bipartisan Patient Protection Act (H.R. 2563/S. 1051), and Lifespan Respite Care Act (H.R. 5241/S. 2489). The Access to Cancer Therapies Act (2001) would provide access to oral anticancer drugs that currently are not covered by the Medicare program. The Quality of Care for Individuals With Cancer Act (2002) called for the development of model programs to integrate palliative care throughout all stages of illness as well as with hospice activities at the end of life. This bill would support a coordinated approach to palliative care delivery throughout the course of an illness. The Bipartisan Patient Protection Act (2001) sought to provide protection for people in managed care plans including providing access to clinical trials and allowing cancer specialists to serve as patients’ primary providers during cancer treatments (ONS, 2002c). This bill would improve continuity of care for people with serious illness and protect patients’ rights based on severity of illness rather than a prognosis of estimated survival time (Americans for Better Care of the Dying, 2001). This provision is important because the severity of a condition is a better predictor of clinical needs and what the system should provide (Lynn, 2002a; Lynn et al., 2001a). Although both the Senate and House versions of this

Table 2. Successful Legislation in the 106th Congress

Act	Summary
Healthcare Research and Quality Act of 1999	<ul style="list-style-type: none"> • Designated people who need chronic or end-of-life care as priority population • Directed the Agency for Healthcare Research and Quality to support research, demonstration projects, and evaluations with respect to the delivery of healthcare services in inner city and rural areas and healthcare for underserved populations, including those with special health needs such as chronic illness or end-of-life care
Consolidated Appropriations Act of 2001	<ul style="list-style-type: none"> • Restored Medicare cuts implemented in 1997 Balanced Budget Act • Provided for 5% increase in Medicare daily payment rates for hospice • Allowed certification of terminal illness to be based on physicians' or hospice directors' clinical judgment • Required Medicare Payment Advisory Commission to study factors affecting hospice utilization • Required demonstration project with disease management services for advanced chronic illness
Older Americans Act Amendments of 2000	<ul style="list-style-type: none"> • Created National Family Caregiver Support Program • Established grants for caregiver support programs and provided funding to states to offer support services for family caregivers • Awarded grants for caregiving projects to state agencies on aging, community service providers, Native American support programs, universities, and national aging organizations

Note. Based on information from Consolidated Appropriations Act, 2001; Healthcare Research and Quality Act, 1999; Last Acts, 2001; Milder & Crowell, 2001a, 2001b; Older Americans Act Amendments, 2000.

bill passed in the 107th Congress, a conference committee never was appointed to resolve the differences between the bills. With regard to other pending legislation addressing palliative and end-of-life care, most of the bills did not see legislative action by the close of the 107th Congress. Key sponsors of these bills are anticipated to reintroduce the legislation in the 108th Congress, which began in January 2003. The Thomas Web site (www.thomas.loc.gov), Americans for Better Care of the Dying Web site (www.abcd-caring.org), and ONS Web site (www.ons.org) provide further details regarding these bills and related legislation.

Nursing Implications

The nursing community is involved closely in the care of people and their families at the end of life. Nurses play a key role in advancing improvements in end-of-life care through

their involvement in educational, research, quality improvement, and policy initiatives. Nursing implications in these areas should be considered with respect to access, cost, and quality. Legislative and grassroots strategies also must be considered.

Access

Nursing shortage: One of the factors associated with access to care is an available, educated work force. The nursing shortage intensifies the problem of limited access to palliative and end-of-life care because an insufficient number of nurses are available to provide care. In addressing this shortage, the AACN is focusing efforts on improving the practice environment and the transition of new graduates into practice. The AACN goals included the development of a postbaccalaureate residency program to strengthen the nursing workforce and target shortage areas such as critical care units and long-term

Table 3. Bills Not Voted on in the 106th Congress

Legislation	Summary
Hospice Improvement Program Act of 2000 (S. 3026)	<ul style="list-style-type: none"> • Sought to establish demonstration project to increase access to Medicare hospice services • Would provide hospice education grants (e.g., public education about Medicare hospice benefit)
Conquering Pain Act of 1999 (H.R. 2188/S. 941)	<ul style="list-style-type: none"> • Sought to provide funds for education projects to improve pain and symptom management • Proposed family support networks in pain and symptom management • Proposed projects to measure provider knowledge in pain and symptom management • Sought to establish mechanisms to examine reimbursement barriers
Advance Planning and Compassionate Care Act of 1999 (H.R. 1149)	<ul style="list-style-type: none"> • Proposed framework for state-to-state portability of advance directive • Standards for evaluating healthcare programs
Pain Relief Promotion Act of 1999 (H.R. 2260/S. 1272)	<ul style="list-style-type: none"> • Proposed to amend the Controlled Substance Act to support healthcare professionals' practices in alleviating pain using controlled substances, consistent with public safety, even if such use may increase the risk for death • Would not permit the use of controlled substances for assisted suicide; the Attorney General would give no effect to state law authorizing assisted suicide. (Proposed to override Oregon's Death With Dignity Act allowing physician-assisted suicide) • Proposed palliative care research and education programs for healthcare professionals

Note. Based on information from Advance Planning and Compassionate Care Act, 1999; Conquering Pain Act, 1999; Emmer, 2001; Hospice Improvement Program Act, 2000; Last Acts, 2001; Pain Relief Promotion Act, 1999.

Table 4. Selected Bills Introduced in the 107th Congress

Legislation	Summary
Advanced Planning and Compassionate Care Act of 2002 (S. 2857)	<ul style="list-style-type: none"> Standards to assess end-of-life care Advance directive policies and interstate portability Demonstration projects for new approaches for end-of-life care
Conquering Pain Act of 2001 (H.R. 2156/S. 1024)	<ul style="list-style-type: none"> Demonstration projects for pain and palliative care Web site containing evidence-based practice guidelines for pain treatment Family support networks to improve access and symptom management Advisory committee on symptom management
Living Well With Fatal Chronic Illness Act of 2002 (H.R. 5139)	<ul style="list-style-type: none"> Tax credit for primary caregivers Demonstration projects for fatal chronic illness Department of Health and Human Services programs to expand research and evaluation of end-of-life care (e.g., Centers for Disease Control and Prevention, National Institutes of Health, Agency for Healthcare Research and Quality) Centers of excellence for research, demonstration, and education programs
Quality of Care for Individuals With Cancer Act of 2002 (S. 2965)	<ul style="list-style-type: none"> Quality measures and indicators to improve cancer care Model programs of palliative care throughout all stages of illness Palliative and end-of-life care education programs for healthcare professionals Pilot palliative care and end-of-life care programs addressing special needs of children and underserved populations
Medicare Chronic Care Improvement Act of 2001 (S. 1589)	<ul style="list-style-type: none"> Medicare coverage for care coordination and assessment services Payment incentives and adjustments to account for additional costs in providing care for serious and chronic conditions Family caregiver education Study of Medicare program to identify use, cost, quality data, and factors that facilitate access to care for chronic illness

Note. Based on information from Advanced Planning and Compassionate Care Act, 2002; Americans for Better Care of the Dying, 2002; Conquering Pain Act, 2001; Living Well With Fatal Chronic Illness Act, 2002; Medicare Chronic Care Improvement Act, 2001; Quality of Care for Individuals With Cancer Act, 2002.

care facilities (AACN, 2002c). The Nurse Reinvestment Act addressed this and other AACN goals. This law also will promote access to care for underserved populations by establishing nursing practice arrangements in medically underserved communities.

Other issues affecting the nursing shortage include the decline in enrollment in all nursing programs and the increased average age of nurses completing advanced degree programs. AACN has focused on “the need for earlier progression into advance practice roles, research, and education” (NINR, 2001b, p. 12). NINR also has initiated strategies to address earlier entry of nurses into research careers. Strategies include the revision of the National Research Service Award mechanism to encourage recent baccalaureate graduates to pursue

doctoral studies, introduce programs to enhance the career development of minority students and faculty, and provide additional research opportunities for doctoral nursing students (Grady, 2002a; NINR, 2001b, 2001c).

Undergraduate education: Nurses have been involved in educational initiatives to improve end-of-life care in nursing programs. Ferrell, Grant, and Virani (1999) described a project designed to strengthen nursing education by (a) improving end-of-life content in nursing textbooks, (b) ensuring testing by a national nursing examination, and (c) supporting nursing organizations that promote education in end-of-life care. Nurse educators completing the ELNEC program are integrating end-of-life content in undergraduate nursing programs (AACN, 2002a). Incorporating clinical rotations in palliative and hospice care in nursing programs may be another valuable contribution. For example, in a recent study of nurses practicing in acute care settings, nurses with previous hospice training, more hospice knowledge, and fewer than 10 years of practice experience reported more frequent use of palliative care skills (Bradley et al., 2001).

Graduate education: On the legislative front, the Michigan House of Representatives adopted a resolution in 2001 that the Boards of Medicine, Nursing, and Pharmacy promote end-of-life care as a distinct area of practice (Milder & Crowell, 2001d). New York University in New York City offered the first palliative care NP program in the United States, including master’s and post-master’s certificate programs. Students are prepared for leadership roles in a variety of settings, including interdisciplinary palliative care teams, inpatient hospital, hospices, and home care (Derby & Sherman, 2000; Emmett et al., 2002). Other colleges offer or

- Public service announcements to promote the nursing profession and encourage people to enter the nursing profession
- National Nurse Service Corps Scholarship Program for nursing students in exchange for working in facilities with a shortage of nurses after graduation
- New technologies in education such as distance learning
- Career ladder programs to promote advancement in the nursing profession
- Internships and residency programs to encourage mentoring and specialty training
- Program to promote nursing involvement in organizational decision making
- Geriatric care training programs for nursing faculty and students
- Faculty loan program to provide loan repayments in exchange for teaching commitments

Figure 2. Nurse Reinvestment Act (P.L. 107-205)

Note. Based on information from American Association of Colleges of Nursing, 2002c; Nurse Reinvestment Act, 2002.

are developing CNS programs in palliative care, including Mount Carmel College of Nursing in Columbus, OH. The Breen School of Nursing at Ursuline College in Pepper Pike, OH, was the first to offer a CNS program in palliative care (D. Deane, personal communication, March 4, 2002; Emmett et al.). The adoption of additional programs that integrate palliative and primary care would help to advance nursing expertise in this area. The Nurse Reinvestment Act (2002) provided scholarships and stipends to encourage more nurses to enter advanced practice roles and increase the pool of expert nurse educators.

Continuing education: Studies support the need for palliative care continuing education programs for practicing nurses. In a recent survey, nurses in homecare settings demonstrated stronger knowledge in pain assessment compared with pain management. This study found a significant association between pain management knowledge and subjective competence, with 37% of nurses over- or underestimating their knowledge about pain management (Glajchen & Bookbinder, 2001). The researchers recommended creative educational approaches to target this discrepancy, including the use of train the trainer models and skills laboratories to strengthen competence. The researchers also described studies that support the benefits of combined didactic and experiential learning including expert mentorship programs. For example, Grant, Ferrell, Rivera, and Lee (1995) described an intervention to improve pain management in a hospital setting. Strategies consisted of the creation of a pain resource training program for staff nurses, pain quality-improvement initiatives, and supportive care services that include a CNS. The training program included didactic and clinical components. These strategies were effective in improving readmission rates for uncontrolled pain.

Bradley et al. (2001) suggested that “further integration of palliative care into the acute care setting will require substantial commitment of resources for on-the job training” (p. 21). Nursing staff development educators participating in the ELNEC project will help to address this issue by providing continuing education for practicing nurses (AACN, 2002a). In addition, private and federal organizations should support mentorship programs and other creative educational models for practicing nurses in various settings with priority given to those working in underserved and shortage areas. The Nurse Reinvestment Act (2002) provided funds to promote continuing education programs including a specific funding category for gerontologic nursing.

CNSs play an important role in implementing continuing education programs. A survey conducted by the Health Resources and Services Administration indicated that fewer than 28% of APNs are prepared as CNSs (NINR, 2001b). This downward trend and the conversion of many positions to case manager roles are concerns because of the CNS’s role in staff development activities, including palliative care education for practicing nurses. Thus, various recruitment and incentive programs are needed to support this role and encourage nurses to enter CNS programs.

Cost

Although many medical services are covered by Medicare, little reimbursement is available for long-term care and palliative services outside of hospice (Metzger & Kaplan, 2001). Medicare payment policies are based on an acute care orientation that focuses on delivery of discrete services rather than

care across episodes of illness. Thus, this system does not promote care coordination and management across multiple providers and settings (Lynn et al., 2001b; MedPAC, 2002a). For example, Medicare does not usually cover case management, interdisciplinary teams, outpatient prescription drugs, custodial care, or other supportive services (Lynn, 2002b; Lynn et al., 2001b; MedPAC, 2002a). Further, reimbursement barriers that limit coordination of care may impede access to quality care, especially for those with chronic illness (MedPAC, 2002a). Lynn et al. (2001b) recommended that Medicare financing encourage continuity of care across settings, use of evidence-based guidelines, quality improvement activities, movement of services to the home or community residence, and “interdisciplinary teams . . . principally relying upon experienced nurses,” among others (p. 226).

Continuity of care: Systems that promote coordinated care have been shown to decrease costs. In a conference sponsored by the NIH End-of-Life Interest Group, Smith (2000) noted that the use of palliative care networks or organizations promoting pain management may result in cost reductions of 10%–15%. Grant et al.’s (1995) study measuring the impact of nursing strategies in decreasing hospital readmissions showed that pain admissions decreased by 1.5%, representing a cost savings of approximately \$2.7 million (NINR, 2000). EverCare, a Medicare managed care plan, represents another creative approach that relies on NPs to manage care for residents of nursing homes and assisted-living facilities. EverCare integrates palliative services in care delivery and is designed to reduce costs associated with hospital use by providing intensive primary care by NP and physician teams (Kane & Huck, 2000; Tilly & Wiener, 2001).

Demonstration projects: Some strategies for reforming financing in end-of-life care include defining eligibility criteria based on severity of illness; providing financial incentives for symptom management, advance planning, and other support services; and expanding existing programs (Last Acts, 2002; Lynn et al. 2001a). For example, the Program of All-Inclusive Care for the Elderly is an innovative approach that provides comprehensive funding and services for the poor elderly living in the community (Lynn et al., 2001a). System reform requires additional demonstration projects conducted on a national level such as large-scale demonstrations funded by Medicare, the Agency for Healthcare Research and Quality, HCFA, and other groups (Last Acts, 2002; Lynn, 2002b; Lynn et al., 2001a, 2001b; Foley & Gelband, 2001). A number of demonstration projects are underway to identify creative ways to coordinate care in the Medicare fee-for-service system. For example, one pilot project will evaluate the effects of providing disease management services for Medicare beneficiaries with advanced heart disease or diabetes. This project will include payment for prescription drugs (*Disease Management and Care Coordination*, 2002).

Reimbursement for nursing services: Reimbursement policies have a significant impact on access to palliative and end-of-life care. Groups that are most vulnerable to problems related to access include the elderly, children, and various ethnic groups, as well as the poor and uninsured; however, nurses, including APNs, have expertise in working with underserved populations (Haylock, 2000). For example, NPs frequently provide care for underserved groups and often are the primary providers for the Medicaid population (Cohen & Juszcak, 1997; Lindeke & Chesney, 1999). Further, APNs

specializing in palliative care are striving to promote clinical excellence and improve cost-effectiveness through innovative practice in a variety of settings, including hospitals, urban cancer research centers, rural primary care, private practice, long-term care, and educational institutions (Emmet et al., 2002).

Reimbursement policies by third-party payors directly affect APN practice and the APNs' ability to provide services that are in their scope of practice. In one survey, NPs in California identified reimbursement obstacles to NP practice, including a lack of uniformity in third-party reimbursement, restrictions in reimbursement, and provider panels that would not admit NPs (Anderson, Gilliss, & Yoder, 1996). Reimbursement for APN services by commercial indemnity insurers and managed care organizations is variable across plans. Medicare and Medicaid reimbursement for APN services varies by state and ranges from 70%–100% of the physicians' usual fee. The Medicaid program is administered by the states, and state regulations vary with regard to APN reimbursement policies (Buppert, 2002). Many Medicaid recipients also are enrolled in managed care plans, and these plans vary with regard to whether NPs may be admitted to their provider panel. In general, a managed care organization only reimburses providers admitted to provider panels. Although some managed care organizations may pay for NP services delegated by a physician on the provider panel, this practice is not universal (Buppert). Thus, patient access to care provided by APNs is limited when managed care organizations do not admit NPs to their panels (American Academy of Nurse Practitioners [AANP], 2001; ACNP, 2001; Lindeke & Chesney, 1999).

The American Nurses Association, AANP, and ACNP support legislation that would improve access to APN care under the Medicaid program. AANP helped to introduce the Medicaid Nursing Incentive Act of 2001 (H.R. 3594), which would allow APNs to be designated as primary care case managers under the Medicaid program (J. Towers, personal communication, April 5, 2002). Currently, APNs and physician assistants (PAs) may be considered case managers at the discretion of each state (ACNP, 2002c). The Hospice Improvement Program Act (2001) also included provisions that would facilitate improved access and reimbursement for NP services related to hospice care. Other legislation that addressed nursing services includes the Home Health Nurse and Patient Act (S. 1169) and the Geriatric Care Act (H.R. 3027/S. 775). The Home Health Nurse and Patient Act (2001) would establish a task force to study the feasibility of allowing NPs and PAs to certify patients for home health care. Although NPs can develop a plan of care, currently only physicians can order home health services (ACNP, 2002b). The Geriatric Care Act (2001) sought to increase the number of geriatric providers and would provide Medicare reimbursement for care coordination and assessment services. This bill would include NPs in the definition of care coordinator (ACNP, 2002a). These bills did not see legislative action before the close of the 107th Congress.

ONS supports the reform of Medicare reimbursement to include reimbursement for oncology nursing services in provision of outpatient chemotherapy (Halpern & Waters, 2002b; ONS, 2002a). Co-chairs of the Senate and House Cancer Coalition circulated a letter to congressional colleagues to encourage support for reimbursement for the range of services provided by oncology nurses. These efforts achieved broad

bipartisan support, which will help ONS advocate for reimbursement for oncology nursing services in upcoming Medicare reform legislation (Halpern & Waters, 2002a). Given the shift in the provision of cancer care from inpatient to outpatient, community-based settings, adequate reimbursement for practice expenses and nursing services are essential to ensure access to quality cancer care (*Medicare Payments for Currently Covered Prescription Drugs*, 2002; ONS, 2002d).

Nurses should contact their congressional representatives to reintroduce and cosponsor legislation in the 108th Congress addressing nursing services in the provision of palliative and end-of-life care. Nursing priorities include legislation that would promote changes in state and federal laws and regulations to facilitate access and direct reimbursement for nursing services (S. Harbison, personal communication, December 2, 2002). Nurses also should inform their representatives that legislation that calls for demonstration projects for palliative and end-of-life care should include provisions that recognize APNs as primary care providers, provide direct reimbursement for nursing services, and allow APNs to directly admit patients to hospice and certify home healthcare services.

Quality

Practice guidelines and evidence-based practice: Foley and Gelband (2001) recommended that professional societies such as ONS and the American Society of Clinical Oncology encourage members to develop practice guidelines and standards of palliative and end-of-life care. The Nursing Leadership Consortium on End-of-Life Care considered the development of nursing standards and practice guidelines as a top priority (American Association of Critical Care Nurses, 1999). Various nursing groups have been working on initiatives as described previously. The shift to capitate reimbursement policies and other cost-containment efforts has encouraged a focus on population outcomes and cost-effectiveness. "To achieve optimal outcomes . . . treatment guidelines and evidence-based practice will expand and play an important role in care decisions" (Mooney, 2000, p. 30). Evidence-based practice is key to achieving quality, cost-effective care (Turk et al., 2000). For example, Mooney (2001) discussed the importance of adopting practice guidelines and setting goals at the beginning of treatment to standardize oncology care. ONS developed an online evidence-based practice resource center to provide a guide for nurses in solving clinical problems and developing guidelines (www.ons.org). Some sources of evidence that may contribute to evidence-based practice guidelines include research studies, authority-based or expert knowledge, and knowledge from quality improvement data or projects that evaluate clinical care (Glanville, Schirm, & Wineman, 2000).

Quality improvement initiatives: Nursing involvement in interdisciplinary quality improvement initiatives may help to improve care in their institutions. For example, nurses at LifePath Hospice and Palliative Care, Inc., are developing interdisciplinary care maps, quality indicators, and outcomes criteria as part of an innovative healthcare delivery model for hospice and palliative care (C. Frank & R. Riley, personal communications, March 21 & 22, 2002). Miaskowski (2001) provided an excellent overview of the process of developing a quality improvement program to improve pain management practices at the nursing unit or organizational levels. She described a "step-by-step" guide to establishing

a multidisciplinary pain management committee, the selection of pain intensity scales, and staff education activities to demonstrate a need for the program.

Legislative Activities

Informed nurses: To influence change on a local level, nurses should be knowledgeable about legislative priorities and the public's concerns regarding end-of-life care. Nurses should support legislation such as the Hospice Improvement Program Act, the Medicaid Nursing Incentive Act, the Conquering Pain Act, the Access to Cancer Therapies Act, and similar legislation. Priorities include legislation that supports access to care, continuity of care, caregiver support, research, quality improvement initiatives, healthcare provider education, financing reform, and reimbursement for palliative care that includes nursing services. Most of the bills related to palliative and end-of-life care introduced in the 107th Congress lacked adequate numbers of sponsors (Lynn, 2002b). Therefore, nurses should ask their representatives to cosponsor legislation addressing these issues. Congress's enactment of the Nurse Reinvestment Act is a major step in addressing the nursing shortage and acknowledging the importance of increasing and retaining an educated nursing workforce in improving access to quality care. Although the Nurse Reinvestment Act authorizes the creation of new programs, funding was not allocated for these programs by the close of the 107th Congress in November 2002. Therefore, nurses should continue to urge their representatives to support full funding of the Nurse Reinvestment Act (I. Halpern, personal communication, November 19, 2002; S. Harbison, personal communication, November 14, 2002).

Nurses can access up-to-date legislative information through their nursing and specialty organizations. Several educational and legislative resources include Last Acts (www.lastacts.org), the Nursing Leadership Consortium on End-of-Life Care (www.palliativecarenursing.net), AACN (www.aacn.nche.edu), HPNA (www.hpna.org), and Americans for Better Care of the Dying. Knowledge of legislative priorities will help nurses to effectively lobby their representatives and community leaders.

Grassroots lobbying: One effective lobbying strategy includes participation in "telephone trees" and e-mail listserves that provide legislative updates. This strategy was used effectively by the NP Association of Maryland to achieve significant support for the Patient Access to Choice of Provider Act in the Maryland General Assembly. Writing letters that include personal stories about patient care or practice issues is also an effective strategy in communicating with policymakers (Halpern, 2002). Health care requires that nurses speak in "two different languages—the language of nursing science with its quantifiable outcomes . . . as well as the language of people" (Leight, 2002, p. 109) and about human experience (Hodges, 1997). The latter allows nurses to "convey with conviction the meaning of health and illness for vulnerable people" (Hodges, p. 353). In addition, nurses can offer to serve as resources for their representatives and staff regarding issues that affect end-of-life care and its delivery.

Conclusions

Changes in societal attitudes and systems of care are needed to achieve real gains in quality end-of-life care (Field & Cas-

sel, 1997). Despite progress made in the fields of hospice and palliative care, recent research and advisory studies, along with the debate stimulated by physician-assisted suicide legislation, have focused attention on the inadequacies in end-of-life care. Contributing factors include organizational, system, regulatory, and financial barriers that limit access to hospice and palliative care services. Underserved populations and minority groups, as well as those with chronic illnesses in which time to death is not easily estimated, experience inequities in access to these services. The integration of palliative care throughout the course of illness may facilitate improved symptom management, quality of life, and continuity of care including timely referrals to hospice. The incorporation of innovative models that promote coordinated care such as disease management programs should support a more cost-effective, integrated approach in delivering palliative care services. Eligibility criteria for hospice care should be based on severity of illness instead of a time-based estimate of prognosis because of the difficulty in estimating time to death for many chronic conditions. Many patients are not referred to hospice care or are referred too late to benefit from the comprehensive services available to patients and family caregivers. Legislation introduced in the 106th and 107th Congresses addressed some of these concerns and reflected the initiatives of many healthcare professionals, advocacy groups, private and federal organizations, and legislators dedicated to improving care at the end of life. Various educational programs, research initiatives, and demonstration projects should contribute to a stronger social consensus regarding quality end-of-life care. Moreover, these initiatives should provide further data to support policy changes at the state and federal levels.

A "feature of nursing that supports its uniqueness is that as a profession it exists in an open system and has to be influenced by and be responsive to society's needs at all time" (Meleis, 1997, p. 78). Nursing initiatives in the areas of education, practice, research, and health policy are ongoing and represent important contributions toward improving palliative and end-of-life care. The development of practice guidelines and standards of care will contribute to cost-effective, high-quality care. Research findings from nursing intervention studies and other integrated practice models have shown cost-savings and improvements in pain management and continuity of care in various settings. Recent legislation addresses access to care, family caregiver needs, the nursing shortage, and demonstration projects to improve care delivery. In addition, financial issues, including reimbursement for nursing services, are addressed. Enactment of legislation addressing these issues will help to improve access to hospice and palliative care, especially for underserved populations. Nurses should strive to improve care for those who are most vulnerable in society, including children, the elderly, the poor, minorities, and those with chronic illnesses. Healthcare professionals and policymakers should work now to make a difference in the lives of those they care for who are approaching the end of life.

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For more information . . .

- Center to Advance Palliative Care
www.capcmssm.org
- International Association for Hospice and Palliative Care
www.hospicecare.com
- National Hospice and Palliative Care Organization
www.nhpco.org

Links can be found using ONS Online at www.ons.org.