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The National Consensus Project for Quality Palliative Care

Background

In 2001, palliative care leaders from across the United States met to discuss the standardization of palliative care with the goal of improving the quality of care. The result was the formation of the National Consensus Project for Quality Palliative Care (NCP) with representation from the five major hospice and palliative care organizations at that time: The American Academy of Hospice and Palliative Medicine (AAHPM – the physician membership association), The Center to Advance Palliative Care (CAPC – a palliative care advocacy and information organization), The Hospice and Palliative Nurses Association (HPNA – the nursing membership association), Last Acts Partnership (a consumer organization- now part of NHPCO), and the National Hospice and Palliative Care Organization (NHPCO – the hospice membership organization). The National Consensus Project for Quality Care created the Clinical Guidelines for Quality Palliative Care which describe core concepts and structures for quality palliative care, including eight domains of practice.

The 2009 revision of these guidelines reflected the ongoing collaboration of the Hospice and Palliative Care Coalition composed of: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, and the National Hospice and Palliative Care Organization. The revision further delineated the domains. This 2013 revision continues as a collaborative process of the National Coalition for Hospice and Palliative Care: AAHPM, CAPC, and HPNA; joined by the newest member of the Coalition, the National Palliative Care Research Center (NPCRC). The National Association of Social Workers (NASW) and NHPCO are participants of the National Consensus Project.

Introduction

In the ten years since the establishment of The National Consensus Project for Quality Palliative Care, the number of hospice programs has increased by 47 percent and non-hospice palliative care programs have increased by 148 percent in hospitals with over 50 beds. In 2011, there were approximately 2,513,000 deaths in the United States with 1,059,000 (46%) of those deaths occurring under the care of one of over 5000 hospices. Palliative care services have expanded similarly across hospital and community care settings including: acute care units, emergency and critical care departments, outpatient settings, and within innovative community programs for patients with chronic conditions, such as neurological, cardiac, and pulmonary disease. Research has demonstrated high value care for patients served by palliative care teams in the hospital. Research has also found that hospices use reduces Medicare program expenditures. One study revealed costs during the last year of life were decreased by an average of $2309 per hospice user. In the years since the 2009 revision of the Clinical Practice Guidelines for Quality Palliative Care, several milestones have been achieved in the field of hospice and palliative care. In 2009, the Accreditation Council for Graduate Medical Education recognized hospice and palliative medicine as a subspecialty of eleven different parent boards, thereby providing legitimacy to the field. This paved the way for the development of hospice and palliative medicine graduate medical education fellowships for physicians, now an eligibility requirement for the hospice and palliative medicine board certifying examination. A new examination is in development for hospice medical directors.
In nursing, an increasing number of graduate programs have incorporated palliative nursing into their curricula. Work is in process for advanced practice nurse education for mid-career clinicians to provide primary palliative care, along with the development of a limited number of advanced practice palliative nursing fellowships for preparation into the specialty. Two new examinations were developed by the National Board of Certification of Hospice and Palliative Nurses: for pediatric hospice and palliative care registered nurses, and hospice palliative care administrators. The development of a new exam for professionals involved in perinatal loss is anticipated in the next year.⁸

In 2008 and 2009, The National Association of Social Workers, in collaboration with the National Hospice and Palliative Care Organization, developed a certification for master’s prepared social workers (MSWs)⁹,¹⁰ and bachelor’s prepared social workers (BSW). The Council on Social Work Education’s Gero-Ed Center created teaching resources related to hospice, palliative care, loss, and grief, to be incorporated in undergraduate and graduate social work curricula.¹¹ Work continues in other disciplines to promote education and clinical experience in hospice and palliative care. Finally, The Joint Commission now offers specialty Palliative Care Certification for hospital programs. Criteria for the certification survey are based on these Clinical Practice Guidelines.¹²

Health Care Reform and Palliative Care

Further development of palliative care occurred with the passage of the Patient Protection and Affordable Care Act of 2010 (PPACA).¹³ The legislation included a new provision allowing children covered under either Medicaid or the Children’s Health Insurance Program (CHIP) to receive simultaneous access to both hospice and curative care.¹³ A similar simultaneous care demonstration project was also a provision of PPACA, with the intent of testing, in 15 sites nationwide, the option for concurrently offering hospice and regular Medicare Part A services. Given palliative care’s demonstrated quality improvement and impact on health care value, new delivery and payment models rewarding quality over quantity of care create an opportunity for hospice and palliative care programs to participate in novel health delivery paradigms such as accountable care organizations (ACOs), bundled payments, and patient-centered medical homes (PCMHs).¹⁴ There is greater potential to promote introduction of palliative care in all settings.

Quality Measures

Quality is an underlying goal of palliative care. The endorsement of the NCP Clinical Practice Guidelines by the National Quality Forum (NQF) in 2006 established initial areas within which to develop outcome measures for palliative care programs.¹⁵ In 2008, the National Priorities Partnership, a consortium of US health care organizations working with NQF, identified palliative care as one of six top priorities for improving the U.S. health system.¹⁶ They developed a National Priority Partners Palliative and End of Life Work Group to consider next steps.

In 2011, as required by the Affordable Care Act, NQF convened the Measure Applications Partnership (MAP), an independent entity that reports directly to the Health and Human Services Secretary and advises on quality measures across all healthcare settings.¹⁷ One of the MAP Work Groups, the Post-Acute/Long Term Care (PAC/LTC) Work Group, is responsible for reviewing and advising on hospice and palliative care measures. The June 2012 MAP Final Report on Performance Measurement Coordination Strategy for Hospice and Palliative Care states that, “while measurement in this area is new, MAP suggests a phased approach that emphasizes clinically-focused measures at first, but quickly expands to more measures that follow the patient and their full set of experiences rather than the setting or fragments of a patient’s care (often referred to in this report as ‘cross-cutting’).”¹⁷ The MAP report also
addresses quality reporting in palliative care, by stating “while there is not a formal quality reporting program for palliative care, settings in which palliative care is provided (e.g., hospitals, home health) are required to participate in federal quality initiatives.”

In 2010, the PPACA directed the Centers for Medicare and Medicaid Services (CMS) to implement an annual quality reporting program for hospice organizations beginning in 2013 that includes a financial incentive for hospice provider participation. In February 2012, the NQF endorsed 14 quality measures for palliative and hospice care. The goal of these measures is to ensure the provision of high quality palliative care and end of life care. The measures, some of which are applicable to all clinical settings and provider types, will help hospice and palliative care providers to improve quality of care and generate ideas for future research.

Research

Recently, published studies confirm that palliative care improves quality of life for patients and their families. Building the evidence base to support quality requires adequate funding for relevant research and its publication. Private foundations continue to be an important funding source to support palliative care researchers, but increased federal funding is also needed to finance larger investigations. In 2004, the year the first version of the Consensus Guidelines was published, the National Institutes of Health (NIH) supported 162 projects related to palliative care, up from 53 relevant projects in 1995. In 2010, 309 palliative care projects received NIH funding. A search for palliative care clinical trials using PubMed shows similar growth: 180 published trials in 2004 and 252 in 2010. The National Palliative Care Research Center (NPCRC) has been a central organizing force promoting and facilitating the conduct of palliative care research and has supported many of the researchers whose work appears in the Bibliography section of this document. The 2011 National Institute of Nursing Research Summit entitled the Science of Compassion reviewed the current research in palliative care, described barriers to research, and suggested strategies for progress and continued research (NINR). Future revisions of the Clinical Practice Guidelines will reflect continued growth in the evidence base underlying palliative care practice with more advanced research.

Populations Served

In an effort to improve access to palliative care within all patient populations in need, NHPCO released three publications in 2009; Standards of Practice for Pediatric Palliative Care and Hospice along with the companion publication, Facts and Figures on Pediatric Palliative and Hospice Care in America, and Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings. In 2010, HPNA produced a pediatric resource, Just in Time Guide: A Primer for Pediatric Palliative Care at Home. In 2010, NHPCO promoted a campaign for Veterans called, “We Honor Veterans” in collaboration with the Department of Veterans Affairs. The End of Life Nursing Education Consortium (ELNEC) provided specialized education for nurses at Veterans Administration Facilities. CAPC supported pediatric palliative care program development and provided training to all U.S. VA Medical Centers in 2009-2011.

With this background, this current revision of the National Consensus Project Clinical Practice Guidelines provides the following updates. For the purposes of this document, the term serious or life-threatening illness is assumed to encompass populations of patients at all ages within the broad range of diagnostic categories, living with a persistent or recurring medical condition that adversely affects their daily functioning or will predictably reduce life expectancy. Correspondingly, populations to be considered for palliative care include:
• Individuals living with chronic and life-threatening injuries from accidents or other forms of trauma
• Neonates, children, adolescents, and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and/or long-term care, supported by others to perform their activities of daily living
• Neonates, children, adolescents, and adults with developmental and intellectual disabilities who develop serious or life threatening illness
• Individuals, of any age, with acute, serious, and life-threatening illnesses (e.g. severe trauma, acute stroke, and leukemia), where cure or reversibility is a realistic goal, but the conditions themselves and/or their treatments pose significant burdens and result in poor quality of life
• People living with progressive chronic conditions (e.g. peripheral vascular disease, malignancies, renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders, and the various forms of dementia)
• Seriously and terminally ill patients (e.g. people living with end-stage dementia, terminal cancer, or severe disabling stroke) who are unlikely to recover or stabilize; and for whom intensive palliative care is the predominant focus and goal of care for the remainder of their lives
• Vulnerable, underserved, and under-resourced populations who develop serious or life threatening illness (e.g. homeless individuals, immigrants, individuals with low income, oppressed racial and ethnic groups, veterans, prisoners, older adults, and individuals with mental illness)

**Defining Palliative Care**

The definition of palliative care used to characterize palliative care in the United States described by both the US Department of Health and Human Services (HHS) Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF) states:

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.\(^{15,28}\)

The following features characterize palliative care philosophy and delivery:

• Care is provided and services are coordinated by an interdisciplinary team;
• Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
• Services are available concurrently with or independent of curative or life-prolonging care;
• Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

Prior versions of the NCP specifically describe palliative care delivery as follows, “Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. Evaluation and treatment should be comprehensive and patient-centered with a focus on the central role of the family unit in decision making. Palliative care affirms life by
supporting the patient and family’s goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process, and death.”29

**Summary of Revisions in the Domains**

In each edition, the Clinical Practice Guidelines are revised to reflect current practice. Except for Domain 7, in which the title has been changed from Care of the Imminently Dying Patient to Care of the Patient at the End of Life, the domains remain consistent with past editions and form the basis of practice. The underlying tenets of palliative care in this document include: patient and family centered palliative care; comprehensive palliative care with continuity across health settings; early introduction of palliative care at diagnosis of a serious disease or life threatening condition; interdisciplinary collaborative palliative care; clinical and communication expertise within palliative care team members; relief of physical, psychological, emotional, and spiritual suffering and distress of patients and families; a focus on quality; and equitable access to palliative care services. Each domain has been significantly updated as described below.

**Domain 1: Structure and Processes of Care**

The Structure and Process Domain was enhanced to describe and accentuate the current state of the field with emphasis on interdisciplinary Team (IDT) engagement and collaboration with patients and families. There is emphasis on coordinated assessment and continuity of care across healthcare settings. Clarity and specificity of interdisciplinary team composition, team member qualifications, necessary education, training, and support are described. Finally, the quality assessment process and improvement section incorporates the new mandates for quality under the Patient Protection and Affordable Care Act.

**Domain 2: Physical Aspects of Care**

The Physical Domain emphasizes the assessment and treatment of physical symptoms with appropriate, validated tools. Management of symptoms is multidimensional with pharmacological, interventional, behavioral, and complementary interventions. The utilization of explicit policies for the treatment of pain and symptom management, as well as safe prescribing of controlled medications is recommended.

**Domain 3: Psychological and Psychiatric Aspects**

The Psychological and Psychiatric Domain has been significantly revised and expanded to focus on the collaborative assessment process of psychological concerns and psychiatric diagnoses. Essential elements are described and include patient-family communication on assessment, diagnosis, and treatment options for common conditions in context of respect for goals of care of the patient and family. New to the domain are the description and required elements of a bereavement program.

**Domain 4: Social Aspects of Care**

The Social Domain now has greater emphasis on interdisciplinary engagement and collaboration with patients and families to identify, support, and capitalize on patient and family strengths. Essential elements of a palliative care social assessment are defined. The role of the professional social worker with a bachelor’s or master’s degree in social work is described.
Domain 5: Spiritual, Religious, and Existential Aspects of Care

The Spiritual Domain now includes a definition of spirituality, stressing assessment, access, and staff collaboration in attending to spiritual concerns throughout the illness trajectory. Requirements for staff training and education in provision of spiritual care are offered. There is stronger emphasis on the responsibility of the interdisciplinary team, inclusive of an appropriately trained chaplain, to explore, assess, and attend to spiritual issues of the patient and family. The domain promotes spiritual and religious rituals and practices for comfort and relief.

Domain 6: Cultural Aspects of Care

The Cultural Domain defines “culture” and cultural competence for the interdisciplinary team, underscoring culture as a source of resilience and strength for the patient and family. New content accentuates cultural and linguistic competence including plain language, literacy, and linguistically appropriate service delivery.

Domain 7: Care of the Patient at the End of Life

The Care of the Patient at the End of Life Domain highlights communication and documentation of signs and symptoms of the dying process in the circle of care: the patient, the family, and all other involved health providers. The importance of meticulous assessment and management of pain and other symptoms is underscored. The essential attention to family guidance as to what to expect in the dying process and the post death period is emphasized. Bereavement support beginning with anticipatory grief in the period before the actual death and continues through the actual death is stressed. Social, spiritual, and cultural aspects of care are of utmost concern throughout the process.

Domain 8: Ethical and Legal Aspects of Care

The Ethical and Legal Domain is now restructured into three sections: advance care planning, ethics, and the legal aspects of care. Under advance care planning, the responsibility of the palliative care team to promote ongoing discussion about goals of care along with completion and documentation of advance care planning documents is emphasized. Under ethical issues, there is acknowledgement and affirmation of the frequency and complexity of ethical issues in palliative care. Team competencies in the identification and resolution of commonly encountered ethical issues are described, with emphasis on the importance of seeking advice and counsel from ethics committees. Under legal issues, there is acknowledgement of the complex legal and regulatory issues that arise in palliative care that require team members to understand their respective scope of practice within the provision of palliative care. Finally, there is new emphasis on the necessity of and access to expert legal counsel, essential for navigating the intricate and sensitive legal and regulatory issues in palliative care.

Conclusion

The Clinical Practice Guidelines for Quality Palliative Care have been updated for several reasons. First, as part of its mission, the National Consensus Project for Quality Palliative Care aims to promote consistent and high quality care. As health care evolves, the Clinical Practice Guidelines require revision to reflect the continuing maturation of the field, changes in practice, and developments in the palliative care evidence base. Second, seminal events, such as health care reform mandated by the Patient Protection and Affordable Care Act, development of The Joint Commission palliative care advanced
certification, and endorsement of new palliative care quality measures by the National Quality Forum, require new perspectives on the role and contribution of palliative care in a changing health system landscape. Finally, publication of significant new palliative care outcomes research findings necessitate that the principles and practices of quality palliative care reflect the highest quality evidence available.

References