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# **National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition: Why is This Important to Chaplains?**

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*The Clinical Practice Guidelines for Quality Palliative Care, fourth edition were recently published. Through the involvement of the Association of Professional Chaplains and the HealthCare Chaplaincy Network, this is the first time that any chaplains have been an official party to the development of these guidelines. The expectation set by the guidelines is that all health care professionals (including all chaplains) caring for people living with serious illness at any stage of illness, at any age, and in any setting will integrate core palliative care principles and best practices into their routine care and have sufficient training to complete an assessment of the patient and address common sources of suffering. The article presents a summary of the content of the guidelines and their implications for clinical practice and training with emphasis on the practice and training of professional chaplains.*

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## INTRODUCTION

The Clinical Practice Guidelines for Quality Palliative Care, fourth edition were developed over the last two years by the National Consensus Project for Quality Palliative Care, and a group of 16 national organizations with extensive expertise in and experience with palliative care and hospice, including the Association of Professional Chaplains (APC) and the HealthCare Chaplaincy Network (HCCN). The guidelines are being published by the National Coalition for Hospice and Palliative Care (the Coalition) of which APC and HCCN are members. Of note is that this is the first time that any chaplains have been officially party to the development of these guidelines as APC and HCCN were not members of the Coalition when the last edition of the guidelines were written.

The purpose of the guidelines is to improve access to quality palliative care by fostering consistent standards and criteria and encouraging continuity of palliative care across settings. The guidelines create a blueprint for excellence by establishing a comprehensive foundation for gold-standard palliative care, including evidence-based processes and practices for providing safe and reliable high-quality care for people living with serious illness.

In general, guidelines improve care and safety for patients and families by defining structures and processes of care, setting expectations for providers, guiding clinical decision making, promote standardization, creating the foundation for accountability. The guidelines can be used to transform the care of individual patients and families as well as populations, design new palliative care programs, develop and refine educational programs, measure the effectiveness of and improve care, develop payer contracts, shape research, and prepare for health care accreditation.

## WHY ARE THE GUIDELINES IMPORTANT?

Health care in the United States is more and more focused on the so-called “triple aims”—patient satisfaction, medical outcomes, and cost savings. Palliative care is one of the few concepts in the system that appears to be able to contribute to all three aims. Past editions of these guidelines

have been very widely used by health care providers, payers, and regulators such as the Joint Commission to set the bar for and evaluate the provision of palliative care and hospice care in the United States. However, the speed and depth of change in health care generally and the evolution of palliative care as a central piece of that change have made more apparent some gaps in the 3rd edition of the guidelines that could helpfully be addressed. The presence of the Joint Commission and the National Quality Forum at the stakeholders meeting for this project and the funding this project has drawn from major foundations is testament to this importance and to the need for a new edition. The significant expansion of the settings and diagnostic categories in which palliative care is now standard practice are both a driver for why this new edition is necessary and evidence for why the guidelines are so important.

The new edition of the guidelines calls for a seismic shift in the delivery of palliative care by urging all health care professionals and institutions to integrate it into their care of people living with serious illness. The guidelines are clearly now inclusive of all people living with serious illness regardless of diagnosis, prognosis, where they live, their age, or where they receive care. Care for caregivers is also a focus for the first time.

For professional health care chaplains, the patient and family-centered philosophy of palliative care and its focus on starting where the patient is have always been at the core of our training and practice. Until now, many of these skills and approaches have not been highly valued in many of the venues of in which chaplains practice. Now with palliative care common in emergency departments and intensive care units (ICU) and considered best practice for diagnoses such as dementia as well as at the end of life, the opportunities for chaplaincy to make a welcomed and even sought after contribution have grown exponentially. With this opportunity, however, comes accountability in areas including spiritual assessment, being the spiritual care authority for the whole team and overseeing the continuity of spiritual care in outpatient and community settings. Under these guidelines, chaplains will be held accountable for reliably delivering on what the guidelines suggest. This situation seems to call for a disciplined and, in some aspects, standardized practice. The reward is that chaplains are recognized as full members of the clinical team that will hopefully, not only benefit patients, but bring added value to chaplain positions.

## SOME ISSUES OF TERMINOLOGY

To understand these guidelines, it is essential to be clear about some of the terms and how they are used. These are terms that are in common

usage but variously defined. Many of them are often not used with precision. Helpfully, the guidelines have an exhaustive glossary to make the communication clear. It is important to understand that the definitions used here are not meant to necessarily be *the* definition for the field. They are, however, meant to make it clear what these terms mean in this particular context.

Guidelines are different from standards. Guidelines constitute general advice for setting standards and recommended suggestions of best practice. They tend to be formulated by having the best evidence in the field evaluated and supported by a consensus panel of acknowledged content experts. Standards are generally understood to be specific actions or rules designed to support and implement guidelines. As an example, the Joint Commission has standards. If the institution does not meet these standards, they do not receive Joint Commission accreditation. Thus, they are rules or baselines. The Joint Commission relies on guidelines to supply the expert opinion to set their standards. For instance, the Joint Commission standards for Advanced Certification for Palliative Care quote the NCP Guidelines as evidence for some of their standards (The Joint Commission, 2018).

Guidelines can be considered under the broad heading of quality improvement. They can be goals to be attained over time. Health care organizations will choose how to best apply guidelines criteria based on their particular patient populations and care settings. Generally, quality goals fall into three categories: structure, process, and outcome. Often one needs to attain structural goals in order to attain process goals. One needs to have reliable processes in place to attain outcomes. As an example, if the desired outcome is to reduce spiritual distress among a client population, the institution needs a reliable process for identifying patients with spiritual distress, usually screening. To best monitor this process well and respond to the need generated by it so the outcome is realized, the institution needs to meet the structural goal of having a professional chaplain on staff.

Palliative care is defined differently in various places. The guidelines quote several definitions as shown in the following paragraphs.

Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care (Institute of Medicine, 2015):

... 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. (Centers for Medicare & Medicaid Services, Department of Health and Human Services, 2014).

It is notable that palliative care is defined as being available to all people with a “serious illness.” This represents a change from previous formulations that focused on “advanced illness” and from the understanding of many practitioners that palliative care is focused only on patients with terminal illness. In these guidelines, serious illness is defined as “a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains their caregiver” (Kelley & Bollens-Lund, 2018). It is important to note the inclusion of stress on caregivers as a criterion for serious illness.

Finally, the guidelines presume the generalist-specialist model of spiritual care in which the professional chaplain is the spiritual care specialist and all other members of the team are spiritual care generalists (Puchalski et al., 2009).

## MAKING THE CASE FOR PALLIATIVE CARE

Today’s fragmented health care system makes it difficult to effectively treat patients with serious illness—just when their numbers and needs are growing exponentially. Studies have consistently shown that people with serious illness experience untreated pain and other symptoms; lengthy hospitalizations involving burdensome, often futile, and costly treatments; and low overall family satisfaction, particularly with the quality of their hospital care (Brumley et al., 2007).

The new guidelines call for correcting this mismatch by standardizing the quality of palliative care and ensuring it is available to all people living with serious illness, regardless of their diagnosis, prognosis, age, or where they live or receive care.

Palliative care is specialized interdisciplinary care focused on providing relief from the symptoms and stress of a serious illness through patient-centered outcomes such as quality of life, symptom burden, emotional well-being, communication, continuity of care, and caregiver burden. The goal is to improve quality of life for both the patient and family. It can be provided concurrently with disease-focused treatment and is based on need, not prognosis (Temel et al., 2010).

Palliative care is provided by a specially trained team of doctors, nurses, social workers, chaplains and other specialists who work together

with a patient's other health care professionals to integrate an extra layer of support. Because there is a limited availability of palliative care specialists and teams many people do not have access to palliative care.

To address this lack of access, the expectation set by the guidelines is that *all* health care professionals caring for people living with serious illness will integrate core palliative care principles and best practices (such as safe and effective pain and symptom management and expert communication skills) into their routine care and have sufficient training to complete an assessment of the patient and address common sources of suffering. Thus, there will be specialty palliative care teams made up of practitioners with special training in palliative care. These teams will often be located in hospitals and other medical facilities and handle the most complex cases. Everyone else in the field will be palliative care generalists integrating core palliative care practices. In chaplaincy, the analogy would be that professional board certified chaplains, increasingly with special training in palliative care, will be the palliative care specialists in spiritual care and staff the palliative care teams. Practitioners in community faith, as well as spiritual and cultural communities will generally be the spiritual care generalists in palliative care. They will often be trained by the professional chaplain who will also be a resource for complicated cases.

Hospice is a type of palliative care for people living with serious illness whose life expectancy is measured in months, rather than years. Palliative care should be provided throughout the community wherever people living with serious illness receive care, including at outpatient clinics, long-term care facilities, office practices, cancer centers, homeless shelters, dialysis units, prisons, and in the home.

Since palliative care helps ensure that resources are matched to patient and family needs and priorities, it results in substantially lower costs and reduced readmissions. It is particularly relevant as a key strategy for population health management (Morrison et al., 2008).

## NATIONAL CONSENSUS PROJECT FOR QUALITY PALLIATIVE CARE (NCP)

This project began in 2002 with a task force of five key national organizations and content experts. Three prior editions of the NCP Guidelines were published: 2004, 2009, and 2013. Each edition has reflected the evolving and expanding field of palliative care. In each one, the specification of spiritual care and chaplaincy care has grown more robust and become more and more central to the guidelines. NCP Guidelines have served as hallmark document to integrate the principles of quality

palliative care for: clinicians, providers, accreditation organizations, professional education, and payers.

## NATIONAL COALITION FOR HOSPICE AND PALLIATIVE CARE

The National Coalition for Hospice and Palliative Care (the Coalition) was founded in 2001 by the leading hospice and palliative care organizations to better communicate, coordinate, and collaborate on issues and activities of importance to the interdisciplinary hospice and palliative care field. The Coalition is now comprised of the ten leading national hospice and palliative care organizations dedicated to advancing care of patients and families living with serious and life-limiting conditions. Coalition organizations represent chaplains, social workers, physician assistants, pharmacists, physicians, and nurses whose work includes palliative care.

The Coalition works together to respond to various health policy opportunities and challenges on behalf of its members and the hospice and palliative care field. It facilitates the work of the NCP. Each month the Coalition meets to discuss various issues of interest and concern and determines what course of action, if any, is needed. The Coalition has submitted comments to various regulatory, legislative, and other external entities on behalf of the members of the Coalition. Their various letters and comments have helped influence policy changes that have improved the care of those with serious illness and at the end of life. Additionally, the Coalition routinely and successfully submits nominations of experts to serve on federal and national advisory bodies.

## THE GUIDELINES

The development of the new edition of the guidelines has been funded by a generous grant from the Gordon and Betty Moore Foundation. Major work began with a Strategic Directions Stakeholder Summit held in the summer of 2016. Out of this meeting, a Steering Committee and a Writing Workgroup were formed. Each member of the Coalition named a representative to each group. The present authors each served on one or both groups. Two members of the Writing Workgroup were assigned to write each domain. Two of the current authors (MA and SW) were the writers for the domain covering spiritual, religious, and existential aspects of care. A project editor oversaw the work and drafts were shared among the two groups. Over the last two years consensus was reached among all involved

on the final wording. Finally, all member organizations of the Coalition endorsed the final document.

The document has now been widely disseminated to a wide range of organizations. It has been endorsed by more than 80 national organizations including major health care organizations including the American Cancer Society, American College of Surgeons, and American Nurses Association and chaplaincy groups including the APC, HCCN, Association for Clinical Pastoral Education, College of Pastoral Supervision and Psychotherapy, National Association of Catholic Chaplains, and Neshama Association of Jewish Chaplains. It was published on October 31, 2018 available for no-cost download or hard copy purchase at [www.nationalcoalitionhpc.org/ncp](http://www.nationalcoalitionhpc.org/ncp).

## WHAT DO THEY COVER?

The guidelines focus on some key concepts including:

- Palliative care is a person-and family-centered approach to care for people living with serious illness.
- Palliative care is inclusive of all people living with serious illness, regardless of setting, diagnosis, age, or prognosis.
- Palliative care is the responsibility of all clinicians and disciplines caring for people living with serious illness.

The guidelines have been periodically updated to reflect the growth and evolution of palliative care. Notable updates in the fourth edition from the previous guidelines include information and emphasis on the importance of: A comprehensive assessment of each person living with serious illness, including their needs and priority goals

- Assessment of families' and caregivers' needs for support and education.
- Coordination of care, especially as the person living with serious illness transitions from one place of care to another.
- Culturally inclusive care, specifically the need for all health care professionals to practice culturally respectful care.
- Communication among all stakeholders, including the palliative care team, the person living with serious illness and the family and other health care professionals and providers of community resources.

The new edition includes and expands on the information provided in the eight domains of palliative care identified in the previous editions:

1. **Structure and Processes of Care:** Outlines the composition of an interdisciplinary team, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Also, defines the

elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.

- What's new: Coordination and continuity of care are integrated into this domain as vital elements of palliative care that ensure the needs of the person living with serious illness are met wherever the person is receiving care and over time.
2. **Physical Aspects of Care:** Describes the palliative care assessment, care planning, and treatment of physical symptoms, emphasizing patient- and family-directed holistic care.
    - What's new: The importance of using validated tools to assess and manage pain and other symptoms, with an emphasis on maximizing functional independence as a key element of quality of life, and specific recommendations to help care for those with substance use disorder.
  3. **Psychological and Psychiatric Aspects of Care:** Focuses on the processes for systematically accessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.
    - What's new: Strengthens the role of the social worker and all palliative care clinicians regarding assessment and treatment.
  4. **Social Aspects of Care:** Outlines the palliative care approach to assessing and addressing patient and family social support needs.
    - What's new: Includes assessment of social supports, relationships, practical resources, and safety and appropriateness of the care environment
  5. **Spiritual, Religious, and Existential Aspects of Care:** Describes the spiritual, religious, and existential aspects of care, including the importance of screening for unmet needs.
    - What's new: Chaplains are the spiritual care specialists, but all health care professionals who care for people living with serious illness must assess and address the spiritual aspects of human experience.
  6. **Cultural Aspects of Care:** Explores the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement.
    - What's new: More focus on the influence of culture in serious illness, particularly in the case of a child or adolescent living with serious illness.
  7. **Care of the Patient Nearing the End of Life:** Focuses on the systems and situations that are common in the final days and hours of life.
    - What's new: The title change of this domain from "Care of the Patient *at* the End of Life" in the previous guidelines to "Care of the Patient *Nearing* the End of Life" emphasizes the needs of patients and their families in the final weeks and months of life. It includes an expanded section on bereavement, noting that all health care professionals must ensure the family has access to these services, even if hospice is not involved.
  8. **Ethical and Legal Aspects of Care:** Discusses advanced care planning, surrogate decision making, regulatory, and legal considerations and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.
    - What's new: Places extra emphasis on ensuring the patient's preferences are known and honored, not just assumed or based on direction from the surrogate.

Each of the eight domains also includes (in addition to specific guidelines):

- Clinical implications
- Operational implications
- Essential skills needed

- Key research evidence
- Practice examples
- Tools/resources
- Glossary
- Recommendations for integrating palliative care principles and best practices.

## SYSTEMATIC REVIEW

In the process of developing the new edition, it was decided that a systematic review of the literature should be done to accompany the guidelines. Additional grants were obtained from the Gordon and Betty Moore Foundation, the Gary and Mary West Foundation, The John A. Hartford Foundation, and the Stupski Foundation. The review was conducted by the Rand Evidence-based Practice Center with support from a Technical Expert Panel made up of leaders in the Coalition.

Systematic reviews follow a standardized and thorough approach to synthesize evidence, including searching multiple sources with comprehensive search strategies, appraising the risk of bias of individual studies, and assessing the study results independently from the original study authors. Newer systematic reviews apply universally accepted criteria to evaluate the quality of the evidence base.

Because the review is meant to inform the fourth edition of the guidelines, RAND limited the search to systematic reviews published since 2013, when the third edition was published. However, included systematic reviews may have reported on study data published well before 2013, thus encompassing a broad timeframe of available evidence.

Findings of the review suggest that more well-designed trials of commonly-used interventions in palliative care across populations are needed to bolster the evidence base in key areas, including of early/integrated palliative care, complementary, and alternative therapies (e.g., acupuncture, massage, meditation) for symptom management, life review/dignity therapy and other spiritual interventions, and advance care planning interventions such as patient-provider discussions and facilitated advance care planning.

The complete findings of the systematic review were published by the *Journal of Pain and Symptom Management* and available online October 31, 2018 (Ahluwalia et al., 2018).

## WHAT DOES THIS MEAN FOR CHAPLAINCY?

Palliative care has long been considered by many in chaplaincy to be in line with our overall philosophy of care. It is a scope of practice with

which chaplains have always felt at home but that has not always seemed to be valued by others. Many of the components of palliative care that receive new emphasis in this edition are in our scope of practice including the focus on serious illness, care for caregivers, cultural awareness, pediatrics, bereavement, and practice in community settings. A major contribution of these guidelines for chaplaincy is that these components that have often operated on the periphery of the chaplaincy scope of practice are now fully folded into what will be expected. The expectation that chaplains will practice and coordinate spiritual care across all inpatient and outpatient settings as a matter of best practice is an example. Thus, while all of these components of care have been part of chaplaincy practice under certain circumstances, these guidelines make them part of routine practice.

The guidelines also are an authoritative source that supports what chaplains claim to do and how chaplains have claimed to contribute. However, this edition includes support of contributions by a highly respected group of experts across the interdisciplinary spectrum. It is important to note that, at least by implication, the 80 organizations that endorse these guidelines endorse the claims for chaplaincy practice contained in it.

The stated Clinical Implications for Spiritual Care include:

- Spiritual care is an essential component of quality palliative care.
- Spiritual care services including screening, history, and assessment are performed on admission and regularly thereafter.
- Interventions using professional standards of practice are part of the basic provision of quality care available to all palliative patients.

Operational Implications for Spiritual Care include:

- Palliative care services include salaried professional chaplain team members and related programmatic expenses.
- Affiliation agreements with spiritual care departments in health systems, hospitals, or hospice programs can provide timely access to professional chaplain services.
- Additionally, partnerships with faith community leaders are encouraged and nurtured.

An additional contribution is the definition of “professional chaplain” in the Glossary that states:

The professional chaplain is master’s level prepared and has taken clinical chaplaincy training. Board Certification in chaplaincy is preferred. Certified chaplains may also specialize in palliative care and have specialized certification. The chaplain is the spiritual care specialist on the IDT and trained to address spiritual and religious concerns of all patients and caregiver regardless of their spiritual or religious beliefs and practices. The chaplain is also an emotional care generalist and interfaces closely with the social worker and other

mental health providers to provide psychosocial-spiritual care as a unified domain.

The guidelines also include practice examples that illustrate the various arrangements possible in practice.

- A large health system has recently expanded to include several outpatient clinics and hospitals across a broad geographic area. The health system has committed to integrating palliative care as a component of patient centered care. The system adapts the NCP Guidelines. Spiritual care is addressed for the increasingly diverse population served and care now includes spiritual assessment on all admissions incorporated in the electronic health record. All staff have been trained in spiritual care and the chaplaincy program is building relationships with community clergy.
- A pediatric oncology program adopts improved spiritual care as a goal for the next quarter, using the NCP Guidelines as a framework for their quality improvement plans. The .20 FTE chaplain assigned to this unit leads these efforts, including the development of strategies to improve the spiritual assessment of all children and their families and a focus on incorporating spiritual care in the plan of care. While resources are stretched in this setting, the team believes that the combined efforts of all the staff, including child psychology, art and music therapy, and child life specialists, can make a major improvement in spiritual care.
- A well-established hospice program has made significant strides in reaching an immigrant population from Eastern Europe and is now struggling with how best to honor their cultural practices and beliefs. Patients and families from this region have asked that spiritual care be provided only by their Imam without any involvement of the hospice chaplain. The hospice is looking for cultural representatives in the community who can help them understand the context of these requests. The chaplains have reached out to local Imams to develop relationships in support of mutual understanding and education.

Taken together, these clinical and operational implications along with the definition of professional chaplain and the case examples lay out the parameters for the presence and full integration on the palliative care team, which is to say the integration into the care of all of those with serious illnesses. While it is beyond the scope of this article, these guidelines have significant implications for chaplaincy education. Education in areas such as pediatrics, community engagement, and integrating with a team could be argued to be essential for any Board Certified Chaplain.

These new guidelines significantly change the landscape of professional health care chaplaincy in several significant ways. The degree of involvement of chaplains in the creation of these guidelines is unprecedented as is the degree of integration across all settings and patient populations. These guidelines firmly place professional chaplains as full participants in the execution of a major program for delivering health care.

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## CONFLICTS OF INTEREST

The authors have no financial or other conflicts of interest to report. Neither the authors nor their organizations benefited from or shared in any financial support for the project.

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