Clinical Practice Guidelines for Quality Palliative Care

4th edition

NATIONAL
CONSENSUS
PROJECT
FOR QUALITY PALLIATIVE CARE

NATIONAL COALITION
FOR HOSPICE AND
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Clinical Practice Guidelines for Quality Palliative Care, 4th edition

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For information, contact:
National Coalition for Hospice and Palliative Care
P.O. Box 29709
Richmond, VA 23242

http://www.nationalcoalitionhpc.org/

https://www.nationalcoalitionhpc.org/ncp

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A systematic review of the evidence for the NCP Guidelines, 4th edition, was conducted by the RAND Evidence-based Practice Center. The complete findings are published online in the Journal of Pain and Symptom Management (doi: 10.1016/j.jpainsymman.2018.09.008).

Foreword

Individuals who are seriously ill need care that is seamless across settings, can rapidly respond to needs and changes in health status, and is aligned with patient-family preferences and goals. Patients of all ages, living in all areas of the country, have unmet care needs that cause a burden on families and the US health care system.

Providing "crisis-care" to individuals with a **serious illness** whose ongoing care needs are poorly managed has resulted in increased health care spending that does not necessarily improve quality of life. Care of individuals with serious illness is often "marked by inadequate symptom control and low patient and family perceptions of the quality of care; and potentially discordant with personal goals and preferences."[1] Patients with serious illness and their family caregivers are seldom able to have their care needs reliably met, leading to symptom exacerbation crises and emergency department visits and/or repeated hospitalizations.[2]

In this document, 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 and Bollens-Lund, 2018).

Palliative Care

Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness. Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family.

Palliative care is:

- *Appropriate at any stage in a serious illness*, and it is beneficial when provided along with treatments of curative or life-prolonging intent.
- *Provided over time* to patients based on their needs and not their prognosis.
- *Offered in all care settings* and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care providers.
- *Focused on what is most important to the patient, family, and caregiver(s),* assessing their goals and preferences and determining how best to achieve them.
- *Interdisciplinary* to attend to the holistic care needs of the patient and their identified family and caregivers.

Palliative care principles and practices can be delivered by any clinician caring for the seriously ill, and in any setting. All clinicians are encouraged to acquire core skills and knowledge regarding palliative care and refer to palliative care specialists as needed. Analogous to the management of hypertension and heart disease by primary clinicians who may turn to cardiology specialists and clinical practice guidelines for consultation or management of more complex cases, specialist level palliative

Note: Words bolded in red are defined in the Glossary.

care is available for consultation, teaching, research, and care of the most complex patients living with a serious illness. Specialist level palliative care is delivered through an interdisciplinary team with the professional qualifications, training, and support needed to deliver optimal patient- and family-centered care.

Recognizing the changes to the practice of palliative care in all care settings, the **National Consensus Project for Quality Palliative Care** defines palliative care as follows:

> Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

In addition, specific definitions of palliative care are applicable depending on the audience and context within which the definition is used:

> The **2015 *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* report** defines palliative care as, "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."[3] The report explicitly states that care outcomes are optimized when palliative care begins early after the diagnosis of a serious illness, is delivered at the same time as curative or disease-modifying treatments, and is available in all settings where patients and families need care.[4]
>
> The **Centers for Medicare and Medicaid Services** defines palliative care as, "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."[5]
>
> The **Center to Advance Palliative Care** and the **American Cancer Society** developed a definition of palliative care (based on public opinion research), "Palliative care is specialized medical care for people with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

The Institute of Medicine (IOM) offers the following definitions (2015):

Specialty palliative care: *"Palliative care that is delivered by health care professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains."*

Primary palliative care (also known as generalist palliative care)*: "Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care."*

> Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment."[6]

Specialist palliative care provides an added layer of support towards maximizing patient and family quality of life during serious illness. Palliative care knowledge and skills, however, should be core competencies for **all** health professionals serving seriously ill patients and their families and caregivers.

Hospice

Hospice is a specific type of palliative care provided to individuals with a life expectancy measured in months, not years. Hospice teams provide patients and families with expert medical care, emotional, and spiritual support, focusing on improving patient and family quality of life.

To be eligible to receive hospice under the Medicare or Medicaid hospice benefit, adult patients must have a defined, time-limited prognosis (certified by two physicians as six months or less if the disease follows its usual course) and desire care focused on comfort, foregoing insurance coverage for further terminal disease-directed curative treatment efforts. The Patient Protection and Affordable Care Act of 2010 contained provisions allowing pediatric patients to receive disease-modifying treatment while also receiving hospice services.

Nearly 50% of Medicare decedents received hospice in 2016,[7] most of which was provided in community settings, primarily the patient's chosen residence, which includes home, nursing homes and other residential facilities, as well as skilled nursing facilities.[8] Hospice is also available to Medicaid recipients in most states and is covered as part of many commercial health plans.

History of the National Consensus Project's Guidelines

Seventeen years ago, leaders from across the country gathered to discuss the development of consensus guidelines for quality palliative care so that patients with serious illness who were not hospice-eligible could access palliative care. Representatives of hospice and palliative care organizations collaborated in the development of the first edition of the *National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines), which described core concepts and structures and processes necessary for quality palliative care, including eight domains of practice.

The first edition of the NCP Guidelines, published in 2004, presented a blueprint for excellence in the delivery of palliative care. For the first time outside of hospice, teams had a framework to guide the development of quality palliative care services. Since that time, palliative care has continued to grow and evolve, necessitating updated NCP Guidelines in 2009 and 2013. The second edition of the NCP Guidelines, published in 2009, reflected the tremendous growth and transformation in the field of hospice and palliative care, acknowledging the diverse array of models and approaches to care for this complex population. The third edition of the NCP Guidelines, published in 2013, emphasized continuity, consistency, and quality of care.

The NCP Guidelines, 4th edition, are organized into 8 domains:

Domain 1: Structure and Processes of Care

The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Domain 1 also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care.

Domain 2: Physical Aspects of Care

The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care.

Domain 3: Psychological and Psychiatric Aspects

The domain focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness.

Domain 4: Social Aspects of Care

Domain 4 outlines the palliative care approach to assessing and addressing patient and family social support needs.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.

Domain 6: Cultural Aspects of Care

The domain outlines 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.

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

This domain focuses on the symptoms and situations that are common in the final days and weeks of life.

Domain 8: Ethical and Legal Aspects of Care

Content includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.

NCP Guidelines, 4th edition

The goal of the 4th edition of the *National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines) is to improve access to quality palliative care for all people with serious illness regardless of setting, diagnosis, prognosis, or age. The NCP Guidelines are intended to encourage and guide health care organizations and clinicians **(including non-palliative care specialists)** across the care continuum to integrate palliative care principles and best practices into their routine assessment and care of all seriously ill patients. Also, the NCP Guidelines formalize and delineate **available** evidence-based processes and practices **as well as consensus recommendations** for the provision of safe and reliable high-quality palliative care for adults, children, and families with serious illness in all care settings.

Specifically, the purpose of the NCP Guidelines, 4th edition, is to promote access to quality palliative care, foster consistent standards and criteria, and encourage continuity of palliative care across settings. Because there is shared responsibility for delivery and quality of palliative care across health care settings and over time, the emphasis is on collaborative partnerships within and between all care providers to ensure access, quality, and continuity of palliative care.

A systematic review of the evidence for the NCP Guidelines, 4th edition, was conducted by the RAND Evidence-based Practice Center. The complete findings are published online in the Journal of Pain and Symptom Management (doi: 10.1016/j.jpainsymman.2018.09.008).

*The NCP Guidelines set **expectations for excellence** among clinicians treating patients with serious illness, rather than basic competence levels for professionals, teams, and organizations.*

Audience

This revision addresses best practices for both palliative care specialists, as well as all clinicians who care for people with serious illness. The expectation is that other clinicians caring for seriously ill patients will integrate palliative care competencies (such as safe and effective pain and symptom management, and expert communication skills) in their practice and palliative care specialists will provide expertise for those with the most complex needs.

The audience for the 4th edition of the NCP Guidelines includes specialty hospice and palliative care practitioners and teams, as well as health systems, primary care and specialist physician practices, cancer centers, dialysis units, long-term care facilities, assisted living facilities, Veterans Health Administration providers, home health and hospice agencies, prisons, and other care providers. The NCP Guidelines are also applicable to social service agencies, homeless shelters, and any other community organizations serving seriously ill individuals.

Most importantly, the goal of the NCP Guidelines is to improve the care that patients and families receive by defining and supporting access to high-quality palliative care in all care settings. All practitioners are encouraged to use the NCP Guidelines to strengthen knowledge and skills to better meet the needs of people living with serious illness. It is our hope that the care children and adults with serious illness, and their families, receive will meet or exceed the criteria in these guidelines.

Settings of Care

Since palliative care is not setting-specific, palliative care principles and practices are applicable throughout the course of a serious illness. Palliative care is available across and between care settings, thereby improving continuity and coordination of care and, as a consequence, decreasing expenses related to duplicative or non-beneficial interventions or waste.

While hospital-based palliative care and hospice are widely available in the United States, access to palliative care in other settings is often unavailable. Reliable access to palliative care in community-based settings is essential to the delivery of expert care and symptom management, as well as psychological, practical, and social support, helping patients and families remain safely in their care setting of choice.

New community-based palliative care models are meeting the needs of those with a serious illness who are neither hospitalized nor hospice-eligible, through provision of care in patient homes, physician offices/clinics, cancer centers, dialysis units, assisted and long-term care facilities, and other community settings. Community-based palliative care services are delivered by clinicians in primary care and specialty care practices (such as oncologists), as well as home-based medical practices, private companies, home health agencies, hospices, and health systems.

Introduction to the 4th edition

For a comprehensive overview of the Stakeholder Summit, read the National Consensus Project Stakeholder Strategic Directions Summit report available at https://www.nationalcoalitionhpc.org/ncp.

In January 2017, the Gordon and Betty Moore Foundation awarded a two-year grant to enable the National Coalition for Hospice and Palliative Care to convene a Stakeholder Summit and develop, disseminate, and implement the 4th edition of the *National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines).

This edition of the NCP Guidelines expands upon the content in the 3rd edition, specifically focusing on two key concepts:

- Palliative care is inclusive of **all people with serious illness, regardless of setting, diagnosis, prognosis, or age**. As a result, language specific to the care of neonates, children, and adolescents was emphasized throughout the NCP Guidelines.
- Timely consideration of palliative care is the responsibility of clinicians and disciplines caring for the seriously ill, including primary care practices, specialist care practices (eg, oncology or neurology), hospitalists, nursing home staff, and palliative care specialist teams such as hospice, hospital and community-based palliative care teams.

In addition, **key themes** were added to each domain:

- The elements of a **comprehensive assessment** are described
- **Family caregiver assessment**, support, and education are referenced in numerous domains
- The essential role of **care coordination**, especially during **care transitions**, is emphasized
- **Culturally inclusive** care is referenced in all the domains and expanded in the Cultural Aspects of Care domain
- **Communication** (within the palliative care team, with patients and families, with other clinicians, and with community resource providers) is a prerequisite for delivery of quality care for the seriously ill and is emphasized throughout

Other changes to the NCP Guidelines, 4th edition, include:

- An emphasis on **community-based** resources and community-based providers
- More attention to anticipatory, as well as post-death, **grief and bereavement**
- Emphasis on continuity of palliative care during **ongoing care** of patients regardless of whether they are followed by a specialist level palliative care team
- Reference to **key research evidence** (based on the findings from the systematic review)

To increase the usability of the document, each guideline is named for easy reference, all criteria are numbered, and the domains are reorganized to follow a temporal format. Domains 2-5 include the following guideline categories:

- **Global** – identifying overarching criteria, such as the composition of the interdisciplinary team

- **Screening and Assessment** – essential elements of screening and assessment
- **Treatment** – key considerations in palliative care treatment strategies
- **Ongoing Care** – responsibilities of providers to monitor and ensure access to patients and families over time

The following elements were added to each domain:

- **Introduction** – context for the domain
- **Operational Implications** – infrastructure elements needed to deliver quality care
- **Essential Palliative Care Skills Needed by All Clinicians** – palliative care principles, knowledge and skills that all clinicians can apply in caring for the seriously ill
- **Practice Examples** – how clinical teams can integrate the NCP Guidelines in diverse settings and patient populations
- **Glossary** – definitions of terms used in this document (see Appendix I)
- **Tools / Resources** – additional resources specific to each domain (see Appendix II)

Summary of Key Revisions in Each Domain

Domain 1: Structure and Processes of Care

Coordination of care is emphasized as an important element of care, especially when patients receive community-based palliative care. New content regarding the need for ongoing sustainability is included.

Domain 2: Physical Aspects of Care

Recognizing advances in the field, the NCP Guidelines highlight the importance of validated tools to assess and manage pain and other symptoms. The impact of functional status on quality of life is emphasized in the revised NCP Guidelines.

Domain 3: Psychological and Psychiatric Aspects

Domain 3 clarifies and strengthens the responsibilities of the social worker and all palliative care clinicians regarding the mental health assessment and treatment in all care settings, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care. Since community-based clinicians may not have adequate access to specialist level psychological and/or psychiatric care, the teams' responsibilities to patients and families is highlighted. Grief and bereavement are described separately to reflect the distinction between the two concepts; bereavement is now in Domain 7, which focuses on care nearing the end of life.

Domain 4: Social Aspects of Care

Domain 4 describes an assessment of social supports, relationships, practical resources, and safety and appropriateness of the care environment.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

This domain outlines the responsibility of all clinicians serving the seriously ill to assess and respond to spiritual care needs, emphasizing the need for training for spiritual care providers to care for patients and families. Flexible approaches to ensuring adequate spiritual support of patients and families are described.

Domain 6: Cultural Aspects of Care

Specific elements of a cultural assessment are outlined in Domain 6. The influence of culture within families is delineated, with specific attention to the role of the child or adolescent in treatment decisions. The conscious practice of cultural humility is emphasized.

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

The title of this domain was changed from "Care of the Patient at the End of Life" to reflect the importance of attending to the changing needs of patients and families in the final days and weeks of life. The guideline on bereavement is expanded, emphasizing the responsibility of all clinicians caring for the seriously ill to ensure bereavement services are offered, even when hospice is not involved in the patient's care.

Domain 8: Ethical and Legal Aspects of Care

Ethical principles are described and integrated into Domain 8 and a clear distinction is made that in all cases the surrogates are obligated to represent the patient's preferences, not the surrogates' preferences.

Systematic Review of Key Research Evidence

A systematic review was conducted, synthesizing evidence for each domain. The review included evidence published as of April 2018, was guided by 10 key questions, and was supported by a panel of technical experts. The review identified areas of strength in the literature, as well as many gaps, to support the NCP Guidelines domains. As with all clinical practice guidelines, evidence from research is combined with consensus of experts in the field to support recommendations for care. The NCP Guidelines Systematic Review provides direction for a future research agenda that will continue to build the evidence that palliative care improves the care of seriously ill patients and family members in all care settings.

The review protocol is publicly available at:
http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018100065.

The methods, literature flow, evidence tables, critical appraisal, and summary of findings and quality of evidence assessment are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Key Concepts / Definitions

The following definitions are provided as references when reviewing the NCP Guidelines. See the Glossary for a complete list of terminology. **Note: Words bolded in red throughout the NCP Guidelines are defined in the Glossary**.

- **Caregiver –** The term caregiver includes family or friends, or others, either paid or unpaid.

- **Clinician** – In the context of the NCP Guidelines, clinician refers to any health professional providing direct care to seriously ill persons and their families, whether primary care practitioners, specialist consultants, or specialist-level palliative care teams. While any clinician can apply palliative care principles and practices, specialist palliative care teams are interdisciplinary, and the team members have certification or specialty-level competency to provide specialist palliative care.

- **Family** – In palliative care, family is always defined by the patient and can include the family of origin (parents, siblings, children), family of choice (spouse, friends, neighbors), and caregivers.

- **Palliative care interdisciplinary team (IDT)** – Specialty palliative care interdisciplinary teams collaborate with other care providers to coordinate care. Depending on the care needs of each patient and family, the IDT can expand to include other clinicians and community service providers.

- **Patient** – Since some patients have cognitive and/or communication impairment or incapacity to make some decisions, references to "patient" in the NCP Guidelines refer to the patient or legal decision-maker.

- **Primary palliative care** – "Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care."[9]

- **Spirituality** – Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered care. It is defined as a dynamic and intrinsic aspect of humanity through which individuals seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.[10] Reference to spiritual care within the NCP Guidelines also refers to religious and/or existential needs depending on the context.

Using the NCP Guidelines

The NCP Guidelines delineate palliative care principles that clinicians should integrate into the care of seriously ill patients and their families. New, emerging, and established specialist palliative care teams can use the NCP Guidelines to expand services to new patient populations or care settings, form new partnerships, and improve the care provided to patients and families. Primary palliative care providers can integrate the knowledge and skills within the criteria and in the **Essential Palliative Care Skills Needed by All Clinicians** section of each domain.

Read the National Consensus Project Stakeholder Strategic Directions Summit report for examples of ways that the 3rd edition of the NCP Guidelines was used by a range of stakeholders.

The NCP Guidelines can be utilized to transform the care of individual patients and families, as well as populations, design new palliative care programs, enhance or expand exisiting programs, develop and refine educational programs, measure the effectiveness of and improve care, develop payer contracts, shape research, and prepare for health care accreditation.

Individual professionals, teams, and organizations will benefit from reading this entire document. While it may be tempting for professionals to focus on the guideline that aligns most closely with their discipline, each Domain reflects a **team-based** approach to palliative care.

Conclusion

This revision of the *Clinical Practice Guidelines for Quality Palliative Care, 3rd edition*, was driven by the innovation and the rapid growth of palliative care as an essential element of high-value care for high-need, seriously ill populations. The NCP Guidelines are intended to help all clinicians and care settings improve access to all patients in need of palliative care, from the point of diagnosis throughout the illness or eventual death of the patient.

As in other editions, the 4th edition of the NCP Guidelines sets a high bar for quality for all professionals serving patients of all ages in all care settings. Those seeking to develop or expand palliative care can integrate the NCP Guidelines into all aspects of their organization and service design.

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Co-Chairs

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Writer/Editor

Kathy Brandt, MS

Steering Committee

Martha L. Twaddle, MD, FACP, FAAHPM, HMDC, *Co-Chair*
American Academy of Hospice and Palliative Medicine

Betty Ferrell, PhD, MA, FAAN, FPCN, *Co-Chair*
Hospice and Palliative Nurses Association

Mindy J. Fain, MD
American Academy of Home Care Medicine

Dianne H. Timmering, MBA, MFA, CNA
American Health Care Association

Elizabeth Ciemins, PhD, MPH, MA
American Medical Group Association

Margie Atkinson, DMin, BCC
Association of Professional Chaplains

Diane E. Meier, MD, FACP, FAAHPM
Center to Advance Palliative Care

Rev. George Handzo, BCC, CSBB
HealthCare Chaplaincy Network

G. Lawrence Atkins, PhD
Long-Term Quality Alliance

Andrea Devoti, MSN, MBA, RN
National Association for Home Care and Hospice

John Mastrojohn III, MSN, MBA, RN
National Hospice and Palliative Care Organization

Nathan Goldstein, MD
National Palliative Care Research Center

Sarah Friebert, MD, FAAP, FAAHPM
National Pediatric Hospice and Palliative Care Collaborative

Karen Johnson, MS
National Quality Forum

Judy Knudson, MPAS, PA-C, BSN
Physician Assistants in Hospice and Palliative Medicine

Tracy A. Schroepfer, PhD, MSW
Social Work Hospice & Palliative Care Network

Kimberly S. Johnson, MD, MHS
Subject Matter Expert: Diversity/Geriatrics

Lee Ellington, PhD
Subject Matter Expert: Patient/Family/Provider Communication

Writing Workgroup

Stacie Sinclair, MPP, LBSW, *Co-Chair*
Center to Advance Palliative Care

Tracy Schroepfer, PhD, MSW, *Co-Chair*
Social Work Hospice & Palliative Care Network

Joe Rotella, MD, MBA, HMDC, FAAHPM
American Academy of Hospice and Palliative Medicine

Elizabeth McCormick, MD
American Academy of Home Care Medicine

Gail Sheridan, RN
American Health Care Association

David Introcaso, PhD
American Medical Group Association

Margie Atkinson, DMin, BCC
Association of Professional Chaplains

Rev. Susan K. Wintz, MDiv, BCC
HealthCare Chaplaincy Network

Denise Stahl, MSN, ACHPN, FPCN
Hospice and Palliative Nurses Association

G. Lawrence Atkins, PhD
Long-Term Quality Alliance

John McIlvaine
National Association for Home Care and Hospice

Judi Lund Person, MPH, CHC
National Hospice and Palliative Care Organization

Nathan Goldstein, MD
National Palliative Care Research Center

Kathie Kobler, PhD, APRN, PCNS-BC, CHPPN, FPCN
National Pediatric Hospice and Palliative Care Collaborative

Karen Johnson, MS
National Quality Forum

Rich Lamkin, MPH, MPAS, PA-C
Physician Assistants in Hospice and Palliative Medicine

Conflicts of Interest

All members of the Steering Committee and Writing Workgroup completed disclosure forms, which requires disclosure of financial and other interests, including relationships with commercial entities that are reasonably likely to experience direct regulatory or commercial impact as a result of promulgation of the guidelines. Categories for disclosure include employment; leadership; stock or other ownership; honoraria; consulting or advisory role; speaker's bureau; research funding; patents, royalties, other intellectual property; expert testimony; travel, accommodations, expenses; and other relationships. The members of the Writing Workgroup and Steering Committee did not disclose any relationships constituting a conflict of interest.

National Coalition for Hospice and Palliative Care

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NCP Staff and Consultants

Amy Melnick, MPA
Executive Director, National Coalition for Hospice and Palliative Care

Gwynn B. Sullivan, MSN
Project Director, National Consensus Project

Cozzie M. King
Manager, National Consensus Project

Vivian J. Miller, LMSW
Research Assistant, National Consensus Project

Systematic Review

The systematic literature review was conducted by the Evidence-based Practice Center (EPC) located at RAND (Research team: Ahluwalia S, Chen C, Raaen L, Motala A, Walling A, Chamberlin M, O'Hanlon C, Cohen C, Larkin J, & Hempel S.)

The technical expert panel (TEP) supporting the systematic review were:

- Betty Ferrell, PhD, MA, FAAN, FPCN (Co-Chair, NCP Steering Committee)
- Nathan Goldstein, MD (Member, NCP Steering Committee and Writing Workgroup)
- Tammy Kang, MD (Chair, National Pediatric Hospice and Palliative Care Collaborative)
- Amy Kelley, MD, MSHS (Co-Director, Serious Illness Quality Alignment Hub)
- Diane Meier, MD, FACP, FAAHPM (President, National Coalition for Hospice and Palliative Care)
- Tracy Schroepfer, PhD, MSW, MA (Co-Chair, NCP Writing Workgroup)

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Endnotes

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Domain 1: Structure and Processes of Care

Palliative care principles and practices can be integrated into any health care setting, delivered by all **clinicians** and supported by palliative care specialists who are part of an **interdisciplinary team** (IDT) with the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Palliative care begins with a comprehensive assessment and emphasizes patient and **family** engagement, **communication**, **care coordination**, and continuity of care across health care settings.

Guideline 1.1 Interdisciplinary Team

Since palliative care is holistic in nature, it is provided by a team of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, chaplains, and others based on need. The palliative care team works with other clinicians and community service providers supporting continuity of care throughout the illness trajectory and across all settings, especially during transitions of care. Depending on care setting and patient population, IDT members may be certified **palliative care specialists** in their discipline and/or have additional training in palliative care. Primary care and other clinicians work with interdisciplinary colleagues to integrate palliative care into routine practice.

Criteria:

1.1.1 The IDT provides care focused on individual physical, functional, psychological, social, spiritual, and cultural needs.

1.1.2 The IDT encourages all team members to maximize their professional skills for the benefit of patients and families.

   a. Physicians focus on the illness trajectory, prognosis, and medical treatments, making patient visits or providing supervision in collaboration with advanced practice registered nurses or physician assistants (see Domain 2: Physical Aspects of Care).

   b. Nurses provide direct patient care, serving as patient advocate, care coordinator, and educator. Nurses are at the center of the immediate assessment and reassessment of patient needs (see Domain 2: Physical Aspects of Care).

   c. **Advanced practice providers** (physician assistants and advanced practice registered nurses) expand the capacity to deliver complex care and provide direct care (see Domain 2: Physical Aspects of Care).

   d. Social workers attend to family dynamics, assess and support coping mechanisms and social determinants of health, identify and facilitate access to resources, and mediate conflicts (see Domain 3: Psychological and Psychiatric Aspects of Care and Domain 4: Social Aspects of Care).

   e. Chaplains, as the spiritual care specialists, assess and address spiritual issues and help to facilitate continuity with the patient's faith community as requested (see Domain 5: Spiritual, Religious, and Existential Aspects of Care).

Note: Words bolded in red are defined in the Glossary.

f. Clinical pharmacists optimize medication management through a thorough review of the patient's medications to identify therapies to further palliate symptoms, resolve or prevent potential drug-related toxicities, and recommend dose adjustment and deprescribing where appropriate.

1.1.3 The IDT may also include other professionals with credentials, experience, and skills to meet the needs of the patient and family, including: mental health professionals, child life specialists, nursing assistants, nutritionists, respiratory therapists, occupational therapists, physical therapists, speech and language pathologists, massage, art, and music therapists, community health workers, paramedics, emergency medical technicians, psychologists, psychiatric-mental health advanced practice registered nurses, case managers, traditional medicine practitioners, and volunteers.

1.1.4 The IDT facilitates the implementation and ongoing refinement of the palliative **care plan** in communication with all care providers to support patient and family goals.

1.1.5 The IDT provides **developmentally appropriate** and culturally sensitive care to patients and families.

1.1.6 The team meets regularly to discuss patient care, IDT functioning, and operational details essential to the provision of quality palliative care. The frequency of IDT meetings is based on the needs of the population served, the care setting(s), and service model.

1.1.7 The patient and family have access to palliative care staff 24 hours a day, seven days a week by phone or telehealth applications.

1.1.8 The IDT accesses and ensures continuity with community services for families caring for neonates, children, or adults with a serious illness.

1.1.9 Policies and procedures are in place for prioritizing and promptly responding to referrals and ongoing patient and family care needs.

1.1.10 For programs with volunteers, policies and procedures are in place to guide volunteer services including recruitment, screening, training, role clarification, support, supervision, and performance evaluation.

1.1.11 A palliative care specialty team includes a certified palliative care specialist. The setting of care or reimbursement may further dictate which clinician must be certified.

Guideline 1.2 Comprehensive Palliative Care Assessment

An interdisciplinary **comprehensive assessment** of the patient and family forms the basis for the development of an individualized patient and family palliative care plan.

Criteria:

1.2.1 An initial comprehensive assessment is completed as soon after the referral as is reasonably possible.

1.2.2 Each member of the IDT contributes to a comprehensive assessment as soon as reasonably possible, depending on the urgency of patient needs.

1.2.3 The initial assessment includes conversations with the patient, **family caregivers**, clinicians, and others according to the patient's preferences.

1.2.4 The initial assessment is conducted in person by one or more IDT members, depending on the needs and concerns of the patient, is documented, and includes:

a. Patient and family understanding of the serious illness, goals of care, treatment preferences, and a review of signed advance directives, if available

b. A determination of **decision-making capacity** or identification of the person with legal decision-making authority

c. A physical examination including identification of current symptoms and functional status

d. A thorough review of medical records and relevant laboratory and diagnostic test results

e. A review of the medical history, therapies, recommended treatments, and prognosis

f. The identification of comorbid medical, cognitive, and psychiatric disorders

g. A medication reconciliation, including over-the-counter medications

h. Social determinants of health, including financial vulnerability, housing, nutrition, and safety

i. Social and cultural factors and caregiving support, including caregiver willingness and capacity to meet patient needs

j. Patient and family emotional and spiritual concerns, including previous exposure to trauma

k. The ability of the patient, family, and care providers to communicate with one another effectively, including considerations of language, literacy, hearing, and cultural norms

l. Patient and family needs related to **anticipatory grief**, loss, and bereavement, including assessment of family risk for prolonged grief disorder

1.2.5 The team identifies and documents if the adult patient or a family member served in the military and whether the patient or family member may be eligible for VA benefits.

1.2.6 For pediatric patients, the team ascertains the developmental status and children or teens' understanding of their disease, as well as parental preferences for their child's care at the time of initial consultation. This is revisited throughout the trajectory of care.

1.2.7 The IDT performs subsequent assessments at regularly defined intervals and whenever the patient's status significantly changes, new problems are identified, or the patient experiences a transition in health care setting or provider.

Guideline 1.3 Palliative Care Plan

In collaboration with the patient and family, the IDT develops, implements, and updates the care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual needs.

Criteria:

1.3.1 The patient's preferences, needs, values, expectations, and goals, as well as the family's concerns, provide the foundation and framework for the plan of care.

1.3.2 The IDT collaboratively discusses and documents patient status, patient and family needs, treatment options, and symptom management.

1.3.3 The IDT develops, implements, and coordinates the care plan in collaboration with the patient and family, other clinicians, and community providers, when indicated and possible.

1.3.4 The care plan is always accessible to the patient, IDT, and other involved clinicians and, with the patient's consent, is shared with family, caregivers, and community providers.

1.3.5 The care plan is updated and reviewed at regular intervals and when the patient experiences a significant change in status; changes are based on the evolving needs of the patient and family, with recognition of complex, competing, and shifting priorities in goals of care.

1.3.6 When appropriate, the patient is referred to **hospice**.

1.3.7 The IDT facilitates the implementation of the plan of care to ensure:

  a. The patient and family have access to medications and treatments

  b. New medications, medical equipment, tests, and therapies are authorized by payers

  c. The patient and family can safely and effectively manage and administer medications

1.3.8 The IDT provides patient and family with anticipatory guidance regarding disease progression and management strategies to maximize quality of life for both the patient and family.

1.3.9 Treatment and care setting alternatives are documented and communicated to the patient and family to promote informed **shared decision-making**.

1.3.10 Treatment recommendations are based on goals of care, assessment of risk and benefit, and best evidence. Re-evaluation of treatment efficacy, patient-family goals, and choices are documented.

1.3.11 The IDT makes referrals and assists in the integration of the additional providers to support the plan of care.

1.3.12 When serving as consultants, palliative care specialists contribute to the care plan developed by the referring provider and overtly clarify their ongoing role in care.

1.3.13 When working with patients with cognitive and/or communication impairment or incapacity, the IDT:

  a. Identifies the availability and willingness of a surrogate decision-maker

  b. Supports the surrogate with education related to signs and symptoms of psychological and psychiatric distress, and techniques to help alleviate distress

  c. Supports health care decision-making in a manner that is patient-focused and goal-concordant using principles of substituted judgment and best interest

Guideline 1.4 Continuity of Palliative Care

The IDT has defined processes to ensure access, quality, and continuity of care, especially during transitions of care.

Criteria:

1.4.1 The IDT has defined processes for identifying patients with palliative care needs specific to the population(s) served.

1.4.2 Patients and families receive an explanation of the palliative care services and, depending upon the setting of care, a written consent for services is signed by the patient and/or **health care surrogate**.

1.4.3 When specialist palliative care is discontinued:

- a. The IDT documents their assessment and recommendations for ongoing care and shares them with the patient and family, as well as involved clinicians
- b. If a patient and family transitions to a care setting where palliative care is unavailable, the IDT reviews the ongoing care plan with the patient and family, as well as the clinicians who will continue or assume care oversight

1.4.4 Upon the death of the patient, the IDT provides grief support to the family and ensures access to long-term **bereavement** support for family members (see Domain 7: Care of the Patient Nearing the End of Life).

1.4.5 The IDT ensures that care providers are informed of the patient's death and plans for bereavement support, as indicated.

Guideline 1.5 Care Settings

Palliative care is provided in any care setting, including private residences, assisted living facilities, rehabilitation, skilled and intermediate care facilities, acute and long-term care hospitals, clinics, hospice residences, correctional facilities, and homeless shelters.

Criteria:

1.5.1 Care is provided in the setting preferred by the patient and family, if feasible, or the IDT helps the patient and family select an alternative setting.

1.5.2 The IDT consults and collaborates with the clinicians and other professionals involved in patient care to maximize the patient's safety and sense of control.

1.5.3 Providers in all settings address the unique needs of children, whether they are patients, family members, or visitors.

1.5.4 Palliative care facilitates visits with family, friends, and pets in accordance with patient and family preferences and policies within the care setting.

1.5.5 The IDT shares information and resources regarding palliative care with clinicians and other professionals involved in the patient's plan of care.

Guideline 1.6 Interdisciplinary Team Education

Education, training, and professional development are available to the IDT.

Criteria:

1.6.1 All members of the IDT have appropriate levels of education, including training in palliative care.

  a. Advanced practice registered nurses, physicians, physician assistants, pharmacists, and physical, occupational or speech therapists have relevant graduate degrees and are licensed in their respective disciplines.

  b. Nurses have appropriate educational preparation to their license and scope of practice.

  c. Social workers have relevant bachelor's and/or graduate degrees and meet state licensing requirements.

  d. Spiritual care providers have relevant master's degrees and are ideally board certified as a professional chaplain.

  e. Nursing assistants and personal care attendants meet state licensing requirements.

  f. Volunteers, when utilized, must have training relevant to their role.

1.6.2 The IDT encourages discipline-specific credentialing and certification, or other recognition of competence including specialized training.

1.6.3 Education, resources, and support are available to enhance IDT communication and collaboration.

1.6.4 Palliative care staff participate in initial orientation and continuing education focused on the NCP Guidelines and document their participation accordingly.

1.6.5 All palliative care clinicians receive training regarding the use of opioids, including:

  a. Safe and appropriate use of opioids

  b. Risk assessment for opioid substance use disorder

  c. Monitoring for signs of opioid abuse and diversion

  d. Managing pain for patients at risk for substance abuse

  e. Safe disposal of opioids in home and community settings

Guideline 1.7 Coordination of Care and Care Transitions

Care is coordinated and characterized as the right care at the right time throughout the course of an individual's disease(s) or condition. The IDT recognizes that transitions of care occur within care settings, between care settings, and between care providers. **Care transitions** are anticipated, planned, and coordinated to ensure patient goals are achieved.

Criteria:

1.7.1 IDT members understand how to effectively facilitate communication, care coordination, and transitions of care, sharing information including procedures that safeguard patient and family privacy.

1.7.2 The IDT establishes policies for optimal communication, including the sharing of documentation with everyone involved in the plan of care.

1.7.3 Before, during, and after transitions of care, the IDT coordinates with the patient and family and other providers to ensure continuity of care.

1.7.4 A timely assessment is completed after each care transition.

Guideline 1.8 Emotional Support to the Interdisciplinary Team

Providing palliative care to patients with a serious illness and their families has an emotional impact, therefore the IDT creates an environment of resilience, self-care, and mutual support.

Criteria:

1.8.1 The program assesses staff for distress and grief.

1.8.2 Administrative staff, IDT, and volunteers receive emotional support provided free from blame or stigma to alleviate the stress of caring for patients and families.

1.8.3 The IDT implements interventions to promote staff support and sustainability, such as opportunities to discuss the impact of providing palliative care.

1.8.4 Workload and workflow are structured to foster professional engagement and maximize time spent on activities that improve patient and family outcomes and staff wellness.

Guideline 1.9 Continuous Quality Improvement

In its commitment to **continuous quality improvement** (CQI), the IDT develops, implements, and maintains a data-driven process focused on patient- and family-centered outcomes using established quality improvement methodologies.

Criteria:

1.9.1 The program measures and improves quality by systematically collecting and analyzing data on care processes and outcomes specific to the patient population and organization's capacity, setting improvement targets, and planning and implementing change. This cycle is repeated in an iterative and ongoing fashion until it achieves sustained improvement.

1.9.2 The IDT considers the six domains of health care quality as defined in 2001 by the Institute of Medicine (safe, effective, patient-centered, timely, efficient and equitable)[1] in the design of its CQI program.

1.9.3 The IDT identifies care coordination measures and integrates these into CQI initiatives.

1.9.4 To the extent possible, the IDT uses assessment instruments, quality measures, and experience of care surveys that are validated, clinically relevant, and cross-cutting across settings or populations.

1.9.5 Patients, families, clinicians, and other partners participate in the evaluation of the IDT.

1.9.6 The IDT participates in quality reporting and accountability programs, as required or necessary to maintain licensure or accreditation.

Guideline 1.10 Stability, Sustainability, and Growth

Recognizing limitations in reimbursement for interdisciplinary palliative care, the IDT endeavors to secure funding for long-term sustainability and growth.

Criteria:

1.10.1 A community needs assessment is conducted to identify populations in need of palliative care, determine if demand and resources are sufficient to support a sustainable palliative care program model, design services specific to the target population(s), and identify partners.

1.10.2 Based on the needs assessment, a business plan with anticipated revenue and expenses is developed to ensure continuity of service to patients and families.

1.10.3 When launching a new program, key performance metrics are agreed on in advance to define when a program is meeting its goals.

1.10.4 The IDT develops strategic plans to prepare for changes in the target population and market forces, as well as other opportunities or threats that may affect the sustainability and growth of the program.

Clinical and Operational Implications

Clinical Implications

Across patient populations and care settings from diagnosis to end of life, palliative care is shown to prevent and relieve suffering and optimize quality of life for patients and families. Its foundation is a well-trained and well-supported IDT that performs comprehensive assessments and develops and implements palliative care plans in coordination with the patient, family, and other health care and community providers. Palliative care is delivered in a safe environment with respect for patient and family values, culture, preferences, and goals.

Operational Implications

The IDT provides consistent patient- and family-centered services, collaborates with partner organizations to facilitate care coordination, fosters a positive organizational culture, strives for continuous quality improvement and financial sustainability, and grows to address the needs of the populations it serves.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians and staff working in all care settings benefit from an understanding of the value of palliative care, as well as an overview of palliative care principles and practices. Clinicians caring for the seriously ill have sufficient training and experience to complete palliative assessments and address common sources of suffering. The palliative assessment addresses the essential elements of the domains of palliative care yet may not be as in-depth as the assessment a palliative care team would provide.

Key Research Evidence

The systematic review addressed two key questions: KQ1a) *What is the effect of interdisciplinary team care on patient and family/caregiver outcomes*; and KQ1b) *What is the impact of palliative care interventions to improve continuity and coordination of care on patient and family/caregiver outcomes?* Thirteen systematic reviews were identified pertaining to KQ1a and 18 pertaining to KQ1b. The evidence tables in the systematic review describe the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D1-A

A **Federally Qualified Health Center** recognizes that its aging population will benefit from the integration of palliative care into its care model. The leadership of the organization accesses training in palliative care for the nurse care navigators and two express interest in pursuing advanced certification in hospice and palliative care to serve as "champions" within the health center. The navigators traditionally assist patients with coordinating services and ensuring appointments with specialty providers, as well as primary care follow-up. Each navigator is the primary contact and liaison between patient and providers, thus ensuring that the patients' needs are met. With enhanced palliative care skills, navigators learn to screen for unmet needs in all the domains of care in the NCP Guidelines and then facilitate assessments and access to support as indicated. The navigators serve as contacts for hospital-based palliative care programs to enhance coordination of care post-discharge. They also have relationships with community home health and hospice programs to facilitate referrals and care coordination to traditional home health and hospice services, as well as home-based palliative care.

Practice Example D1-B

Staff at a **community hospital** identify a trend in after hours and weekend utilization of the emergency department (ED). A significant proportion of patients they see are seriously ill children with symptom issues following a hospitalization at the pediatric hospital, which is 30 miles away. The local hospice has a large home-based pediatric palliative and hospice program, with just one board-certified hospice and palliative medicine pediatrician. The hospital's pediatric service partners with a large community pediatric practice and the hospice pediatric physician, to implement a collaborative quality improvement initiative. Outcomes include staff education for hospital ED personnel, the development of decision-support tools for symptom management, processes to clarify after-hours access to specialty palliative care, and a community resources guide specifically for families with seriously ill children.

Practice Example D1-C

A small **rural hospital** with limited resources and no formal palliative care services has an increasingly aging population. It has a long relationship with a community hospice partner, providing home-based palliative care, and two local skilled nursing facilities that provide rehabilitation. These three entities collaborate to improve post-acute care for their community by providing staff education, which includes formal training in communication skills and goals of care discussions for their staff. They evaluate, refine, and formalize their communication and referral processes between the entities. This collaboration leads to the formation of a Palliative Care Steering Committee with representatives from all the entities, including the hospital's home health department. Together, they identify and codify all the community resources available that would benefit their seriously ill patient population and compile a resource guide. The hospice hires an advanced practice registered nurse with advanced training in palliative care and the entities collaborate to form an interdisciplinary team (IDT) for palliative care which includes: the social worker from the nursing home, the hospital chaplain, and a hospitalist/emergency department physician. As a result of this collaboration and regular discussions by the palliative care IDT, they demonstrate improvement in their net promoter scores (which indicates the likelihood to recommend the program as a measure of patient satisfaction with care), increased community volunteerism, and decreased hospital re-admissions and non-beneficial emergency department visits for their sickest patients. The hospitalist also becomes a hospice medical director, furthering collaboration and continuity.

Practice Example D1-D

A large **academic medical center** has operated an inpatient palliative care service for 10 years. In the strategic plan, the hospital leadership commits to the integration and growth of palliative care into the ambulatory specialty clinics, as well as home-based services. Phase one implementation includes embedding palliative care physicians and advanced practice providers into the oncology clinic several days a week. The cancer center and palliative care service share the expenses of an outpatient palliative care social worker. Phase two includes embedding palliative care into the pulmonary and heart failure clinics, including the integration of palliative advanced practice registered nurses, clinical nurse specialists, and physician assistants for both clinic and home-based visits. The inpatient palliative care team meeting expands to include representatives from home health, physical therapy, and the community hospice program. The entire team attends the first part of the meeting, which focuses on inpatients, and a subsection of the team continues the team meeting to discuss care planning for outpatients.

Practice Example D1-E

A **Department of Veterans Affairs (VA) Healthcare System** serves an increasingly diverse and aging population of patients, many with serious illness and co-morbid psychological illnesses. The VA Healthcare System provides care to Veterans who drive hundreds of miles to receive care. The VA Healthcare System has a strong palliative care service in their hospital and regional clinics and uses triggers based on routine palliative care assessments in its electronic medical record to prompt referrals to palliative care specialty services. The local VA hospital has strong relationships with hospices and palliative care programs in the communities where Veterans live so that if a patient wants to receive care at home, the local hospice or palliative care program can continue the care plan started by the VA, coordinating care on an ongoing basis.

Practice Example D1-F

A non-profit **community hospice** develops a palliative care service that is well received in the community, but struggles to sustain the program financially. Advanced practice registered nurses providing palliative care work with their hospice colleagues for interdisciplinary input, but express a need for greater IDT support and expertise for non-hospice patients. Internal tensions and role confusion hurt morale. Hospice medical directors feel they are stretched too thin to oversee both palliative care and hospice teams. The hospice clinical leadership approaches the hospital-based palliative care practice regarding a possible collaboration to serve seriously ill patients. The teams organize a pilot of an advanced practice registered nurse based post-acute palliative care program for patients with advanced heart failure in an effort to improve coordination, reduce readmissions, and increase timely referral to palliative care. The pilot includes education from the cardiologists on the progression and treatment of advanced heart failure and communication skills practice for all heart failure and palliative care team members with specific attention to discussions on use of cardiac technology (eg, left ventricular assist device, automated implantable cardioverter defibrillators). The teams create procedures for identifying eligible patients, referrals, coverage and communication, and choice of quality metrics for regular review. Monthly team meetings focus on collaborative care planning and analysis of the metrics of the pilot, which demonstrate improvement in patient and family satisfaction, confidence in their care, time spent at home, and earlier hospice utilization for eligible patients. Hospitalizations, readmissions, and emergency department utilization decrease by over 50 percent. The hospital agrees to a contract with hospice to provide post-acute care for heart-failure patients and initiates a separate pilot for pulmonary disease.

Practice Example D1-G

A **free-standing hospice** identifies a need to provide community-based palliative care services. The hospice utilizes the NCP Guidelines to develop the program structure and processes. One of the hospice medical directors oversees the program. An advanced practice registered nurse, registered nurse, social worker, and chaplain utilize the comprehensive assessment to develop a care plan, which guides patient and family care. The team utilizes evidence-based tools that promote patient and family self-report and self-management, including the Edmonton Symptom Assessment System - revised. The electronic health record includes documentation tools to support health care team communication, trending of clinical information, and data extraction for continuous quality improvement. Clinical, operational, financial, and patient and family experience of care metrics are reviewed on a monthly, quarterly, and annual basis and shared with the board members and other stakeholders to promote program integrity and sustainability. The program demonstrates significant reductions in pain and dyspnea within 24 to 72 hours of initial consult, almost 100 percent completion of advance directives, frequent use of Physician Orders for Life Sustaining Treatment (POLST) medical orders using the Appropriate POLST Form Use Policy, significant reductions in utilization of the emergency room and hospitalizations, significant reductions in the total cost of care, and patient experience score ratings consistently ranked as "very satisfied."

Endnotes

1 *Crossing the quality chasm a new health system for the 21st century*. (2001). Washington: National Acad. Press. http://www.nationalacademies.org/hmd/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx. Accessed November 7, 2017.

Domain 2: Physical Aspects of Care

Physical care of seriously ill patients begins with an understanding of the patient goals in the context of their physical, functional, emotional, and spiritual well-being. The assessment and care plan focus on relieving symptoms and improving or maintaining functional status and quality of life. The management of symptoms encompasses pharmacological, non-pharmacological, interventional, behavioral, and complementary treatments. Physical care, acute and chronic symptom management across all care settings is accomplished through communication, collaboration, and coordination between all professionals involved in the patients' care, including primary and specialty care providers.

Guideline 2.1 Global

The **palliative care interdisciplinary team** (IDT) endeavors to relieve suffering and improve quality of life, as defined by the patient and family, through the safe and timely reduction of the physical symptoms and functional impairment associated with serious illness.

Criteria:

2.1.1 The goal of symptom management is to improve physical well-being, functionality, and quality of life to a level acceptable to the patient, or to the health care surrogate if the patient is unable to report distress.

2.1.2 The symptoms associated with serious illness and treatments are anticipated and prevented.

2.1.3 The IDT recognizes that culture can influence the approach to illness, reporting of symptoms, preferences around treatment and decision-making process.

2.1.4 Effective symptom management requires attention to the physical, emotional, spiritual, and cultural factors, as well as the **social determinants of health** that contribute to the **total pain** and suffering associated with serious illness.

2.1.5 Symptom management requires an IDT, including access to professionals with specialist-level skill in symptom control for all types of serious illnesses.

2.1.6 Palliative care clinicians receive training on symptom management, including:

- a. Safe and appropriate use of opioids
- b. Risk assessment for opioid substance use disorder
- c. Monitoring for signs of opioid abuse and diversion
- d. Managing pain for patients at risk for substance abuse

2.1.7 The IDT has training and awareness of applicable policies and protocols for opioid management.

Note: Words bolded in red are defined in the Glossary.

Guideline 2.2 Screening and Assessment

The IDT assesses physical symptoms and their impact on well-being, quality of life, and functional status.

Criteria:

2.2.1 Assessments are conducted in the language preferred by the patient or family, using a professional medical interpreter (see Domain 6: Cultural Aspects of Care).

2.2.2 Attention is given to assessing the onset, quality, severity, provoking and relieving factors, response to prior treatment, level of burden, impact on functionality and quality of life, and meaning of distressing symptoms, as well as the patient's goals of care.

2.2.3 The IDT utilizes validated symptom and functional assessment tools, treatment policies, standards, and guidelines appropriate to the care of neonates, children, adolescents, and adults with serious illnesses.

2.2.4 The IDT conducts and regularly documents ongoing assessments of pain, other physical symptoms, functional status, symptom distress, and quality of life. After treatment is initiated, the IDT performs a timely reassessment to ascertain the effectiveness of the treatment.

2.2.5 There is attention to symptom assessment in patients with communication challenges due to delirium, **cognitive impairment**, developmental capacity, or mechanical interference of voice due to intubation, tracheostomy, injury, or disease processes.

2.2.6 When controlled substances are prescribed, the risk of diversion and substance use disorder are assessed.

2.2.7 The IDT assesses patient and/or caregiver cognitive and physical ability to manage medications and meet caregiving needs.

Guideline 2.3 Treatment

Interdisciplinary care plans to address physical symptoms, maximize functional status, and enhance quality of life are developed in the context of the patient's goals of care, disease, prognosis, functional limitations, culture, and care setting. An essential component of palliative care is ongoing management of physical symptoms, anticipating changes in health status, and monitoring of potential risk factors associated with the disease and side effects due to treatment regimens.

Criteria:

2.3.1 The IDT encourages and facilitates active involvement of patients and caregivers in developing the plan of care and managing physical symptoms. Patients and families are encouraged and given frequent opportunities to ask questions, seek support, and communicate changes in status including worsening symptoms and treatment-associated side effects.

2.3.2 Treatment of distressing symptoms and side effects are evidence-based and include the spectrum of pharmacological, interventional, behavioral, and complementary therapies or interventions. The need for and effectiveness of a bowel regimen is regularly assessed whenever opioids are prescribed.

2.3.3 The IDT will anticipate the impact of new symptom interventions on existing treatment regimens (eg, rapid down titration of opioid following successful surgical pain-relieving procedure).

2.3.4 The patient's response to treatments is regularly re-evaluated.

2.3.5 The IDT collaborates with appropriate specialists, including child life specialists, when meeting the symptom management needs of neonatal and pediatric patients.

2.3.6 Caregivers are assessed, trained, and supported to provide safe and appropriate care to the patient, including medication administration, safe transfers, and use of medical equipment.

2.3.7 When physical symptoms are refractory to standard treatments, the IDT evaluates the potential benefit of advanced and/or interventional therapies.

2.3.8 The plan of care incorporates community services and specialists based on the needs and preferences of the patient and family (eg, day care, home health, hospice, complementary therapies, and other services).

2.3.9 When prescribing medications with significant side effects and/or risk of misuse or abuse, a risk assessment and management plan consistent with state and federal regulations are implemented. Patients, families, and all clinicians are instructed regarding the safe usage of these medications including safe storage, inventory, and appropriate medication disposal.

2.3.10 The ongoing care of patients being treated with opioids for physical symptoms, such as pain and dyspnea, includes documentation of functional and symptoms goals, ongoing assessment of the risk of opioid misuse, and reassessment intervals.

2.3.11 The plan of care for patients with addiction identifies how symptoms will be managed, in concert with addiction specialists when needed.

2.3.12 A regular and systematic medication reconciliation, justification, and optimization is performed to review accuracy and necessity of medications, screen for drug interactions, minimize polypharmacy, and reduce any burdens medications impose on patients and families.

2.3.13 The IDT helps to educate, enable, and empower the patient and family regarding proper medication administration. Consideration is given as to whether patients and families can access and afford the medications, interventions, and services prescribed or recommended.

2.3.14 When indicated, referral to rehabilitation therapies, including but not limited to physical, occupational, and speech therapy, is provided based on patient and caregiver goals and the anticipated benefit and burden of the intervention.

Guideline 2.4 Ongoing Care

The palliative care team provides written and verbal recommendations for monitoring and managing physical symptoms.

Criteria:

2.4.1 Processes are in place to ensure:

a. Ongoing monitoring during periods of stability in symptom management and functional status
b. Referral and care coordination to manage ongoing physical symptoms and functional impairment
c. The recommendations are documented and communicated to primary and specialist care providers involved in the patient's ongoing care

Clinical and Operational Implications

Clinical Implications

In all care settings, palliative care seeks to improve physical comfort and optimal functional status. Physical concerns, including ongoing access to medications, can be exacerbated as patients transfer across settings of care. Services align with the goals, needs, culture, ages, and developmental status of the patient and family. Expert symptom management focuses not only on physical factors but also emotional, spiritual, religious, and cultural factors, which set the foundation of palliative care and promote comfort and quality of life.

Operational Implications

Clinicians develop and follow policies and protocols related to the assessment and treatment of physical symptoms, including controlled substances. Systems are in place to facilitate communication and coordination of care, especially during care transitions, to ensure the patient's plan of care continues to be implemented.

Essential Palliative Care Skills Needed by All Clinicians

All clinicians need expertise in the assessment of patient symptom burden, functional status, and quality of life, and in the development of a palliative treatment plan that is consistent with patient and family needs and preferences. Clinicians need the skills to identify and treat symptoms associated with serious illness and related treatments, including pain, nausea, constipation, dyspnea, fatigue, and agitation.

Palliative care specialists can assist other clinicians as consultants or care coordinators based on the specific needs of the patient, particularly in instances of complex and intractable symptoms. Consultations with specialist-level palliative care can assist when patients have complex pain and symptom management needs.

Key Research Evidence

The systematic review addressed the following key question: KQ2) *What is the impact of palliative care interventions on physical symptom screening, assessment, and management of patients?* Forty-eight systematic reviews were identified pertaining to KQ2. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D2-A

A palliative care service in a large **public hospital** serves patients from a broad geographic area. Many patients come from rural communities or are too frail or functionally impaired to travel easily to the clinic. The palliative service uses a telehealth application (app) on smartphones with secure video to stay connected with their patients between face-to-face appointments. The smartphone app allows the patients and families to create a record of their symptoms and indicate responses to treatments. The data entered creates graphs of pain and symptom levels and well-being that show trends in symptom control. The application has an encrypted camera so that patients and caregivers can send confidential photos of wounds or speak with their providers by video. When the home health nurse visits, she coordinates a video chat with several members of the clinic palliative team to review symptoms and medications and make necessary changes. Patients and families can see their team and vice versa, which adds to their confidence and engagement with their plan of care. The home health nurse feels empowered in facilitating team-based care and can review her concerns in real time with the prescribing physician and the families. Tele-palliative care "brings" clinicians to patients' homes to assess new or exacerbated symptoms in a patient-centered, time- and cost-efficient manner, avoiding unnecessary or burdensome visits to the physician office or emergency department.

Practice Example D2-B

A **cancer center** has a growing cancer survivors population and has developed a survivorship clinic. These individuals often struggle with ongoing symptoms and the delayed effects of cancer treatments, and some experience psychological repercussions of surviving a life-threatening diagnosis and living with uncertainty about recurrence. The palliative care service does not have capacity to see both new and active cancer treatment patients, as well as long-term cancer survivors. The cancer survivorship program decides to collaborate formally with the palliative care service to integrate principles of palliative care into survivorship care. The clinical nurse specialist and physician assistants responsible for survivorship care participate in palliative care education and develop decision-support tools for managing common concerns, such as persistent fatigue, peripheral neuropathy, anxiety, and depression. The survivorship and palliative care programs share the cost of two full-time social workers who work with psychologists and psychiatrists as needed to expedite care. Patients at high-risk of recurrence are identified and continue to see the palliative care team along with their intermittent oncology follow-up.

Practice Example D2-C

A large **multi-site, multi-specialty community pediatric practice** cares for children with neurological disease, muscular dystrophy, and cystic fibrosis. Ongoing review of their quality metrics identifies that parent satisfaction has been decreasing, particularly related to symptom management for children who have been hospitalized and are discharged home. In response, the practice invests in training several advanced practice providers as "palliative care champions" to support patients with serious illness and to facilitate care coordination when they are hospitalized. The practice initiates a palliative care clinic one day per week at rotating sites attended by a consulting palliative medicine physician to collaborate with the palliative care champions. The quality improvement plan strengthens the practice relationships with home care and hospice, with a goal of better care coordination for their patients.

Practice Example D2-D

A **home-based primary care practice** with a physician, advanced practice registered nurse, and medical assistant cares for elderly people with multi-morbidities and functional impairment. The practice has demonstrated its value by helping people avoid non-beneficial emergency department visits and hospital stays. The practice receives some financial support from the local medical center but still relies heavily on inadequate fee-for-service reimbursement. The providers can see that many of their patients and families would benefit from an interdisciplinary approach to care, especially for the social and spiritual aspects of care, and roughly 40 percent of their patients transition to hospice each year. The practice meets with the local community hospice, which is working to establish its own palliative care program. The hospice needs a palliative care medical director and its advanced practice registered nurses need more training in caring for people with complex medical illnesses who are not hospice-eligible. The two entities engage in joint staff education and create processes to identify which patients need access to the hospice's social worker. The practice begins to systematically screen for spiritual distress using the FICA spiritual history tool and requests consultations from the hospice chaplain as indicated. The hospice personnel identify themselves as part of the primary care practice when visiting patients and families. The entities obtain legal consultation and establish contracts to support their collaboration, setting forth clear lines of communication and responsibilities and meeting regularly to review their patient outcomes.

Practice Example D2-E

A **community-based home health and hospice agency** also offers a palliative care program. The palliative care program utilizes advanced practice providers who collaborate with the primary care provider and/or treating specialists and are supported by commercial insurance and Medicare Part B reimbursement. Several nurses in the home health program have advanced certification in hospice and palliative care. All home health patients are screened for palliative needs by the home health nurse – most people who screen positive have cancer or chronic progressive illnesses with recurrent hospitalizations. The home health nurse identifies the patient and family needs and obtains consents and an order for palliative care support when indicated. The social workers and chaplains from the hospice program collaborate actively with the nurses in home health to develop a coordinated plan of care. The advanced practice registered nurse or physician assistant engage with these patients simultaneously with home health, particularly when prescribing authority is needed, to facilitate continued support for high-risk patients once home health care goals are reached. Patient/family and provider satisfaction with the program is high. The hospice sees an increase in appropriate and timely admissions with the growth of the program. When eligible patients are admitted to hospice care, they experience greater continuity with team members; this continuity is identified as a key value-add to the program.

Practice Example D2-F

The clinicians in a health clinic in a **state prison** have become aware of the need for palliative care for their aging, seriously ill inmates. The very burdened prison clinic is affiliated with a university hospital, but prisoners are often not cared for until days before death in the prison due to limited security and resources to care for them in the hospital. The prison clinic staff is aware of some model programs nationally that train inmate volunteers to provide hospice services, and with bereavement support and counseling provided by prison psychologists and chaplains. However, their efforts to date have been limited due to economic and organizational barriers in the prison system. The prison health clinic staff are committed to improving palliative care, so they begin with a quality improvement plan that includes staff education provided by the university hospital palliative care service for the prison clinic physicians, medication aides, pharmacists, nurses and physician assistants. They also meet with the prison volunteer community clergy to arrange for increased chaplaincy in the clinic. The pharmacist is committed to help create symptom management protocols. A community hospice serving the university hospital has offered to open their bereavement services to families of those who die incarcerated.

Despite the many challenges, the prison clinic staff believe that much can be done to improve care of seriously ill and dying patients. They are committed to a long-term plan that they hope eventually may incorporate more structured hospice services and palliative care throughout the facility.

Domain 3: Psychological and Psychiatric Aspects of Care

The palliative care interdisciplinary team (IDT) systematically addresses psychological and psychiatric aspects of care in the context of serious illness. The IDT conducts comprehensive developmentally and culturally sensitive mental status screenings of seriously ill patients. The social worker facilitates mental health assessment and treatment in all care settings, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care. The IDT communicates to the patient and family the implications of psychological and psychiatric aspects of care in establishing goals of care and developing a treatment plan, addressing family conflict, delivering grief support and resources from the point of diagnosis onward, and providing referrals for patients or family members who require additional support.

Guideline 3.1 Global

The IDT includes a social worker with the knowledge and skills to assess and support mental health issues, provide emotional support, and address emotional distress and quality of life for patients and families experiencing the expected responses to serious illness. The IDT has the training to assess and support those with mental health disorders, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care.

Criteria:

3.1.1 Palliative care patients have access to a social worker who can assess and respond to a range of expected responses to serious illness, as well as mental health issues.

3.1.2 Recognizing its capacity to care for patients with a comorbid mental health disorder, the IDT collaborates with specialists as needed. The palliative care team has defined processes for the provision of mental health care, including specific roles and responsibilities of IDT members and specialists.

3.1.3 The IDT includes professionals who have received training in the potential psychological and psychiatric impact of serious illness – including potential distressing behavioral changes – on both patients and families as they relate to psychological well-being. The IDT has, or has access to, staff with training to:

  a. Recognize and treat common psychological issues (eg, anxiety, depression, delirium, hopelessness, post-traumatic stress disorder, and substance use disorder and withdrawal symptoms) and more complex psychiatric issues (eg, suicidal ideation, serious and persistent mental illness), as well as personality disorders

  b. Determine whether presenting issues are diagnosable conditions or usual responses to serious illness

  c. Support patients, families, and staff experiencing compassion fatigue, moral distress, grief, loss, and bereavement (see Domain 7: Care of the Patient Nearing the End of Life)

3.1.4 The IDT maintains a safety plan acknowledging potential risks for patients, families, staff, and volunteers that

Note: Words bolded in red are defined in the Glossary.

can arise in caring for patients with psychological and psychiatric disorders, especially in community-based care settings.

3.1.5 The IDT has processes to ensure regular and ongoing care coordination and collaboration with specialty clinicians who are treating the patient and family, including clinical social workers, psychologists, psychiatric-mental health advanced practice registered nurses, counselors, addiction medicine specialists, psychiatrists, and clinicians with expertise in treating trauma-based disorders (see Domain 1: Structure and Processes of Care).

Guideline 3.2 Screening and Assessment

The IDT screens for, assesses, and documents psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.

Criteria:

3.2.1 The IDT performs developmentally and culturally sensitive screening and assessment that at a minimum includes:

a. Emotional distress, anxiety, and depression

b. Patient and family, including parents and siblings, coping strategies and dynamics related to psychological concerns and distress

c. The presence of delirium and/or dementia

d. Learning or developmental disabilities

e. Cultural considerations related to psychological concerns and distress

f. Spiritual assessment related to psychological concerns and distress

g. Risk of, history, or current substance use disorder

h. Risk or history of attempted suicide

i. Current or previous trauma and/or evidence of posttraumatic stress disorder (PTSD)

j. Dual diagnosis, pre-existing **psychological/psychiatric** diagnoses vs. those stemming from serious illness diagnosis (eg, depression on diagnosis, side effects of medication)

3.2.2 In cases where the patient does not have decisional capacity, the IDT identifies the surrogate decision-maker and assesses their capacity to participate in decision-making on behalf of the patient.

3.2.3 The IDT assesses the full spectrum of how the patient and family, including parents and siblings, are coping with serious illness or, if present, identifies a behavioral health condition. The IDT incorporates specialists to assist with complex diagnostic assessment and psychopharmacology management as needed.

3.2.4 The IDT regularly reassesses and documents treatment efficacy, response to treatment, and patient and family preferences.

3.2.5 The IDT conducts ongoing assessment and reassessment for anticipatory grief, as well as the risk of prolonged grief disorder starting at diagnosis and throughout the illness trajectory (see Domain 7: Care of the Patient Nearing the End of Life).

Guideline 3.3 Treatment

The IDT manages and/or supports psychological and psychiatric aspects of patient and family care including emotional, psychosocial, or **existential** distress related to the experience of serious illness, as well as identified mental health disorders. Psychological and psychiatric services are provided either directly, in consultation, or through referral to other providers.

Criteria:

3.3.1 The IDT systematically and regularly reviews screening and assessment data related to mental health and psychological well-being, needs, and gaps in care. Response to identified concerns is prompt, evidence-based, and in accordance with patient and family goals of care.

3.3.2 Psychological, mental health, and psychiatric treatment may include behavioral, therapeutic, and pharmacologic interventions, as well as complementary therapies, and culturally specific practices or rituals.

3.3.3 Child and adolescent patients and family members receive care to address their mental health needs from child life specialists, integrative therapy professionals, and emotional or mental health services for pediatric patients.

3.3.4 Either directly or through referral, patients and families, including parents, children, and siblings at risk for prolonged grief disorder are provided with services and support based on best practices.

3.3.5 Regardless of whether the psychological or psychiatric concern was pre-existing or distinct from the serious illness, treatment includes:

a. Patient and family education about the disease or condition, symptoms, treatments, and side effects

b. Patient and family decision-making support

c. Patient and family support in coping with uncertainty, postoperative complications, and decisional regret

d. Patient support related to a change in prognosis, anticipatory grief, loss, and emotional responses related to coping with advanced illness and end of life

e. Prompt information, resources, or referral to professionals as needed for patients and families at risk for prolonged grief disorder and/or bereavement, intractable depression and anxiety, suicidal ideation, delirium, behavioral disturbances, co-morbid substance use disorder, co-morbid psychiatric diagnoses, and other more complex psychological and/or psychiatric needs

f. Family support related to anticipatory grief, the emotional aspects of caregiving, caregiver burden, or practical needs related to caregiving

g. Child, parent, and sibling psychological and mental health support throughout the trajectory of care, including at times of significant shift in a patient's baseline

3.3.6 The IDT addresses the mental health and emotional needs of perinatal palliative care families receiving the diagnosis of serious illness during pregnancy, including meeting the needs of a pregnant mother throughout the duration of her pregnancy, labor, delivery, and post-partum care.

3.3.7 Either directly or through referral, the IDT supports opportunities for emotional growth, optimal coping, cognitive reframing, and completion of important tasks.

3.3.8 The IDT has policies and procedures to respond to requests for physician aid in dying (see Domain 8: Ethical and Legal Aspects of Care).

Guideline 3.4 Ongoing Care

The IDT provides recommendations for monitoring and managing long-term and emerging psychological and psychiatric responses and mental health concerns.

Criteria:

3.4.1 An ongoing plan is developed to monitor and address psychological responses, emotions, and/or changes in cognition as prognosis and goals of care evolve.

3.4.2 Ongoing treatment related to psychological, psychiatric, existential concerns, post-illness trauma, and PTSD that is managed by the IDT is coordinated with other care providers.

Clinical and Operational Implications

Clinical Implications

Palliative care teams rely upon social workers and specialists to ensure all patients and families have access to treatments that are evidence-based and provided in accordance with their values, assessed needs, and goals of care. Education related to assessment and treatment of psychological and psychiatric aspects of care, including substance use disorder, is an essential element of quality palliative care. Grief assessments and services are fundamental components of the ongoing palliative plan of care.

Operational Implications

The IDT has policies and procedures related to psychological and psychiatric care, including timely access to developmentally appropriate clinical specialists, either directly or through referral.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians in all care settings can help ease the burden of a serious illness by screening for, assessing, and managing psychological and/or psychiatric concerns that may occur. Specific knowledge and skills needed include the identification and treatment of basic psychological conditions, such as depression, an understanding of both pharmacological and non-pharmacological interventions, and effective patient and family education strategies specific to the mental health diagnosis in the context of serious illness. In addition, clinicians benefit from an understanding of the psychological reactions to serious illness, grief, and loss.

When the symptoms are beyond the clinician's capacity to treat, palliative care specialists and/or mental health specialists are integrated into the plan of care. Clinicians need expertise in care coordination between providers when patients have a cognitive and/or communication impairment or incapacity or are experiencing extreme mental distress.

Key Research Evidence

The systematic review addressed the following key question: KQ3) *What is the impact of palliative care interventions on psychological and psychiatric assessment and management of patients?* Twenty-six systematic reviews were identified pertaining to KQ3. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D3-A

A **long-term care facility** in a suburban area is concerned with the high hospitalization rate of its residents, especially near the end of life. The leadership of the facility commits to incorporating palliative care into routine care of their seriously ill patients and structuring their program around the NCP Guidelines. They meet with the case management group at the local hospital, along with leadership of two area hospices, and strategize how they can work together to improve the outcomes of their patients. They identify shared metrics and outcomes and implement shared palliative care education for all staff. The long-term care facility invests in further training for the social workers and supports one individual as she works towards certification in palliative care. The facility enhances the psychological assessment for all residents and improves the distress screening for new admissions to long-term care. It standardizes training in facilitating goals of care discussions and documenting advance care plans with patients and families. Furthermore, it offers access to grief support for patients and their families, along with bereavement services for families and staff in collaboration with its hospice partners.

Practice Example D3-B

A **community geriatric practice** serves a continuing care retirement community (CCRC) by providing consultations and ongoing co-management, with a particular focus on patients with Alzheimer's and other dementias. The geriatric advanced practice registered nurses provide regular home-based follow-up and see patients in the CCRC's skilled care section, communicating and collaborating with the facility medical director and/or the patient's primary physician. An interdisciplinary team meeting occurs weekly with the geriatric advanced practice registered nurses, physicians, the medical director, the director of nursing, the CCRC spiritual care director, and the nursing home social worker and rehabilitation therapists. Team members express concern regarding caregiver stress and capacity for couples living in the assisted living community or independent living when one member of the couple has dementia. As a result, the practice hires an advanced practice registered nurse certified in both geriatrics and hospice and palliative care nursing; he facilitates the development of an expanded assessment of patient and family caregiver needs and distress. Procedures are developed to guide symptom assessment and management with an emphasis on the psychological needs of both patients and family caregivers, including validated screening for depression. The practice and CCRC form collaborative relationships with the local hospital palliative care service for help with patients with concurrent medical illnesses and complex symptom needs along with a psychiatric practice that includes psychologists and grief counselors. This growing collaboration between the CCRC and the hospital palliative care service calls itself the Advance Illness Steering Committee (AISC) and selects a well-respected community hospice program as a preferred provider, setting up agreements to share data. The AISC evaluates ongoing needs for its shared patients, including how to further share education and resources across the entities to reach quality outcomes and ways to identify patients as soon as they are eligible for hospice. The hospice provides additional spiritual care resources and grief and bereavement support for all families served.

Practice Example D3-C

A large inner-city **homeless shelter clinic** delivers primary care to seriously ill homeless people. The homeless shelter clinic collaborates with the hospital palliative care service, including palliative care training for all the homeless shelter staff, clinic social workers and psychologists, and volunteer chaplains. The clinic establishes procedures for screening and managing depression and other emotional responses to illness, as well as screening for physical illnesses and symptoms. The homeless shelter clinic forms collaborative relationships with hospices that offer inpatient care in long-term care facilities or inpatient units when needed for end-of-life care.

Practice Example D3-D

A pediatric palliative care team at a **tertiary children's hospital** developed a collaborative practice with the pediatric oncology program to optimize well-being of children throughout their cancer care trajectory. When a young girl with newly diagnosed metastatic cancer developed severe anxiety in the presence of clinicians, the palliative care team worked with the child and her parents to gain trust and assess the causes of her distress. The palliative team collaborated with child life specialists and the pediatric clinical psychologist to address the child's anxiety, using a combination of play therapy, art therapy, relaxation techniques, and medication. The child's mother played an integral role in helping the team to adjust strategies based on the child's needs in the hospital, clinic, and home settings. Co-therapy sessions were facilitated to help the child and her identical twin process their feelings and anxiety as the disease advanced, providing opportunities for the child to identify and communicate what was most important to her at end of life.

Practice Example D3-E

A **hospice agency** has established a relationship with a **Department of Veterans Affairs Medical Center (VAMC)** as one of their community partners. The hospice agency recognizes the opportunity to improve their care of Veterans with dual diagnoses of advanced medical conditions along with psychiatric illnesses. The VAMC identifies palliative care-trained staff members to collaborate with the hospice interdisciplinary team and give specialty input. Along with a psychiatrist, one of the VAMC's pharmacists voluntarily collaborates with the team. This leads to shared educational sessions for both entities and improvement in medication and symptom management for the patients.

Domain 4: Social Aspects of Care

Social determinants of health, hereafter encompassed in the term "social factors," have a strong and sometimes overriding influence on patients with a serious illness. Palliative care addresses environmental and social factors that affect patient and family functioning and quality of life. The palliative care interdisciplinary team (IDT) partners with the patient and family to identify and support their strengths and to address areas of need. The IDT includes a social worker to maximize patient functional capacity and achieve patient and family goals.

Guideline 4.1 Global

The palliative care IDT has the skills and resources to identify and address, either directly or in collaboration with other service providers, the social factors that affect patient and family quality of life and well-being.

Criteria:

4.1.1 The palliative care IDT includes a social worker with expertise and experience in:

- a. Assessing and supporting emotional aspects of care and improving quality of life (see Domain 3: Psychological and Psychiatric Aspects of Care)
- b. Identifying and addressing social consequences of a serious illness
- c. Collaborating with community-based services and supports and the organizations providing them
- d. Applying care management and care coordination techniques and evidence-based models of care transitions
- e. Working as part of an interdisciplinary team
- f. Utilizing patient- and family-centered and developmentally appropriate approaches to assessment, care planning, care management, and care delivery

4.1.2 All members of the IDT understand the impact of social factors on seriously ill patients and family members. The IDT:

- a. Is aware of the implications on care when patients are uninsured, under-insured, undocumented, homeless, or under the custody of the county or state
- b. Is cognizant of the financial impact of serious illness, including the cost of medications and other treatment, as well as the costs to the family
- c. Provides, directly or through referral, access to follow-up appointments, treatments, medications, nutrition, and other resources, as indicated in the plan of care

4.1.3 Palliative care teams serving perinatal and pediatric patients have expertise in meeting the needs of neonates, children, and adolescents living with serious illness. Expertise is also needed to support siblings, as well as parents, in their role as care providers and decision-makers for their children.

Note: Words bolded in red are defined in the Glossary.

4.1.4 Eligibility for Medicaid or other benefits is determined and reviewed with the patient and family. The IDT offers assistance with benefit applications, as needed.

Guideline 4.2 Screening and Assessment

The IDT screens for and assesses patient and family social supports, social relationships, resources, and care environment based on the best available evidence to maximize coping and quality of life.

Criteria:

4.2.1 Before involving family or caregivers, the patient or legal decision-maker identifies who can participate in the assessment and care planning process, as well as their level of involvement.

4.2.2 The IDT performs developmentally and culturally sensitive screening and assessment in the setting in which the patient receives care.

4.2.3 The social assessment includes:

a. Family structure and function, including roles, quality of relationships, communication, and decision-making preferences and patterns, as well as an assessment of those involved if the patient is in the custody of the county or state

b. Patient and family strengths, resiliency, social and cultural support, and **spirituality**

c. The availability and ability of a support system to provide respite, assist with errands and chores, and guard against social vulnerability

d. The effect of illness or injury on intimacy and sexual expression, prior experiences with illness, disability and loss, risk of abuse, neglect or exploitation, incarceration, or risk of social isolation

e. Functional limitations that impact **activities of daily living** (ADLs), **instrumental activities of daily living** (IADLs), and cognition

f. Changes in patient or family members' school enrollment, employment or vocational roles, recreational activities, and economic security

g. Identification and documentation if the adult patient or a family member served in the military, and whether the patient or family member may be eligible for VA benefits

h. Living arrangements and perceived impact of the living environment on patient and family quality of life, including safety issues

i. Patient and family perceptions about caregiving needs, including caregiver availability and capacity

j. The need for adaptive equipment, home modifications, or transportation

k. Financial vulnerability (eg, ability to pay rent or mortgage and other bills)

l. Ability to access prescription and over-the-counter medications for any reason, including functional or financial issues

   m. Nutritional needs and food insecurity
   n. Advance care planning and legal concerns (see Domain 8: Ethical and Legal Aspects of Care)
   o. Patient and caregiver ability to read and understand information from health and social service providers, insurance companies, and the IDT, as well as the ability of the patient and family to ask questions and advocate for their needs
   p. The ability of the patient and/or family to adhere to medication or treatment regimens
   q. Patient and family willingness and ability to engage or accept resources and referrals

4.2.4 A separate assessment of the family's needs, resources, resiliency, and capacity to provide care is also conducted.

Guideline 4.3 Treatment

In partnership with the patient, family, and other providers, the IDT develops a care plan for social services and supports in alignment with the patient's condition, goals, social environment, culture, and setting to maximize patient and family coping and quality of life across all care settings.

Criteria:

4.3.1 The IDT engages the patient and family in developing a care plan that addresses the social needs and is in alignment with their goals. The care plan:

   a. Reflects patient and family culture, values, strengths, goals, and preferences, which may change over time
   b. Assesses factors that prevent the patient from remaining independent and connected with family and friends
   c. Specifies the role and contributions of family members and the types and sources of support that will be provided to the family
   d. Identifies community service providers and the type and amount of care they will provide
   e. Includes developmentally appropriate support for the patient and family, including children and adolescents
   f. Identifies outcomes specific to each goal

4.3.2 The IDT coordinates care with care manager(s) and care team(s) to address patient- and family-identified social needs, providing referrals to resources and services as needed.

Guideline 4.4 Ongoing Care

A palliative care plan addresses the ongoing social aspects of patient and family care, in alignment with their goals and provides recommendations to all clinicians involved in ongoing care.

Criteria:

4.4.1 The IDT reviews the care with **long-term services and supports** and providers involved in ongoing care.

Clinical and Operational Implications

Clinical Implications

The palliative care IDT assesses the social and environmental strengths and vulnerabilities of patients and families to determine the effect on their ability to cope with serious illness and maximize quality of life. The IDT plans for, arranges, and coordinates services and supports to address patient and family social and functional goals that enable the patient to remain in the setting of their choice, to the extent possible. The IDT incorporates specialists in social aspects of care specific to the cultural and developmental needs of each patient.

Operational Implications

Patients with serious illness in all care settings often have substantial social and functional needs that require social services and supports. The IDT allocates resources to ensure ongoing communication and coordination with existing care managers and providers to optimize patient and family outcomes.

Essential Palliative Care Skills Needed by All Clinicians

All clinicians can learn how to perform and integrate social assessments into the care of seriously ill patients to identify patient strengths, availability of caregiving and social support, access to reliable food, housing and transportation, need for adaptive equipment, and other social or environmental issues. This knowledge helps the clinician identify and implement developmentally appropriate approaches to assessment, care planning, care management, and care delivery. Understanding the social consequences of a serious illness enables the clinician to support the ongoing practical and social needs, including the identification of patient and family coping strategies. In addition, indentifying and addressing indicators of caregiver isolation and burnout are critically important in achieving patient and family goals. Palliative care specialists can provide consultations or ongoing care management as needed to address complex family dynamics or intense social needs.

Key Research Evidence

The systematic review addressed the following key question: KQ4) *Does an assessment of environmental or social needs as part of a comprehensive palliative assessment improve needs identification and access to relevant services?* Two systematic reviews were identified pertaining to KQ4. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D4-A

A **community hospital** recognizes the need to integrate palliative care into the care of patients with serious illness. The hospital is served by independent physician practices and also has employed intensivists and emergency department staff. To support the needs of the patient population, the hospital pays for palliative care training for all inpatient and outpatient social workers, and three achieve advanced certification. Seriously ill patients are screened at admission to identify those with high-risk and high utilization patterns; these patients receive a more in-depth social work assessment. Out- and inpatient social workers are asked to do a joint visit at the end of the hospitalization for these patients to facilitate continuity. The hospital conducts a biweekly care conference to review all palliative care patients – the conference is expanded to include hospitalists, advanced practice providers, registered nurses, spiritual care, and emergency department leaders. The emergency department recruits a physician trained and certified in palliative care.

Practice Example D4-B

A **children's hospital** has recognized the need to expand palliative care integration beyond the current inpatient palliative care team. Social workers and child life therapists in the outpatient setting already conduct an in-depth psychosocial assessment of every new patient and family within 14 days of the start of outpatient care. This information is recorded in the outpatient medical record and has not been available to inpatient teams, yet it has great importance in managing transitions of care. The hospital commits to implementing a single electronic medical record for inpatient and outpatient care. Representatives of the psychosocial outpatient team begin attending the inpatient palliative care interdisciplinary team meetings to enhance communication and information sharing. Patients admitted who will not be seen in follow-up in the hospital clinics receive the in-depth psychosocial assessment while hospitalized. A process to routinely identify these patients and to share this information with the healthcare providers who will be seeing the patient and family after discharge is under development.

Practice Example D4-C

A **community hospital** has its own medical group including disease specialists. The hospital's strategic plan includes improving care for patients with advanced heart failure, as these patients represent the highest utilizers and greatest expense to the health system. The hospital endorses the creation of a specialty heart failure clinic and asks clinical leadership to guide the development, including the integration of palliative care services. Although the heart failure clinic team has physicians, advanced practice registered nurses, nurses, a therapist, a social worker, and a chaplain, there is little direct communication and collaboration between team members. The heart failure clinic social worker identifies caregiver stress as a key driver of hospital re-admission and collaborates with the palliative care advanced practice registered nurse to develop an assessment of caregiver capacity and distress. Poor family member understanding of what to expect in progressive heart failure and lack of confidence in handling after hour emergencies emerge as central themes. The social worker and advanced practice registered nurse work with all members of the heart failure team to create patient and family teaching materials in multiple languages. The chaplain initiates a weekly family support group for caregivers that includes a telephone option for those who can't leave the house. A regular heart failure team meeting is established to review the needs of patients and their caregivers and identify those patients eligible for hospice services. These changes in the clinics' function lead to improvement in utilization patterns and the hospital invests in a new telehealth system to further enhance monitoring and communication in support of high-risk heart failure patients and their caregivers.

Practice Example D4-D

An independent **rural community dialysis center** serves a broad geographic area and recognizes high levels of distress and ED and hospital utilization among its patients and their family caregivers. The dialysis staff (its nephrologists and nurses) have pursued palliative care training and the practice has hired a physician assistant with several years' experience working in palliative care at one of the tertiary hospitals that serves the same geographic area. The dialysis center team discusses the worrisome connection between caregiver strain and patient outcomes and decide to target family caregiver support as a quality improvement project. Led by the dialysis center social worker, two initiatives are launched: a recurring instructional session for patients and family caregivers on symptom management at home; and a monthly peer support group for family caregivers. The center also recognizes many adult children of the dialysis patients have moved away from the rural area. The social worker arranges web-based technologies to allow participation of remote family members in care conferences with the interdisciplinary team, which are now held routinely and with any changes in patient status or goals of care.

Practice Example D4-E

A social worker in a **community hospice** has a particular interest in perinatal loss and has studied how programs across the country provide support for mothers and extended family members anticipating such a loss. With leadership support, she and others in the hospice reach out to the hospital-based obstetrics practice to see if there is an interest in co-creating a palliative team to serve these patients and their families. These conversations lead to a collaborative service that provides early access to grief support for expectant mothers and their families while the woman are pregnant, and bereavement follow-up after the loss. The hospice identifies and coordinates with other programs if the women do not live locally or if family members from out of town request grief and bereavement support.

Practice Example D4-F

A **hospice program** affiliated with a critical access hospital recognizes a high number of its patients prefer not to die at home. After exploration of the cultural norms of the community the hospice decides to build a hospice house to provide an alternative home-like setting. The house is well received and supported by the community. Soon, the hospice house begins receiving calls from community members who have a variety of needs unrelated to a terminal condition. The hospice utilizes the NCP Guidelines to develop a community-based palliative care program focused on the social determinants of care needs of community members. The hospice medical director oversees the work of a registered nurse, and the registered nurse collaborates with the hospice social worker as needed. The registered nurse facilitates the work of a trained group of volunteers to facilitate advance care planning and connect people to services within the community. The primary care physician receives visit documentation when applicable. The program tracks completion of advance directives and connections to various services to demonstrate the need for and value of the program to the local hospital and the community.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Reference to spiritual care within the NCP Guidelines also refers to religious and/or existential depending on the context.

Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered palliative care. It is a dynamic and intrinsic aspect of humanity through which individuals seek meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.[1] Palliative care interdisciplinary teams (IDT) serve each patient and family in a manner that respects their spiritual beliefs and practices. Teams are also respectful when patients and families decline to discuss their beliefs or accept spiritual support.

Guideline 5.1 Global

Patient and family spiritual beliefs and practices are assessed and respected. Palliative care professionals acknowledge their own spirituality as part of their professional role and are provided with education and support to address each patient's and family's spirituality.

Criteria:

5.1.1 The IDT has clearly defined policies and processes in place to ensure spiritual care is respectful of patient and family age, developmental needs, culture, traditions, and spiritual preferences.

5.1.2 Either directly, through referral, or in collaboration with the **professional chaplain**, the IDT facilitates spiritual and cultural rituals or practices as desired by the patient and family.

5.1.3 IDT members respect patient and family beliefs and practices, never imposing their individual beliefs on others.

5.1.4 The spiritual needs of family members may differ from those of the patient and are recognized and supported.

5.1.5 Care of children, adolescents, and their family members recognizes that spirituality is integral to coping with serious illness and is provided in a developmentally appropriate manner.

5.1.6 In all settings, the IDT includes professional chaplains who have evidence-based training to assess and address spiritual issues frequently confronted by pediatric and adult patients and families coping with a serious illness.

5.1.7 The professional chaplain is the spiritual care specialist, conducting the assessment and addressing the spiritual aspects of the care plan.

5.1.8 Professional chaplains develop community partnerships to ensure patients have access to spiritual care providers trained and supervised by a professional chaplain. The IDT and community spiritual care providers share information and coordinate services.

Note: Words bolded in red are defined in the Glossary.

5.1.9 The IDT integrates the patient's and/or family's faith community into the care plan when requested.

5.1.10 Led by the professional chaplain, opportunities are provided to engage staff in self-care and self-reflection regarding their own spirituality.

5.1.11 Every member of the IDT is trained in spiritual care and recognizes the importance of the spiritual aspects of care.

5.1.12 Members of the IDT receive training to cultivate an openness to the spirituality of patients and families through empathic listening.

Guideline 5.2 Screening and Assessment

The spiritual assessment process has three distinct components – **spiritual screening**, **spiritual history**, and a full **spiritual assessment**. The spiritual screening is conducted with every patient and family to identify spiritual needs and/or distress. The history and assessment identify the spiritual background, preferences, and related beliefs, values, rituals, and practices of the patient and family. Symptoms, such as **spiritual distress** and spiritual strengths and resources, are identified and documented.

Criteria:

5.2.1 All aspects of the screening, history, and assessment are conducted using standardized tools.

5.2.2 Spiritual screening is completed as part of every clinical assessment to identify spiritual distress and the need for urgent referral to a professional chaplain. Screening is designed to evaluate the presence or absence of spiritual needs and spiritual distress.

5.2.3 IDT members also include a spiritual history as part of the clinical evaluation in the initial assessment process. A spiritual history identifies patient preferences and values that may affect medical decision-making.

5.2.4 A spiritual assessment is triggered based upon the results of the spiritual screening and history. It is an in-depth and ongoing process of evaluation of spiritual needs, results in a plan of care, and is conducted by a professional chaplain as the spiritual care specialist, in collaboration with the faith community, based upon patient wishes.

5.2.5 The spiritual assessment explores spiritual concerns including, but not limited to:

a. Sources of spiritual strength and support

b. Existential concerns such as lack of meaning, questions about one's own existence, and questions of meaning and suffering

c. Concerns about relationship to God, the Holy, or deity, such as anger or abandonment

d. Struggles related to loss of faith, community of faith, or spiritual practices

e. Cultural norms and preferences that impact belief systems and spiritual practices

f. Hopes, values and fears, meaning, and purpose

g. Concerns about quality of life

h. Concerns or fear of death and dying and beliefs about afterlife

i. Spiritual practices

j. Concerns about relationships

k. Life completion tasks, grief, and bereavement

Guideline 5.3 Treatment

The IDT addresses the spiritual needs of the patient and family.

Criteria:

5.3.1 Spiritual elements of the plan of care are based on needs, goals, and concerns identified by patients and families, recognizing and maximizing patient and family spiritual strengths. The care plan, including religious rituals and other practices, details the expected outcomes of care.

5.3.2 Patient and family spiritual needs are addressed according to established processes, documented in the interdisciplinary care plan, and emphasized during transitions of care, including identification of significant practices which bring strength and comfort to the patient.

5.3.3 Professional and institutional use of symbols and language are inclusive of patient and family cultural and spiritual preferences.

5.3.4 The patient and family are supported and accommodated in their desires to display and use their own spiritual and/or cultural symbols.

5.3.5 Palliative care teams serving pediatric patients have expertise in honoring and meeting the spiritual needs of children and adolescents, including in situations where children or adolescents have differing values, beliefs and needs from their parents or designated decision-makers.

Guideline 5.4 Ongoing Care

Patient and family spiritual care needs can change as the goals of care change or patients move across settings of care.

Criteria:

5.4.1 Throughout the trajectory of the patient's illness, the IDT performs spiritual screening to identify new or emergent issues, identifying services and supports to help navigate these transitions. Changes in prognosis and other significant transitions prompt reassessment of spirituality.

5.4.2 The plan of care continues to evolve based upon the changing needs of the patient and family.

Clinical and Operational Implications

Clinical Implications

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

Specialist-level palliative care programs include salaried professional chaplains and related programmatic expenses. Clinicians serving seriously ill populations may develop affiliation agreements with spiritual care departments in health systems, hospitals, or hospice programs that can provide timely access to professional chaplain services. Even when these resources are available, partnerships with faith community leaders are encouraged and nurtured. The IDT has policies and procedures regarding spiritual care consultation and processes for referrals.

Essential Palliative Care Skills Needed by All Clinicians

The process and tools needed to conduct a spiritual screening and assessment for spiritual distress and spiritual needs can be learned by all clinicians. In addition, clinicians can learn to identify and utilize resources available on the team, within the patient and family, or in the community or care setting to ensure that spiritual needs are promptly addressed.

Key Research Evidence

The systematic review addressed the following key question: KQ5) *What is the effect of a spiritual assessment and/or interventions on patient and family/caregiver spiritual and emotional wellbeing?* Eleven systematic reviews were identified pertaining to KQ5. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D5-A

A large **health system** includes several outpatient clinics and hospitals across a broad geographic area. Not every site has the same scope of services and staff resources and budgets are tight. The health system has committed to integrating palliative care as a component of patient-centered care and to align with the NCP Guidelines. The expanding service area and diverse patient populations reveal the need for expansion of spiritual care services across the system. A board-certified professional chaplain at one of the larger hospitals in the health system serves as a champion and convener of spiritual care resources across the health system. She and her team promote implementation of screening for spiritual distress for all inpatients, along with a template for this information in the medical record. This screening tool is integrated into the outpatient oncology clinics across the system. The central team creates educational materials and procedures that help the regional hospitals and clinics to develop relationships with community spiritual care providers and local faith community leaders to meet the diverse needs of their local patient populations.

Practice Example D5-B

A **rural hospital** has no formal palliative care team, but the hospitalist physicians, physician assistants, advanced practice registered nurse, and hospital nurses, commit to developing and growing palliative care at their institution. They form a workgroup of interested hospital staff and community members. The hospital has seen a dramatic shift in the population served as its community has welcomed many Eastern European immigrants. Furthermore, the closure of the county hospital in the neighboring urban area has led to higher ethnic diversity than the hospital had known. Working through the NCP Guidelines, the palliative care workgroup recognizes that it should prioritize the diverse spiritual needs of patients who are seriously ill or dying in the hospital. The Ethics Committee also notes that many consultations have been related to cultural clashes involving spiritual beliefs and practices. The social work department works with the palliative care workgroup to identify spiritual care providers in the community who are available to come to the hospital as requested to meet the diverse needs of the patients. An educational series is held for all staff to increase understanding of the range of spiritual and religious traditions of community members. The hospital adopts a new policy on "Compassionate Care Near the End of Life" which incorporates key principles from the NCP Guidelines. The palliative care workgroup arranges to meet via videoconference with the palliative care specialty service at a regional hospital each quarter to discuss challenging cases.

Practice Example D5-C

A **pediatric oncology** program has recruited a physician dually boarded in oncology and palliative medicine, along with a pharmacist skilled in the pharmacology of symptom management. Staff and family caregiver education in symptom management improves rapidly. At the monthly staff meeting, several individuals acknowledge these improvements but request attention to the spiritual care of the children and families they serve. The staff feels poorly equipped to address the needs of parents and families from diverse religious traditions. They feel unsure of how to respond effectively to the spiritual experiences children may report, such as communication with deceased relatives, visits from "angels," and awareness of their impending death. The pediatric oncology program adopts improved spiritual care as a goal for the next quarter, using the NCP Guidelines as a framework for its quality improvement plans. The 0.20 full-time equivalent (FTE) professional chaplain assigned to this unit leads these efforts, including the development of strategies to standardize 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.

Practice Example D5-D

A **national company** establishes specialty practices to deliver home-based palliative care in rural and urban settings. Spiritual distress screening during the comprehensive palliative assessment reveal that more than 90% report no unmet spiritual needs, as they are actively engaged with their own faith community. To meet the needs of the remaining patients, families, and the IDTs, the central office employs a professional chaplain to actively participate in all the IDT meetings by phone, with some site visits. The chaplain creates policies and procedures on the spiritual care of patients and families. He helps local practices facilitate connection with local faith community leaders and develops contracts with local hospices for home-based spiritual care services when necessary. These visiting hospice chaplains are contracted to the local palliative care practices to provide patient and family visits. They identify themselves as part of the palliative care team, rather than their hospice employer. However, their connection with the local hospice is helpful when a hospice transition occurs to provide continuity and a familiar face for the patient and family.

Endnotes

1 Puchalski CM, Ferrell B. *Making health care whole: integrating spirituality into patient care*. West Conshohocken, PA: Templeton Press; 2010.

Domain 6: Cultural Aspects of Care

Assessing and respecting values, beliefs and traditions related to health, illness, family caregiver roles and decision-making are the first step in providing culturally sensitive palliative care. Palliative care interdisciplinary team (IDT) members continually expand awareness of their own biases and perceptions about race, ethnicity, **gender identity** and **gender expression**, sexual orientation, immigration and refugee status, social class, **religion**, spirituality, physical appearance, and abilities. Information gathered through a comprehensive assessment is used to develop a care plan that incorporates culturally sensitive resources and strategies to meet the needs of patients and family members. Respectful acknowledgment of and culturally sensitive support for patient and family grieving practices is provided.

Guideline 6.1 Global

The IDT delivers care that respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences and builds upon the unique strengths of the patient and family. Members of the IDT works to increase awareness of their own biases and seeks opportunities to learn about the provision of culturally sensitive care. The care team ensures that its environment, policies, procedures, and practices are culturally respectful.

Criteria:

6.1.1 The IDT asks the patient or surrogate to identify and define family, which may include members of the family of origin, as well as the patient's family of choice.

6.1.2 IDT members recognize that the provision of quality palliative care requires an understanding of the patient's and family's culture and how it relates to their decision-making process, and their approach to illness, pain, psychological, social, and spiritual factors, grief, dying, death, and bereavement.

6.1.3 The IDT understands that each person's self-identified culture includes the **intersections of race**, ethnicity, gender identity and expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities.

6.1.4 The IDT recognizes that patients and families may have experienced barriers to receiving culturally respectful health care, and that these prior experiences may result in mistrust of the health care system.

6.1.5 The IDT commits to continuously practice **cultural humility** and celebrate diversity.

6.1.6 In delivering culturally sensitive care, the IDT regularly participates in trainings to increase cross-cultural knowledge, empathy, and humility. The IDT focuses on building and practicing these skills to avoid imposing personal values, beliefs, and biases on the patient and family. The IDT also recognizes that culture is a strength that patients and family members bring to their plan of care.

Note: Words bolded in red are defined in the Glossary.

6.1.7 Communication occurs using verbal, nonverbal, and/or symbolic means appropriate to the patient, with particular attention to cultural and linguistic considerations, cognitive capacity, the presence of learning or developmental disabilities, and the developmental stage across the lifespan.

6.1.8 The IDT implements policies regarding recruitment, hiring, retention, and promotion practices to reflect the cultural and linguistic diversity of the community it serves, to the extent possible.

6.1.9 The care team regularly evaluates and, if needed, modifies services, policies, and procedures to maximize cultural sensitivity and reduce disparities in care. Input from patients, families, and community stakeholders is elicited and integrated into this process.

6.1.10 The IDT is aware of cultural factors that may necessitate changes in staffing assignments (eg, a patient who can only receive hands-on care from someone of the same gender). Policies and procedures are in place to identify these issues and substitute staff, when possible, so that patient preferences are respected.

6.1.11 The IDT performs a community assessment to identify underserved populations in need of palliative care.

Guideline 6.2 Communication and Language

The IDT ensures that patient and family preferred language and style of communication are supported and facilitated in all interactions.

Criteria:

6.2.1 Palliative care staff tailor their communication to the patient and family's level of health literacy.

6.2.2 When patients and families do not speak or understand English, or prefer communicating in a language other than English, the IDT uses qualified medical interpreter services, either in person or via telephone or video.

a. When possible, the need for medical interpreter services is assessed and addressed before the patient and family encounter to reduce the likelihood of communication issues and misunderstandings.

b. Prior to the patient and family encounter, the medical interpreter is provided a summary of the anticipated focus of the conversation.

c. If medical interpreter services are unavailable, bilingual clinicians provide information in the patient and family's preferred language. Family members are not placed in the role of interpreter.

6.2.3 The IDT asks about preferred ways of receiving materials and information and uses culturally representative images and language in printed and online materials.

6.2.4 Written materials in each patient- and family's preferred language is provided by the IDT. When accurately translated written materials are unavailable, the program utilizes medical interpreter services to facilitate patient and family understanding of program information.

6.2.5 The IDT uses the patient's preferred pronouns (eg, he, she, they) in all communication, including documentation.

6.2.6 As needed or upon request, the IDT incorporates cultural representatives/cultural brokers in the plan of care.

Guideline 6.3 Screening and Assessment

The IDT uses evidence-based practices when screening and assessing patient and family cultural preferences regarding health care practices, customs, beliefs and values, level of health literacy, and preferred language.

Criteria:

6.3.1 Before the screening and assessment, the IDT recognizes the need to be:

- a. Non-judgmental of the patient and family
- b. Mindful of potential biases
- c. Conscious of **historical trauma** and how it can impact patient and family care
- d. Aware of power dynamics inherent in patient and family care

6.3.2 During the assessment process, the IDT elicits and documents:

- a. Cultural practices, customs, beliefs, and values relevant during serious illness, the dying process, at the time of death, and post-death
- b. Patient's preferred name, pronouns, and gender identity
- c. Preference for IDT interaction, including whether decision-making will be communal, collective, or individualistic, with attention to patient and/or family preferences for participation in the decision-making process
- d. Truth-telling and whether the preferred cultural practice is to share or not share diagnosis and/or prognosis with the patient
- e. Preferred and taboo practices (eg, using the words "dying" and "death" or the place of death)
- f. Community resources and supports, including community leaders, faith community, or cultural groups
- g. Preferences related to physical contact
- h. Level of health literacy
- i. Prior health care experiences with attention to historical trauma and impact on care
- j. Perception of illness and disability, including patient understanding of, and what caused, their illness

  k. Beliefs about pain and suffering
  l. Perceptions of and approaches to help-seeking (eg, reluctance to accept "charity" or from anyone other than the family and/or faith community)
  m. Differing levels of **acculturation** within the family that can impact decision-making
  n. Use of traditional healing practices and involvement of traditional medicine practitioners or healers

6.3.3 When the patient is a child or adolescent the IDT assessment also identifies:

  a. The role of the child or adolescent in the family and how culture defines a minor's status in the family
  b. Whether parents share information about important matters with their child(ren), including siblings and foster children, and whether these decisions reflect the family's cultural preferences
  c. How the parents define being a good parent, and how that impacts medical decision-making
  d. Whether the family's culture permits parents to make decisions for their minor or if medical decision-making authority is deferred to religious or cultural leaders
  e. The meanings attributed by the minor and family regarding how and why the illness occurred, childhood suffering and death, and how that impacts decision-making
  f. When serious illness is diagnosed in utero (perinatal), the meaning of the pregnancy and childbirth practices are valued in the parent's culture(s)

6.3.4 The IDT reaches out to cultural representatives if lacking information and/or experience with regard to the patient's culture.

Guideline 6.4 Treatment

A culturally sensitive plan of care is developed and discussed with the patient and/or family. This plan reflects the degree to which patients and families wish to be included as partners in decision-making regarding their care. When hosting meetings to discuss and develop the plan, the IDT ensures that patient and family linguistic needs are met.

Criteria:

6.4.1 The plan of care incorporates and the IDT verbally and non-verbally communicates respect for:

  a. Who the patient defines as their family
  b. Beliefs, values, and traditional practices
  c. Language and communication preferences
  d. Level of health literacy

6.4.2 If historical trauma was assessed the treatment plan adopts a trauma-informed approach to develop trust over time.

6.4.3 When a traditional healer is involved, the care team ensures that the healer participates in care planning discussions.

6.4.4 With patient and/or family permission, IDT members involve cultural representatives to develop a care plan that honors cultural practices.

6.4.5 When discussing diagnosis and/or prognosis, preferences regarding taboo language, as well as truth telling are respected, prioritizing fidelity to the patient (see Domain 8: Ethical and Legal Aspects of Care, including 8.4.6 for truth-telling with children and adolescents living with serious illness).

6.4.6 The IDT ensures that culturally respectful grief support is available.

Clinical and Operational Implications

Clinical Implications

In order for patients and family members to receive culturally sensitive care, it is incumbent on professionals to continually explore their own biases, work to suspend judgment, and seek frequent training to further enhance and strengthen their cultural assessment, treatment, and communication skills.

Operational Implications

Palliative care teams perform a cultural assessment of all policies, processes, and practices, build strong relationships with communities and their cultural representatives, maximize service delivery to vulnerable populations, and address disparities in care. All employees receive training in cultural humility, the provision of patient-centered culturally sensitive care, and appropriate use of interpreter services and translated materials.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians can acquire knowledge and skills to recognize how culture influences patient and family decision-making, their approach to illness, pain, psychological, social and spiritual factors, and grief, dying, death and bereavement. Clinicians incorporate palliative care specialists and cultural representatives into the care plan to navigate cultural nuances, as needed.

Key Research Evidence

The systematic review addressed the following key question: KQ6) *What is the impact of culturally- and linguistically-sensitive care on physical, social, emotional, and spiritual wellbeing of the patient and family/caregiver?* Three systematic reviews were identified pertaining to KQ6. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D6-A

A **long-term care community** incorporates palliative care screening and assessments into the care plan for all its residents with serious illness, and includes an interdisciplinary team in the regular family case review. This community has experienced a significant demographic shift over time with more aging residents who have recently immigrated to the area to be near family, as well as an aging lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) community. To promote culturally respectful palliative care, this long-term care community expands its comprehensive assessment to better assess values, beliefs, and traditions related to health, illness, chosen family, caregiver roles, and decision-making. All patients are asked to identify their gender identity and preferred pronouns. A more comprehensive cultural assessment is completed on admission and reviewed with status changes of the resident's condition. The community provides an ongoing educational series for all staff related to culturally respectful care.

Practice Example D6-B

A palliative care program on a **Native American reservation** provides palliative care to adults in the hospital and clinic settings. The program has three palliative care specialist physicians within its family medicine practice. The interdisciplinary team is created to reflect the needs of the people it serves and includes team members with shared roles:

- Registered nurses who provide hands on care and care coordination
- Social workers who also serve as translators for native-speaking patients and families
- Patient advocates from the community who help patients complete advance directives
- Dieticians who provide supplements to eligible patients and help with diabetes teaching and counseling
- A medicine man who offers spiritual support performing rituals for patients, family members, as well as the staff

Practice Example D6-C

A hospice provides a **rural telehealth palliative care program** to support underserved populations. The program consists of a comprehensive in-person assessment conducted by a palliative care specialist followed by weekly nurse coaching sessions by telephone. The registered nurse coaches receive intensive training in symptom management, as well as problem solving and supporting patient-family decision-making skills. They help coordinate and connect the patients and families to other resources and prompt clinical visits when necessary.

Practice Example D6-D

A **public hospital** struggles to provide palliative care services with limited resources and the complex needs of its socioeconomically disadvantaged and culturally diverse patient population. Some patients do not live in areas where there are hospice programs, so the hospital has made referrals to the public health department for follow-up nursing care for the seriously ill patients. A hospital discharge to the home of a dying Hmong child demonstrated the need for better communication and training of the expanded team. The public health nurse making the home visit had not been briefed on the imminent death of the child or the cultural observances of the family and unfortunately misinterpreted them – prompting a 911 transport despite the family's objections. The child died in the ambulance. The palliative care service is working with others to better highlight and explicitly communicate the cultural context of care within the written and verbally transmitted medical discharge plans, and to collaborate more actively with community partners through education and training.

Practice Example D6-E

A large **community hospice** would like to better serve the Hispanic and Latino population in its urban community. There are many misconceptions regarding hospice care and advance care planning. The hospice and the local community center work together to create a program for local public radio. The program is set up as a multi-episode radio novella story of a family with an aging grandmother who is reaching the end of life, and the challenges the family faces with her care and with the hospital. The radio novella is an entertaining and engrossing way to present information around advance care planning, correct misunderstandings about hospice, and educate people about end-of-life care. Families in the community identify the radio program as helping pave the way for them to understand and utilize hospice care when it is indicated. The process also creates a powerful collaboration between the hospice and local community center that better supports families with grief and bereavement needs and creates a more culturally sensitive bereavement program.

Practice Example D6-F

A large **pediatric tertiary care hospital** provides palliative care to a diverse patient population. To better serve patients and families whose primary language is not English, the team partners with the medical interpreter services department to provide education on palliative care topics. The team meets with the interpreter prior to patient and family encounters to prepare the interpreter for the topics that will be discussed. In addition, an interpreter is assigned primary responsibility for palliative care patients and is a member of the weekly palliative care interdisciplinary rounds. Palliative care team members have found incorporating medical interpreter services into the IDT to be extremely helpful, and it has resulted in improvements in patient- and family communication and increased cultural sensitivity. Incorporating the interpreter into the palliative care team offers opportunities for additional support for the interpreter staff, for debriefing for both the team and the interpreter staff, and enhanced cultural competency for IDT members.

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

This domain highlights the care provided to patients and their families near the end of life, with a particular emphasis on the days leading up to and just after the death of the patient. The meticulous and comprehensive assessment and management of pain and other physical symptoms, as well as social, spiritual, psychological, and cultural aspects of care, are critically important as the patient nears death. It is essential that the interdisciplinary team (IDT) ensures reliable access and attention in the days before death, and provides developmentally appropriate education to the patient, family and/or other caregivers about what to expect near death, as well as immediately following the patient's death.

The interdisciplinary model of hospice care is recognized conceptually and philosophically as the best care for patients nearing the end of life. Discussion regarding hospice as an option for support should be introduced early so that patients and families can understand eligibility, and the benefits and limitations of accessing this care model. Early access to hospice support should be facilitated whenever possible to optimize care outcomes for the patient and the family. Palliative care teams, hospice providers and other healthcare organizations must work together to find innovative, sustainable supportive care solutions for all patients and families in their final months of life.

Guideline 7.1 Interdisciplinary Team

The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement. The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent.

Criteria:

7.1.1 IDT members have training and expertise regarding care of patients nearing the end of life. Staff training includes:

a. Ensuring frequent telephone and in-person contact with patient and family caregivers in the days before death

b. Supporting notification of distant family and friends, as desired by the patient and family caregivers

c. Assessing and managing physical symptoms that are common among patients nearing the end of life, including, but not limited to, pain, dyspnea, nausea, agitation, delirium, and terminal secretions (see Domain 2: Physical Aspects of Care)

d. Identifying signs and symptoms of approaching death, and what can be expected before and after the patient dies

e. Talking about approaching death with patients and families

f. Identifying spiritual concerns related to dying, death, and beliefs about the afterlife (see Domain 5: Spiritual, Religious, and Existential Aspects of Care)

Note: Words bolded in red are defined in the Glossary.

g. Facilitating cultural assessments and attending to the cultural aspects of care at the end of life, including cultural rituals and beliefs related to dying, death, or the afterlife (see Domain 6: Cultural Aspects of Care)

h. Supporting legacy building activities, including life review, notes to family and friends, or a video diary

i. Supporting resolution of legal issues (see Domain 8: Ethical and Legal Aspects of Care)

j. Coordinating care for patients and the importance of seamless care transitions

k. Discussing hospice eligibility and services

l. Planning for post-death care, including funeral planning

m. Assessing and addressing the needs of children or adolescents facing the loss of a family member, including custody arrangements as needed, and coordinating with perinatal and pediatric grief specialists as needed

n. Providing grief and bereavement support

Guideline 7.2 Screening and Assessment

The IDT assesses physical, psychological, social, and spiritual needs, as well as patient- and family preferences for setting of care, treatment decisions, and wishes during and immediately following death. Discussions with the family focus on honoring patient wishes and attending to family fears and concerns about the end of life. The IDT prepares and supports family caregivers throughout the dying process, taking into account the spiritual and cultural background and preferences of the patient and family.

Criteria:

7.2.1 The IDT:

a. Assesses for signs and symptoms that the patient is nearing death

b. Prepares family and other caregivers regarding how to recognize and manage common symptoms

c. Reviews and confirms treatment decisions, including potential transitions in care settings, and documents patient wishes and preferences

d. Reviews advance directives (as applicable) and honors the patient's wishes

e. Provides information and support to the family and others who are providing care to the patient

7.2.2 For patients who have not accessed hospice, the IDT discusses the benefits of hospice with the patient and family.

7.2.3 Before the patient's death, the IDT discusses autopsy, organ and tissue donation, and anatomical gifts in a culturally sensitive and age-appropriate manner, adhering to applicable organizational policies and laws.

Guideline 7.3 Treatment Prior to Death

In collaboration with the patient and family and other clinicians, the IDT develops, implements, and updates (as needed) a care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual symptoms. The care plan addresses the focus on end-of-life care and treatments to meet the physical, emotional, social, and spiritual needs of patients and families. All treatment is provided in a culturally and developmentally appropriate manner.

Criteria:

7.3.1 With the involvement of the patient and family, a plan is developed to meet patient needs during the dying process, as well as the needs of family members before, during, and immediately following the patient's death. Cultural and spiritual preferences of the patient and family are particularly relevant when developing this plan. Reassessment and revision of the plan occurs regularly, with the frequency identified in agency or program policies.

7.3.2 Care of the patient at the end of life is time- and detail intensive, requiring expert clinical, psychological, social, and spiritual attention to the process as it evolves.

7.3.3 The IDT continues to evaluate the best setting of care for the patient, including consideration of patient- and family wishes and caregiver capacity, as well as the evaluation of symptom management issues that may need an inpatient stay or a higher level of staff support. The IDT is in regular communication with the patient and family to evaluate options and prepare for transitions in care if needed.

7.3.4 The IDT ensures access to medications, supplies, and equipment that may be needed.

7.3.5 In all care settings, the IDT provides education and instructions to family members and/or caregivers in preparation for the patient's death, with emphasis on whom to notify, and what to expect when symptoms change and after the patient dies.

   a. Education and instructions are provided in accordance with the patient- and family's health literacy levels and cultural preferences.

7.3.6 Family expectations regarding IDT availability during the dying process are identified in advance so that staff can alleviate concerns and communicate realistic expectations.

7.3.7 The IDT elicits and honestly addresses hopes, fears, and expectations about the dying processes in ongoing communications with the patient and their family in a developmentally appropriate and culturally sensitive manner.

7.3.8 The IDT provides anticipatory grief support to the family and caregivers.

Guideline 7.4 Treatment During the Dying Process and Immediately After Death

During the dying process, patient and family needs are respected and supported. Post-death care is delivered in a manner that honors patient and family cultural and spiritual beliefs, values, and practices.

Criteria:

7.4.1 The IDT communicates signs and symptoms of imminent death in culturally and developmentally appropriate language, taking into account the cognitive abilities of the patient and family.

7.4.2 Consistent with commitments to the patient and family, the IDT is available to provide support during the dying process.

7.4.3 Immediately following death, the IDT either directly or in collaboration with others, provides respectful care of the body and support for the family based upon the cultural and spiritual practices identified by the patient and family. Post-death care is in accordance with agency practice, local laws, and state regulations.

7.4.4 An IDT member supports the family before and immediately following the patient's death, assisting with cultural or spiritual practices, funeral arrangements, and cremation or burial planning.

7.4.5 Medications are disposed of in accordance with Drug Enforcement Administration (DEA) disposal guidelines, local, state or federal laws, and agency policies in all care settings. If the medications are in the home, providers must adhere to the drug disposal policy of the DEA, paying particular attention to the role of the health care professional in the home setting.

Guideline 7.5 Bereavement

Bereavement support is available to the family and care team, either directly or through referral. The IDT identifies or provides resources, including grief counseling, spiritual support, or peer support, specific to the assessed needs. Prepared in advance of the patient's death, the bereavement care plan is activated after the death of the patient and addresses immediate and longer-term needs.

Criteria:

7.5.1 The IDT directly, or through referral, provides bereavement services and support to the family for a minimum of 13 months after the death of the patient. Bereavement services include:

a. Support, including individual counseling or group support as desired

b. Information and educational resources regarding grief, including the potential physical manifestations of grief

c. Rituals that acknowledge loss and transition, provide opportunity for remembrance, and establish a sense of community

7.5.2 The IDT has processes in place outlining specific roles and responsibilities of IDT members in the provision of bereavement services, and identifies one IDT member with bereavement care expertise to help other staff and volunteers offering bereavement support utilize evidence-based practices.

7.5.3 The IDT refers to the care plan to review issues identified during the assessment of anticipatory grief (see Domain 3: Psychological and Psychiatric Aspects of Care), and formulates and activates a post-death bereavement plan based on a social, cultural, and spiritual grief assessment.

7.5.4 Either directly or through referral, patients and families at risk for prolonged grief disorder are identified and provided with services and support consistent with the assessed need.

7.5.5 Prior to and after death, the IDT works with the family to identify cultural beliefs and traditions, as well as emotional, spiritual, and social resources that can provide them with comfort and support in their grieving process.

7.5.6 Grief and bereavement support and interventions are in accordance with developmental, cultural, and spiritual needs and the expectations and preferences of the family.

7.5.7 Grieving children are referred to pediatric grief specialists, programs, and camps based on their age and needs.

7.5.8 The IDT assesses resiliency, cumulative loss, and grief, and offers supports and services to IDT members. Emotional support services are also made available to ancillary team members involved in supporting palliative care patients.

Clinical and Operational Implications

Clinical Implications

While the IDT may follow patients receiving palliative care from early in their disease process, additional clinical skills help to identify signs and symptoms of approaching death. Discussions about, and referral to, hospice are offered as early as possible. The IDT must assess for fears, address concerns, provide caregiver training, and support the family through the dying process and post-death. It is essential that the IDT attends to patient and family cultural and spiritual beliefs, values, and practices to promote a peaceful, dignified and respectful death, in all settings of care.

Operational Implications

Caring for patients nearing the end of life may take place in any setting (eg, hospital, nursing home, assisted living facility, hospice inpatient facility, or at home). Decisions regarding preference and need for transitions in care settings may be required. Attention to patient comfort and wishes, as well as support to family members during the dying process are paramount operational concerns. Care near the end of life is often more intense than care earlier in the disease process, requiring increased visit length and frequency, as well as timely telephone response, to adequately care for patients and their families. In addition, staffing is needed to support families during the grief process. Specialist-level pediatric palliative care may be required when the patient is a minor or when the patient's immediate family includes children.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians in all care settings who learn the hospice eligibility criteria can make timely referrals to hospice. In addition, clinicians can improve patient care by learning how to assess and manage physical symptoms common among patients nearing the end of life. All clinicians must have the knowledge and skills to talk to patients and families about dying.

Key Research Evidence

The systematic review addressed two key questions: KQ7a) *What is the effect of grief and bereavement programs on family/caregiver outcomes*; and KQ7b) *What is the impact of hospice and palliative care in the final days of life on quality of care and quality of death/dying?* Six systematic reviews were identified pertaining to KQ7a and two pertaining to KQ7b. The evidence tables in the systematic review describe the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D7-A

A large **children's hospital** recognized that all units, particularly those caring for children with a higher risk of death, should provide excellent palliative care. The perinatal and neonatology teams provide training for all staff in palliative care, and a team of prenatal/neonatal clinicians, including social work, physicians, nurses, child life, and chaplaincy, have become the leaders for this care. This team has developed protocols for symptom management, and converted a hospital room dedicated to imminently dying infants to provide privacy and support. A comprehensive perinatal and pediatric bereavement program provides support to grieving parents, siblings, and grandparents, including follow-up through the first year after the baby's death.

Practice Example D7-B

A large **renal dialysis group** has several dialysis centers located in urban and rural settings. They identify that few of their patients are referred to hospice, and most are dying in acute care settings (often in intensive care). They receive complaints from families who felt ill-prepared for the sudden death of their loved one. The dialysis group commits to improving care at the end of life for their patients and looks to the NCP Guidelines. The dialysis centers begin with palliative care education for all staff, and establish a collaborative relationship with an area hospice to develop educational materials and resources for staff regarding hospice eligibility. The social workers in the dialysis centers take the lead in implementing a systematic approach to advance care planning for all dialysis patients, often facilitating family meetings. This advance care planning initiative identifies the need for more family- and caregiver support, such as educational materials and support groups for family members while patients are receiving dialysis. The dialysis centers in several locations work closely with area hospice programs to ensure that transitions of care are optimized for patients who have decided to stop dialysis. As a result of these efforts, recent audits of patient deaths document better preparation for end of life, increased hospice utilization, and more patients dying in their preferred setting.

Practice Example D7-C

A **pediatric neurology practice** serves a large population of children with severe neuromuscular diseases and brain tumors. Many of these children utilize the emergency department in the last month of life, and often die in the hospital, emergency department or intensive care unit (ICU). Once hospitalized, the children and families receive support from an inpatient palliative care service, but at discharge there are few resources available to them. In consultation with the palliative care service, the neurological practice recruits an advanced practice registered nurse who is certified in hospice and palliative care. The nurse works with the inpatient service to create protocols for symptom management, and improve support for parents caring for children at home. This leads to a more active collaboration with home health and home hospice agencies and both agencies commit to rapidly scaling their capacity to care for pediatric patients, particularly those with end-of-life needs.

Practice Example D7-D

A well-established **hospice program** expands into a new region and is quickly challenged by the cultural beliefs of the population it now serves. Increasingly, patients and families ask that only their own spiritual leader provide care, and decline any involvement of the hospice chaplains. Many male patients decline hands-on care from a female nurse (unless she is accompanied by a male physician), and likewise decline care from male physicians and nurses for female patients. Many families request that their family member be hospitalized as death nears, expressing that death in the home is not culturally acceptable and marks them unfavorably. The hospice engages cultural representatives from the community who can help the team better understand the context for these requests in an effort to meet the needs of the patients and families. The hospice chaplains create a monthly interfaith discussion group with community spiritual care leaders, which gives rise to a community advisory council. The hospice explores ways to hire a male staff to increase its capacity. Hospice leaders contract with local nursing homes for beds so that patients do not have to die at home.

Practice Example D7-E

A **community-based palliative care program** finds a small, but substantial, percentage of its patients are not willing to access hospice support when they become eligible. Despite education, support, and frequent conversations, approximately 15% of the patients and families in the palliative care program end up waiting until a few days before death to access hospice. This sets up repeated occurrences of stressful deaths for both patients and family members, as well as hospice staff. The palliative care and hospice teams meet to develop a rapid response program for late admissions in order to work together more seamlessly. They pilot integrating the hospice social worker and/or chaplain into the palliative care team for patients who are eligible but decline to use hospice care. They track outcomes, including time spent on hospice care, and family caregiver distress and satisfaction with this intervention. They also systematically meet to debrief short length of stay hospice patients to gather lessons, identify opportunities for improvement, and support and affirm one another in the work.

Domain 8: Ethical and Legal Aspects of Care

The palliative care interdisciplinary team (IDT) applies ethical principles to the care of patients with serious illness, including honoring patient preferences, as well as decisions made by legal proxies or surrogate decision-makers. It is important to note that in all cases surrogates' obligations are to represent the patient's preferences or best interests. Familiarity with local and state laws is needed relating to advance care planning, decisions regarding life-sustaining treatments, and evolving treatments with legal ramifications (eg, medical marijuana), especially when caring for vulnerable populations, such as minors, prisoners, or those with developmental disability or psychiatric illness.

Guideline 8.1 Global

The core ethical principles of **autonomy**, **substituted judgment**, **beneficence**, justice, and **nonmaleficence** underpin the provision of palliative care.

Criteria:

8.1.1 Palliative care in all care settings is modeled on and consistent with existing professional codes of ethics, conflicts of interest, scopes of practice, and standards of care for all relevant disciplines.

8.1.2 All IDT members have education in the fundamental ethical, legal, and regulatory principles guiding care of the seriously ill.

8.1.3 Clinicians aim to prevent, identify, and resolve ethical dilemmas common to the provision of palliative care, such as forgoing or discontinuing treatments, instituting do not resuscitate (DNR) orders or other state-specific portable medical orders (eg, POLST/MOLST), and the use of sedation of the imminently dying.

8.1.4 Ethical issues are documented, and referrals are made to ethics consultants or an ethics committee for case consultation and assistance in decision-making and conflict resolution, as needed.

8.1.5 Ethics consultants or committees guide policy development and provide staff education in areas, such as:

a. Medically **non-beneficial care**

b. A patient's right to decline treatments of any kind

c. Cessation of medically provided nutrition and hydration

d. Foregoing or discontinuing technology (eg, ventilators, dialysis)

e. Use of high-dose medications

f. Sedation of the imminently dying

g. Requests for physician-assisted death

Note: Words bolded in red are defined in the Glossary.

8.1.6 IDT protocols are developed to ensure patient and family access to ethics resources and support in all care settings.

8.1.7 IDT members maintain professional boundaries, setting clear role expectations with patients, family members, and caregivers, balancing objectivity with caring compassion.

8.1.8 Attention is paid to patient and family cultural and spiritual values that impact care preferences and potentially conflict with clinicians' values. The IDT is aware that cultural factors can influence decision-making and autonomy (see Domain 6: Cultural Aspects of Care).

8.1.9 Guidance is provided to surrogate decision-makers about the legal and ethical basis for surrogate decision-making, including honoring the patient's known preferences, substituted judgment, and best-interest criteria.

8.1.10 Social justice principles and costs of care are considered in the allocation of resources across all populations to improve the health outcomes of seriously ill people and address healthcare disparities.

8.1.11 IDTs without ready access to ethics consultation identify avenues to access consultations and resources (eg, consult with specialty palliative care experts or establish a collaborative relationship with a medical center ethics program).

8.1.12 Ensuring IDT sustainability and avoiding clinician burnout is considered an ethical obligation in all care settings to preserve team members' health and ability to remain engaged in palliative care (see Domain 1: Structure and Processes of Care).

Guideline 8.2 Legal Considerations

The provision of palliative care occurs in accordance with federal, state, and local regulations and laws, as well as current accepted standards of care and professional practice.

Criteria:

8.2.1 Clinicians who care for patients with serious illness are knowledgeable about organizational policies, as well as federal and state statutes, regulations, and laws regarding:

- a. Disclosure of medical records and health information
- b. Medical decision-making
- c. Advance care planning and advance directives
- d. The roles and responsibilities of surrogate decision-makers
- e. Guardianship
- f. Abuse and neglect
- g. Concurrent hospice care provision for pediatric patients
- h. Prescribing of controlled substances

i. Death pronouncement and death certification processes

j. Autopsy requests, organ and anatomical donation

k. Emerging issues (eg, medical marijuana, physician aid in dying, opioid abuse)

8.2.2 The IDT adheres to legal and regulatory requirements for disclosure, decision-making **capacity** assessment, confidentiality, and informed consent.

8.2.3 Attention is paid to the rights of children and adolescents in decision-making, as well as applicable statutes.

8.2.4 The IDT establishes and implements policies regarding:

a. IDT compliance with state and federal legal and regulatory requirements regarding patient and family abuse, neglect, suicidal ideation, self-harm, and potential harm to others

b. Conflicts of interest, including the receipt of gifts from patients, families, or other care providers

c. Care of and communication about minor patients in state custody, including involvement of biological, adoptive, or foster families in decision-making and treatment planning

d. Other emerging issues, as needed

8.2.5 Legal counsel is accessible to advise providers regarding common palliative care situations including, but not limited to:

a. Determination of capacity to make medical decisions

b. Safety and other considerations for patients without caregivers or support

c. Patient or family requests for care that is not medically indicated or may cause undue burden on the patient

d. Withdrawal of technology (eg, ventilators, dialysis, cardiac devices)

e. Cessation of medically provided oral nutrition and hydration

f. Sedation of the imminently dying

g. Requests for physician aid-in-dying

h. Patients who are in custody, on parole, or have other legal issues impacting their care

i. Children in foster care or protective custody

8.2.6 The IDT recognizes the role of cultural and spiritual factors in the application of professional obligations, including diagnosis, disclosure, decisional authority, acceptance of, and decisions to forgo treatments (see Domain 6: Cultural Aspects of Care).

8.2.7 Patients and families are routinely encouraged to create or update legal and financial documents, such as wills, guardianship agreements, and custody documents.

8.2.8 Clinicians are aware of legal guidelines and processes to determine and document when a patient has no surrogate (ie, the unbefriended patient), as well as the laws relevant to clinicians making care decisions for these patients.

Guideline 8.3 Screening and Assessment

The patient's preferences and goals for medical care are elicited using core ethical principles and documented.

Criteria:

8.3.1 Clinicians discuss achievable goals of care in the context of patient values and preferences.

8.3.2 Advance care planning education is provided to the patient and family to promote communication and understanding of the patient's preferences across the care continuum, including completion of advance directives, such as:

a. Designation of a surrogate health care decision-maker (except for minors)

b. Living wills

c. Inpatient and out-of-hospital do-not-resuscitate orders and other portable medical orders

8.3.3 The patient-expressed values, care preferences, spiritual beliefs, and cultural influences are elicited, routinely reviewed, and documented, with particular attention to changes in health care status or transitions of care.

8.3.4 Acknowledging that preferences change over time, the IDT revisits and updates a patient's decisions and desires for care when the clinical status changes. All changes are documented in the medical record, especially prior to care transitions.

8.3.5 To ensure availability of **advance care planning documents**, the IDT uses electronic medical records or advance directive registries whenever possible. Clinicians ensure that the treatment plan is concordant with the patient's evolving goals across settings.

8.3.6 Patients with disabilities are assumed to have decision-making capacity unless determined otherwise, according to applicable laws.

8.3.7 When caring for pediatric patients with serious illness, the child or adolescents' views and preferences for medical care, including assent for treatment (when developmentally appropriate), are assessed, documented, and given appropriate weight in decision-making.

8.3.8 For patients who are not developmentally able, or have cognitive and/or communication impairment or incapacity, and have not previously expressed their values, preferences, or beliefs, IDT members follow state laws to identify a default decision-maker.

8.3.9 Clinicians consider the aspects of patient care that may burden or have ill effects on family members. The IDT has a responsibility to identify these difficulties when possible and within its scope of practice and assist in identifying resources to meet these needs.

Guideline 8.4 Treatment and Ongoing Decision-Making

Within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice, person-centered goals form the basis for the plan of care and decisions related to providing, forgoing, and discontinuing treatments.

Criteria:

8.4.1 The patient's plan of care reflects ethical principles and the assessment of treatment preferences. The plan of care is accurately documented to reflect the patient's previously stated goals in terms of providing, forgoing, and discontinuing care.

8.4.2 The IDT ensures that existing treatments align with the patient's goals and the standard practices of care, and the team actively works to prevent medically non-beneficial care.

8.4.3 When a family member or surrogate decision-maker seeks to override the patient's documented treatment decisions, the patient's preferences are reviewed, and ethics consultation is sought if needed.

8.4.4 Failure to honor patient preferences is considered an ethical concern and is addressed by the IDT.

8.4.5 Children receive open and honest, developmentally appropriate information about their serious illness and treatment options, and are given the opportunity to participate in decision-making according to their wishes, age, and developmental capacity. When the child's wishes differ from those of the adult decision-maker, staff is available to assist the child and family work towards a resolution, prioritizing fidelity to the patient.

8.4.6 When parents or legal decision-makers express a strong preference for non-disclosure of a poor prognosis to a seriously ill child or adolescent, the IDT assesses family motivations and values regarding truth-telling practices and preferences. While it is sometimes ethically permissible to defer to family values regarding nondisclosure of prognosis, clinicians work collaboratively with the family to meet the child or adolescent's individual needs while respecting the parent or decision-makers' expectations and boundaries.

8.4.7 All treatments provided are directed at the relief of suffering, in accordance with the **doctrine of double effect**.

8.4.8 The IDT educates the patient and family regarding the cost of care and financial burdens associated with treatment options.

8.4.9 In cases where the wishes of the patient (or patient preferences expressed by the surrogate) conflict with the clinicians caring for the patient, processes are in place to honor clinician conscientious objection in a manner that ensures patients are never abandoned and continue to receive quality, safe care.

8.4.10 When treatments are forgone or discontinued, the IDT ensures appropriate symptom control at all times, as aligned with the ethical principle of nonmaleficence.

Clinical and Operational Implications

Clinical Implications

Ethical and legal principles are inherent to the provision of palliative care to patients with serious illness, including principles of self-determination, beneficence, nonmaleficence, and justice. Clinicians caring for seriously ill patients understand ethical principles underlying health care delivery in the context of their own professional practice setting and discipline, as well as the laws and statues governing health care. In all contexts, the IDT provides attention to moral agency and emphasis on collaborative practice. The IDT works to recognize and be mindful of its own values and beliefs when facilitating informed decision-making, and participating in ethical dilemma resolution. As the team works to maintain relationships with the patient and family, it also recognizes the importance of maintaining professional boundaries across all settings and contexts, regardless of patient age.

Operational Implications

Clinicians caring for seriously ill patients have access to legal and ethical experts for consultation to deliver high-quality palliative care regardless of setting or location of care. Conference calls and video-conferencing provides access to experts in all care settings.

Essential Palliative Care Skills Needed by All Clinicians

Many clinicians have studied medical ethics and understand the ethical principles most applicable at the end of life. All clinicians working with seriously ill patients benefit from learning about advance care planning and common scenarios that cause ethical and legal conflicts. In addition, all clinicians know how to access legal experts, ethicists, or ethics committees, as well as specialist-level palliative care teams, to ensure the provision of high-quality care in alignment with patient goals.

Key Research Evidence

The systematic review addressed the following key question: KQ8) *What is the impact of advance care planning on substituted decision-making regarding life-sustaining treatments?* Thirty-six systematic reviews were identified pertaining to KQ8. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D8-A

A **long-term care** setting is incorporating palliative care for patients in its day center, residential care, and long-term care programs. A physician assistant and social worker lead efforts to improve advance care planning and completion of formal directives. Varying levels of decision-making capacity pose a challenge to completing advance directives, and staff need help determining capacity. The facility develops a consultative relationship with a hospital-based palliative care team and ethics consult service for education on determination of capacity and help with challenging scenarios.

Practice Example D8-B

A **community hospice** regularly cares for patients who are discharged from the tertiary hospital. A number of these patients come to hospice without clear directives, often without clear understanding of their condition, prognosis, and what to expect in the future, sometimes leading to their continued desire for attempts at cardiopulmonary resuscitation at the time of death. Hospice staff are stressed by these situations and accuse the hospital teams of failing to get these patients and families "on the hospice page." The groups meet to identify ways they can better manage care transitions for patients and families in general, and especially for patients without a do-not-resuscitate order. The hospice liaison begins to talk daily with the palliative care team to discuss ways to meet the needs of patients. This brings valuable context and history to patients' care plans as they transition to hospice. The hospice team has a deeper appreciation for what the palliative team has done, and what patients are able (or unable) to understand and retain despite communication, and the palliative team is better equipped to communicate to the hospice team the patient's level of understanding and preparation for hospice care.

Practice Example D8-C

A large, **multi-site health system** has reviewed its patient and family satisfaction reports, as well as staff surveys, to plan new initiatives. Staff surveys reveal feelings of inadequacy in how to best care for lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) patients and their families. In some cases, staff voice distress in providing hands-on care for these patients, particularly when they are transgender. Staff members also highlight the challenges in navigating family conflicts, such as when the biological family is in overt conflict with the LGBTQIA partners or spouses. Some family members have also reported high levels of dissatisfaction at the time of death, and instances in which patients' wishes were disregarded, partners/spouses were not notified of a change in patient status, or were excluded from family conferences despite clear patient directives about their wishes to have their partner/spouse involved. The health system addresses this gap in patient-centered care, asking for involvement from the palliative care service and ethics committee. The Human Resources Department Cultural Diversity committee, which had previously focused only on issues of ethnicity and race, has asked a local LGBTQIA center for consultation, education, and resources to effectively address the issues identified.

Practice Example D8-D

A **rural palliative care program** provides care in patients' homes across a large geographic area. The staff is often alone on these visits and sometimes do not see other team members for several days at a time. Team members express stress with some of the ethical issues they confront, particularly when patients have impaired decision-making, when they receive requests for physician aid-in-dying, and when there are family conflicts. The program develops an ethics forum for education, discussion of challenging cases, and identification of practical measures for support. The forum is hosted online, so staff can either listen in or see each other via the computer. The program provides educational podcasts for team members. Leadership facilitates dual visits of the practitioners and social workers to help with challenging cases, and facilitate greater professional and team support.

Practice Example D8-E

A **hospital-based pediatric palliative care** team was approached by members of the pediatric intensive care unit (PICU) care team, who expressed that they were often uncomfortable with the ethical and legal implications of withdrawal of life-sustaining therapies. The PICU care team did not feel that issues including decision-making capacity of the patient, disclosures to the child, staff moral distress, and sedation of the imminently dying were consistently addressed prior to withdrawing the therapies. A multidisciplinary group, including members of the children's hospital Ethics Committee, was convened to initiate the standardization of the withdrawal of life-sustaining therapies process that included addressing potential legal and ethical issues. The process included structured huddles, or team discussions, using a new withdrawal of life-sustaining therapies checklist to document decision-making in the medical record in real time. The checklist of items to be addressed included ensuring presence of child life, chaplaincy and social work, anticipatory symptom management strategies, confirmation with medical decision-maker and, if appropriate, the patient. Following these interventions, staff reported improvement in team communication and reduction of distress surrounding withdrawal of life-sustaining therapies.

Practice Example D8-F

A **community pediatric palliative care** team routinely assesses parental and child/adolescent preferences regarding goals of care, working to meet each family's individualized communication and decision-making needs. A teen with advanced cancer disclosed to the team that he no longer wanted chemotherapy and was ready to die, but he did not want to disappoint or anger his parents. The palliative care team acknowledged the teen's honest expression of his wishes and provided support. With his permission, the team coordinated goals of care discussions with the parents separately, and subsequently with the parents and teen together. The palliative team also drew upon the expertise of their child life specialist, the teen's oncology team at the hospital, along with the hospital's pediatric ethics committee to facilitate a new plan that honored all family members' needs.

Appendix I: Glossary

Acculturation: "…the process of cultural and psychological change that results following meeting between cultures."[1]

Activities of daily living (ADLs; also see "Instrumental activities of daily living"): "…are activities related to personal care. They include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating."[2]

Advanced practice providers: Defined in the NCP Guidelines as physician assistants and advanced practice registered nurses utilized to expand the capacity of palliative care interdisciplinary teams to deliver complex care and provide direct care.

Advance care planning documents: "…allow individuals to share their treatment preferences in the event they can no longer speak for themselves." There are two kinds: legal documents and medical orders (eg, legal: living wills, health care surrogate; medical: do not resuscitate (DNR) orders, physician orders for life-sustaining treatment (POLST)).[3]

Anticipatory grief: "…a complex concept that encompasses grief in anticipation of the future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness."[4]

Autonomy: "The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive."[5]

Beneficence: "The ethical principle of beneficence requires healthcare professionals to treat their patients in a way that provides maximum benefit to that patient."[6]

Bereavement: "The process of grieving and letting go of a loved one who has died."[7]

Capacity: See "Decision-making capacity."

Care coordination: "Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care."[8 9]

Care plan: In palliative care, the interdisciplinary team develops the care plan, with input from all health and social support providers. The care plan is based on the patient's goals of care, as well as information gathered via the comprehensive assessments. The services and support needed to achieve those goals and reduce suffering are described, including plans to monitor and adjust the plan based on subsequent patient and family assessments.

Care transitions: "The term care transition describes a continuous process in which a patient's care shifts from being provided in one setting of care to another, such as from a hospital to a patient's home or to a skilled nursing facility and sometimes back to the hospital."[10] In addition, care transitions occur when patients change care providers.

Note: Words bolded in red are defined in this Appendix.

Caregiver assessment: "Caregiver assessment is a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to the needs of the care recipient."[11]

Clinician: In the context of the NCP Guidelines, clinician refers to any health professional providing direct care to seriously ill person sand their families, whether primary care practitioners, specialist consultants, or specialist-level palliative care teams. While any clinician can apply palliative care principles and practices, specialist palliative care teams are interdisciplinary, and the team members have certification or specialty-level competency to provide specialist palliative care.

Cognitive impairment: "Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently."[12]

Communication: In palliative care, "promoting and facilitating open communication to foster patient- and family-centered shared decision-making, and advance care planning is essential. Ethnic and cultural differences should be acknowledged. Family members' decision-making strategies around options of care, location, and preferences should take into account cultural, ethnic, and religious preferences. The earlier these discussions can occur, the better, so when there are unexpected changes in a patient's condition, discussions have already happened, and decisions have been made."[13]

Comprehensive assessment: "Rather than gathering information exclusively from the patient (or caregivers) and medical records, palliative evaluation utilizes a broad range of sources, each contributing to the final assessment. In an interdisciplinary manner, the physician collaborates with nursing staff, chaplains, social workers, therapists, and nutritionists to perform discipline-specific evaluative tasks, together developing the comprehensive palliative assessment. Tasks that are best shared with expert nonphysician team members may include evaluation of existential and spiritual domains, economic needs, and care coordination; however, specific distribution will vary depending on local expertise."[14]

Continuous quality improvement (CQI): uses an "'iterative approach that aims to reduce and eventually eliminate 'unexplained clinical variation.' Reducing such variation addresses the root of many of health care's inefficiencies, excess costs, and poor outcomes. CQI calls for a cultural shift that relies on clinicians constantly asking themselves, 'How could this process be better?' and 'How can I impact this change?' The underpinnings of this approach view each clinician as an informed agent who can identify bad processes and implement changes. It views medical errors and inefficiencies as results, not of bad people, but of suboptimal processes of care. CQI also recognizes that heterogeneity in patient characteristics, values, and clinical settings dictates that prudent decision-making formulated to reduce unnecessary clinical variation does not mean that 100% of care may meet a quality measure."[15]

Cultural humility: "In a multicultural world where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning."[16]

Decision-making capacity: "Medical decision-making capacity refers to the time-sensitive determination of a patient's ability to make a specific clinical choice." [17] Thoughtful assessment of capacity is essential for providing care that preserves and respects a patient's autonomy, while meeting the ethical and legal standards of informed consent.

Developmentally appropriate: Providers of palliative care seek to provide developmentally appropriate care to all people living with a serious illness. Such care "incorporates advanced decision making based on young adult cognitive abilities, acknowledges and treats the high symptom burden, promotes this time of psychological and spiritual growth, and ultimately, empowers and honors this special time of life."[18]

Doctrine of double effect: "…draws a distinction between impermissible intended consequences and permissible (merely) foreseen consequences." There are four conditions that are applied: 1) "the action itself (as distinct from its consequences or effects) must not be inherently morally wrong," 2) "the intention must be to produce the good effect," 3)"the good effect must not be brought about via the bad effect," 4) "…there is an appropriate balance (ie, proportionality) between the good and the bad effects, such that the good effect must outweigh the bad."[19]

Existential: Existential refers to a philosophical approach in which one's primary task is to find what determines one's own level of meaning in life. Often this may involve an anguished process where prior beliefs no longer seem valid, and one begins a journey to find one's own meaning in life. Meaning is often conceived in a way that is personal and acknowledges that others may hold other quite different meanings. At the end of life, terminally ill individuals may expand their curiosity in the hope that this will lead to new self-discovery. This often takes an individual through a process of uncertainty and ambiguity that includes the re-examination of prior understandings to determine what one holds for the self to be true.[20]

Family: The patient defines who constitutes their family and "determine how they will participate in care and decision-making."[21]

Family caregiver: "A family caregiver is someone who is responsible for attending to the daily needs of another person. Family caregivers are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend."[22]

Gender expression: "The way individuals express or present to others their internal sense of masculinity or femininity."[23]

Gender identity: "One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth."[24]

Grief: **"**The emotional, cognitive, functional and behavioral responses to the death. Also, grief is often used more broadly to refer to the response to other kinds of loss; people grieve the loss of their youth, of opportunities, and of functional abilities."[25]

Health care surrogate (health care proxy, health care agent): A health care surrogate is someone appointed to make health care decisions when the patient is unable to make or communicate decisions. The surrogate can be appointed by the patient via an advance directive, or serve as a court-appointed guardian. If the health care providers are unable to locate a decision-maker, a decision-maker may be appointed in accordance with state laws.

Historical trauma: The "cumulative emotional and psychological wounding across generations, including the lifespan, which emanates from massive group trauma; the historical trauma response is the constellation of features in reaction to this trauma…includes depression self-destructive behavior, suicidal thoughts and gestures, anxiety, low self-esteem, anger, and difficulty recognizing and expressing emotions."[26]

Hospice: "Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well."

"Hospice focuses on caring, not curing and in most cases care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations."[27]

Instrumental activities of daily living (IADLs; see also "Activities of daily living"): "Instrumental Activities of Daily Living (IADLs) are activities related to independent living. They include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone."[28]

Interdisciplinary team: "The interdisciplinary model is based on synergistic and interdependent interaction of team members who each possess particular expertise. Team members work closely together, actively communicating and sharing information. Leadership is often task-dependent, defined by each situation. Collaboration is identified as the process central to the interactions between members."[29]

Intersections of race (Intersectionality): "A way of understanding and analyzing the complexity in the world, in people, and in human events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people's lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axis that work together and influence each other."[30]

Long-term services and supports (LTSS): "…encompasses the broad range of paid and unpaid medical and personal care assistance that people may need – for several weeks, months, or years – when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability."[31]

Non-beneficial care: "A treatment determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient's well-being or of achieving agreed-on goals of care."[32]

Nonmaleficence: "Obligation not to inflict harm intentionally."[33]

Palliative care: Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing seriously ill people relief from the symptoms and stress of an illness. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

Palliative care interdisciplinary team (IDT): Specialty palliative care interdisciplinary teams collaborate with other care providers to directly provide and coordinate care. Depending on the care needs of each patient and family, the IDT can expand to include other clinicians and community service providers. All team members are responsible to screen for unmet needs outside of their scope and access team members with expertise for full assessments. (See Domain 1: Structures and Processes for Care for a list of palliative care interdisciplinary team disciplines.)

Palliative care specialists: Palliative care specialists include "physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains."[34]

Primary palliative care (also known as generalist): "Palliative care that is delivered by health care professionals who are *not* palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care."[35]

Professional chaplain: The professional chaplain is master's level prepared and has participated in 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 interdisciplinary team, and is trained to address spiritual and religious concerns of all patients and caregivers, 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.

Psychological/psychiatric: **"**The psychosocial implications of disease progression result in a range of challenges for both the patient and the caregiver. The consequences of advanced disease can comprise emotional states such as anxiety, distress and depressive episodes, fear of being a burden to others, loss of control, anger, loss of sense of dignity, uncertainty, and changes in close relationships and social roles. Adjustment disorder, anxiety disorder, depressive disorder, and the demoralization syndrome represent common disorders and phenomena among patients with advanced cancer. Moreover, uncontrollable pain and high unrelieved physical symptom burden, depression, feelings of helplessness and hopelessness, delirium, and low family support are major factors in the desire for thoughts of suicide and the desire for hastened death. Caregivers play an important and challenging role, providing emotional and social support for the patient, helping with medical needs, and meeting increasingly complex instrumental needs such as running the household and work."[36]

The psychiatric syndromes that may manifest for a patient and/or family member during a serious or life-threatening illness include depression, anxiety, and delirium. Patients and family members may already be diagnosed with a mental health disorder, which could include any listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). Psychiatric conditions can be challenging for palliative care staff to differentiate from the serious illness because symptoms may intersect with those of the medical conditions. Psychiatry can assist in these situations, as well in the use of psychotropic medications.[37]

Religion: "…involves beliefs, practices, and rituals related to the sacred. Religion may also involve beliefs about spirits, both good (angels) and bad (demons). Religion may be organized and practiced within a community, or it may be practiced alone and in private. In either case, religion originates in an established tradition that arises out of a community with common beliefs and practices."[38]

Serious illness: 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."[39]

Shared decision-making: "At its core, shared decision making is an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care."

"Three essential elements must be present for shared decision making to occur. First, both the health care provider and the patient must recognize and acknowledge that a decision is, in fact, required. Second, they must both know and understand the best available evidence concerning the risks and benefits of each option. Third, decisions must take into account both the provider's guidance and the patient's values and preferences."[40]

Social determinants of health: "The social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries."[41]

Specialist palliative care: Specialist palliative care is the active, total care of patients with serious illness and their families. Care is provided by an interdisciplinary team whose members have undergone recognized specialist palliative care training.

Spirituality: Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered care. "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."[42]

Spiritual assessment: "Formal spiritual assessment refers to a more extensive process of active listening to a patient's story conducted by a board-certified chaplain that summarizes the needs and resources that emerge in that process. The chaplain's summary should include a spiritual care plan with expected outcomes that is then communicated to the rest of the treatment team. Unlike history taking, the major models for spiritual assessment are not built on a set of questions that can be used in an interview. Rather, the models are interpretive frameworks that are based on listening to the patient's story as it unfolds. Because of the complex nature of these assessments and the special clinical training necessary to engage in them, this assessment should be done only by a board-certified chaplain or an equivalently prepared spiritual care provider."[43]

Spiritual distress: "…a state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being. This definition contains the attributes of spiritual distress: suffering, impaired spirituality, contrary to spiritual well- being, and related to meaning in life."[44]

Spiritual history: "…history-taking uses a broader set of questions to capture salient information about needs, hopes, and resources. The history questions are asked in the context of a comprehensive examination by the clinician who is responsible for providing direct care or referrals to specialists. The information from the history permits the clinician to understand how spiritual concerns could either complement or complicate the patient's overall care. It also allows the clinician to incorporate spiritual care into the patient's overall care plan. Unlike spiritual screening, which requires only brief training, those doing a spiritual history should have some education in and comfort with issues that may emerge and knowledge of how to engage patients comfortably in this discussion."[45]

Spiritual screening: "Spiritual screening or triage is a quick determination of whether a person is experiencing a serious spiritual crisis and therefore needs an immediate referral to a board-certified chaplain. Spiritual screening helps identify which patients may benefit from an in-depth spiritual assessment. Good models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family screening. Examples of such questions include, '*Are spirituality or religion important in your life?*' and '*How well are those resources working for you at this time?*'"[46]

Substituted judgement: Substituted judgement refers to the ethical duty of guardians and surrogate decision-makers to make an effort to understand the patient's beliefs and values prior to making decisions on the patient's behalf.

Total pain: A holistic experience that extends beyond the physiological domain and was first introduced by Dame Cicely Saunders in the 1960s. Total pain recognizes the holistic nature of pain and the interplay of psychological and social well-being, spirituality, and culture. Symptoms rarely occur in isolation; rather, they cluster with other symptoms and are influenced by the psychological, social, and cultural characteristics of the individual.[47]

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Appendix II: Tools and Resources

Domain 1: Structure and Processes of Care

- American Academy of Hospice and Palliative Medicine – Quality Initiatives: Links to resources on quality improvement, *Measuring What Matters* and other quality initiatives. http://aahpm.org/education/quality

- California Health Care Foundation – Community-based Palliative Care Resource Center: This online resource center provides strategies and support for organizations that are planning, implementing, or enhancing a community-based palliative care (CBPC) program. http://www.chcf.org/projects/2015/cbpc-resource-center

- California State University Institute for Palliative Care – National Resources: Links to national resources for palliative care programs, on a variety of topics including ACP, special populations, bereavement, hospice and more. https://csupalliativecare.org/resources/

- Center to Advance Palliative Care – Host to the National Palliative Care Registry and other resources to help programs learn about measures and metrics to improve patient and family care. https://www.capc.org/topics/metrics-and-measurement-palliative-care/

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- Institute for Healthcare Improvement – Plan-Do-Study-Act (PDSA) Worksheet http://www.ihi.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx

- National Hospice and Palliative Care Organization – Quality Resource Center: Tools to assess and monitor the quality of care and services hospices provide. https://www.nhpco.org/quality

- National Palliative Care Research Center – Measurement and Evaluation Tools: Links to a selection of tools for assessing pain and assessing and tracking the level of symptoms (some are patient reported). http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx

- National POLST Paradigm – Appropriate POLST Form Use Policy: http://polst.org/appropriate-use-pdf

- Patient Care Quality Network – Templates and resources to improve quality care: https://www.pcqn.org/

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- NHPCO's Standards for Pediatric Care: https://www.nhpco.org/quality/nhpco%E2%80%99s-standards-pediatric-care

Domain 2: Physical Aspects of Care

National Comprehensive Cancer Network Guidelines for Palliative Care, Management of Cancer Pain, Distress Management https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf

Symptom Assessment Tools:

- Edmonton Symptom Assessment: http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf
- Memorial Symptom Assessment Scale: http://www.npcrc.org/files/news/memorial_symptom_assessment_scale.pdf
- Brief Pain Inventory Long Form: http://www.npcrc.org/files/news/briefpain_long.pdf
- Brief Pain Inventory Short Form: http://www.npcrc.org/files/news/briefpain_short.pdf
- Brief Fatigue Inventory: http://www.npcrc.org/files/news/brief_fatigue_inventory.pdf
- McGill Pain Inventory Short Form: http://www.npcrc.org/files/news/mcgill_pain_inventory.pdf
- Palliative Care Outcome Score (POS): https://pos-pal.org/
- MD Anderson Brief Symptom Inventory: https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/md-anderson-symptom-inventory.html
- NCCN Distress Thermometer: https://www.nccn.org/about/permissions/thermometer.aspx
- Confusion Assessment Method: https://www.medscape.com/viewarticle/481726
- Patient Health Questionnaire (PHQ-9): http://www.phqscreeners.com/sites/g/files/g10016261/f/201412/PHQ-9_English.pdf
- Patient Health Questionnaire (PHQ-2): http://www.cqaimh.org/pdf/tool_phq2.pdf
- PainAD Scale: https://www.mdcalc.com/pain-assessment-advanced-dementia-scale-painad

- Wong-Baker Faces Pain Rating Scale: http://www.npcrc.org/files/news/wong_baker_FACES_pain_rating_scale.pdf
- Tools to Assess Self Administration of Medication: https://www.pharmacy.umaryland.edu/practice/medmanagement/assisted_living/Tools-to-Assess-Self-Administration-of-Medication/

Performance/Functional Status Assessment Tools:

- Palliative Performance Scale: http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf
- Karnofsky Performance Scale: http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf
- ECOG Performance Status: http://www.npcrc.org/files/news/ECOG_performance_status.pdf

Pediatric Symptom Assessment Tools:

- Malviya S, Voepel-Lewis T, Burke C. The revised FLACC observational pain tool: Improved reliability and validity for pain assessment in children with cognitive impairment. *Pediatr Anesth, 2006;16*(3):258-265. Available at: http://prc.coh.org/PainNOA/Flacc_Tool.pdf
- Solodiuk J & Curley MAQ. Pain assessment in nonverbal children with severe cognitive impairments: The individualized numeric rating scale (INRS). *J Pediatr Nurs,2003;18*(4):295-299.
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- Krechel SW, Bildner J. CRIES: A new neonatal postoperative pain measurement score: initial testing of validity and reliability. *Pediatr Anesth,1995;5*:53-61.
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- Hummel P, Puchalski M, Creech SD, Weiss MGl. Clinical reliability and validity of the N-PASS: Neonatal pain, agitation and sedation scale with prolonged pain. *J Perinatol, 2008;28*(1): 55-60. Available at: http://www.anestesiarianimazione.com/2004/06c.asp
- Stevens B, Johnston C, Petryshen P, et al. Premature Infant Pain Profile: Development and initial validation. *Clin J Pain*, *1996;12*(1):13-22.
- Lansky Play-Performance Scale for Pediatrics: http://micmrc.org/system/files/Lansky%20Scale.pdf
- Fatigue Assessment: Crichton A, Knight S, Oakley E, Babl FE, Anderson V. Fatigue in child chronic health conditions: A systematic review of assessment instruments. *Pediatrics, 2015;135*(4):e1015-e1031.
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- Hain R, Douglas H. Neurological symptoms. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care.* Philadelphia, PA: Elsevier Saunders, 239-250;2011.
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- Hellsten MB, Stephens K, Sanborn S. Pediatric pain and symptom management. In Kobler, K., & Limbo, R. (Eds.). *Conversations in perinatal, neonatal, and pediatric palliative care.* Pittsburgh, PA: Hospice and Palliative Nurses Association, 58-62;2017.
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Tools and Resources Regarding Opioid Use and Risks:

- Cancer Pain (PDQ®)–Health Professional Version: https://www.cancer.gov/about-cancer/treatment/side-effects/pain/pain-hp-pdq
- Management of Chronic Pain in Survivors of Adult Cancers: American Society of Clinical Oncology Clinical Practice Guideline: http://ascopubs.org/doi/full/10.1200/JOP.2016.014837

- Opioid Risk Tool: https://www.drugabuse.gov/sites/default/files/files/OpioidRiskTool.pdf
- CAGE-AID: https://www.integration.samhsa.gov/images/res/CAGEAID.pdf
- SOAPP-R: http://www.ccwjc.com/Forms/Chronic%20Pain/SOAPP-R.pdf
- Current Opioid Misuse Measure (COMM): http://mytopcare.org/wp-content/uploads/2013/05/COMM.pdf
- DIRE Score: Patient Selection for Chronic Opioid Analgesia http://www.emergingsolutionsinpain.com/content/tools/esp_9_instruments/pdf/DIRE_Score.pdf

Domain 3: Psychological and Psychiatric Aspects of Care

- Distress Thermometer (National Comprehensive Cancer Network, 2003): https://www.nccn.org/about/permissions/thermometer.aspx
- Edmonton Symptom Assessment Scale (ESAS): http://www.palliative.org/NewPC/professionals/tools/esas.html or https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2644623/
- Patient Health Questionnaire (PHQ): http://www.phqscreeners.com/ or http://www.agencymeddirectors.wa.gov/files/AssessmentTools/14-PHQ-9%20overview.pdf
- Beck Depression Inventory (BDI-II): http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/beck-depression.aspx or https://www.sciencedirect.com/topics/medicine-and-dentistry/beck-depression-inventory
- Hospital Anxiety and Depression Scale (HADS): https://hqlo.biomedcentral.com/articles/10.1186/1477-7525-1-29 or http://www.svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf
- State-Trait Anxiety Inventory (STAI): http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/trait-state.aspx or http://growingleadersfoundation.com/wp-content/uploads/2017/03/State-Trait-Anxiety-Inventory.pdf
- Generalized Anxiety Disorder scale (GAD-7): https://www.psychcongress.com/saundras-corner/scales-screeners/anxiety-disorders/generalized-anxiety-disorder-7-gad-7 or https://www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf
- Fear of Disease Progression scale (FoP): http://www.psycho-oncology.info/FOP12.pdf or https://www.ncbi.nlm.nih.gov/pubmed/16125517 or http://media.axon.es/pdf/100475_1.pdf
- Mini-Mental State Examination (MMSE): http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.1992.tb01992.x/full
- Addenbrooke's Cognitive Assessment – Revised (ACE-R): https://www.ipa-online.org/news-and-issues/addenbrookes-cognitive-examination-revised-ace-r or https://www.ncbi.nlm.nih.gov/pubmed/16977673 or https://www.meded.help/wp-content/uploads/2017/04/Addenbrookes_A_SVUH_MedEl_tool.pdf?x30812

- Abbreviated Mental Test Score (AMTS): http://www.oxfordmedicaleducation.com/geriatrics/amts/ or http://onlinelibrary.wiley.com/doi/10.1111/psyg.12276/abstract or https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2560932/
- 6-item Cognitive Impairment Test (6CIT): https://academic.oup.com/ageing/article/47/1/61/4101644 or https://link.springer.com/chapter/10.1007/978-3-319-44775-9_11 or http://www.wales.nhs.uk/sitesplus/documents/862/FOI-286g-13.pdf
- Mental Adjustment to Cancer scale (MAC): https://www.ncbi.nlm.nih.gov/pubmed/18626853 or http://www.oxfordclinicalpsych.com/view/10.1093/med:psych/9780199605804.001.0001/med-9780199605804-interactive-pdf-003.pdf
- Experiences in Close Relationships scale (ECR): https://www.ncbi.nlm.nih.gov/pubmed/17437384 or http://fetzer.org/sites/default/files/images/stories/pdf/selfmeasures/Attachment-ExperienceinCloseRelationshipsRevised.pdf or https://openpsychometrics.org/tests/ECR.php
- Diagnostic Criteria for Psychosomatic Research (DCPR): https://www.ncbi.nlm.nih.gov/pubmed/23383664
- Adverse Childhood Experiences (ACEs) Assessment: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/resilience/Pages/Clinical-Assessment-Tools.aspx
- Medical Outcomes Study Short Form (SF)-36: https://www.sralab.org/rehabilitation-measures/medical-outcomes-study-short-form-36

Domain 4: Social Aspects of Care

- National Association for Social Workers Standards for Palliative & End-of-Life Care: https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3d&portalid=0
- National Academies of Science: Capturing Social and Behavioral Domains and Measures in Electronic Health Records: Phase 2: This consensus study document identifies social and behavioral domains that most strongly determine health that can be used in electronic health records. http://nationalacademies.org/hmd/Reports/2014/EHRdomains2.aspx
- Delgado-Guay M, Ferrer J, Rieber AG, et al. Financial Distress and Its Associations with Physical and Emotional Symptoms and Quality of Life Among Advanced Cancer Patients. *Oncologist. 2015;20*(9):1092-1098. doi:10.1634/theoncologist.2015-0026.
- Cyranowski JM, Zill N, Bode R, et al. Assessing Social Support, Companionship, and Distress: NIH Toolbox Adult Social Relationship Scales. *Health Psychol. 2013;32(3)*:293-301. doi:10.1037/a0028586. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3759525/
- Health Literacy Measurement Tools: https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html
- Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) Assessment tool to assess for social determinants of health: http://www.nachc.org/research-and-data/prapare/
- Military Health History: https://www.va.gov/OAA/pocketcard/

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Domain 5: Spiritual, Religious, and Existential Aspects of Care

- Handbook of Patient's Spiritual and Cultural Values for Health Care Professionals. HealthCare Chaplaincy Network: https://www.healthcarechaplaincy.org/docs/publications/landing_page/cultural_sensitivity_handbook_from_healthcare_chaplaincy_network_11_11_2015.pdf
- Handbook of Religion and Health, 2nd Edition. Koenig H. Oxford University Press. 2012: https://www.amazon.com/Handbook-Religion-Health-Harold-Koenig/dp/0195335953/ref=sr_1_2?ie=UTF8&qid=1513615858&sr=8-2&keywords=koenig+handbook
- Spiritual Care: What It Means, Why It Matters in Health Care. Hall EJ, Hughes BP, Handzo GH: https://healthcarechaplaincy.org/docs/about/spirituality.pdf

Spiritual Screening:

- "Are You at Peace" Screening Tool: https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/409431
- Rush Religious/Spiritual Screening Protocol: http://bishopandersonhouse.org/wp-content/uploads/2013/07/Spiritual-Screening.pdf
- King SDW, Fitchett G, Murphy PE, Pargament KI, Harrison DA, Trice Loggers E. Determining best methods to screen for religious/spiritual distress. *Support Care Cancer 2017;25*:471–479.

Spiritual History:

- FICA: https://smhs.gwu.edu/gwish/clinical/fica
- HOPE: Questions https://www.aafp.org/afp/2001/0101/p81.html

Spiritual Assessment:

- Outcome Based Chaplaincy: https://www.amazon.com/Professional-Spiritual-Pastoral-Care-Practical/dp/1683362446
- Spiritual Aim Assessment Model: https://pmr.uchicago.edu/sites/pmr.uchicago.edu/files/uploads/Spiritual%20AIM%20and%20the%20work%20of%20the%20chaplain-%20A%20model%20for%20assessing%20spiritual%20needs%20and%20outcomes%20in%20relationship_Kestenbaum.pdf
- Fitchett George, *Assessing spiritual needs: a guide for caregivers*, 2nd ed. Augsburg: Academic Renewal Press;2002.

Pediatrics:

- Lyndes KA, Fitchett G, Berlinger N, Cadge W, Misasi J, Flanagan E. A survey of chaplains' roles in pediatric palliative care: Integral members of the team. *J Health Care Chaplain,2012;18*(1-2):74-93.

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- Ferrell B, Wittenberg E, Battista V, Walker G. Nurses' experiences of spiritual communication with seriously ill children. *J Palliat Med, 2016;19*(11): 1166-1170.

Domain 6: Cultural Aspects of Care

- National Center for Cultural Competence: https://nccc.georgetown.edu/
- Hmong Health: http://www.hmonghealth.org
- Chinese American Coalition for Compassionate Care: http://www.caccc-usa.org/en/aboutus.html
- Office of Minority Health Resources Center U.S. Department of Health and Human Services: http://www.minorityhealth.hhs.gov
- National Research Center on Hispanic Children & Families: http://www.hispanicresearchcenter.org/
- Indian Country Media Network: https://indiancountrymedianetwork.com/

LGBTQIA:

- National LGBT Health Education Center: https://www.lgbthealtheducation.org/
- SAGE: https://www.sageusa.org/
- LGBTQ Inclusive Hospice and Palliative Care Resources & Checklists: https://www.lgbtq-inclusive.com/resources-and-checklists

Disabilities:

- Thinking Ahead Matters—Supporting and Improving Healthcare Decision-Making and End-of-Life Planning for People with Intellectual and Developmental Disabilities: http://coalitionccc.org/wp-content/uploads/2015/10/thinking_ahead_matters_final.pdf
- Disabilities Outreach Guide: https://www.nhpco.org/sites/default/files/public/Access/Outreach_Disabilities.pdf

Health Literacy:

- Health Literacy Tool Shed: https://healthliteracy.bu.edu/
- Health Literacy and Palliative Care: Workshop Summary http://nationalacademies.org/hmd/reports/2016/health-literacy-and-palliative-care-workshop-summary.aspx
- Easy to Read Advance Directive: https://www.iha4health.org/our-services/advance-directive/

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

- DEA regulations on drug disposal: https://www.deadiversion.usdoj.gov/drug_disposal/

Advance Care Planning:

- Aging with Dignity, Five Wishes: https://www.agingwithdignity.org/
- CaringInfo: http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1
- Living Will Registry: http://www.uslivingwillregistry.com/faq.shtm
- National POLST Paradigm: http://polst.org/programs-in-your-state/

Grief and Loss:

- Association of Death Education and Counseling: https://www.adec.org/
- Hospice Foundation of America: https://hospicefoundation.org/Grief-(1)

Hospice and End of Life Care:

- Education in Palliative and End-of-life Care (EPEC): http://bioethics.northwestern.edu/programs/epec/
- End-of-life Nursing Education Consortium (ELNEC): http://www.aacnnursing.org/ELNEC
- National Association of Home Care and Hospice: https://www.nahc.org/
- National Hospice and Palliative Care Organization: https://www.nhpco.org/

Pediatrics:

- Courageous Parents Network: https://courageousparentsnetwork.org/
- Perinatal Hospice & Palliative Care – An extensive website with resources for parents and health care professionals: http://www.perinatalhospice.org
- Pregnancy Loss and Infant Death Alliance: http://www.plida.org
- RTS Bereavement Services -- Resources for team education in perinatal, neonatal, and pediatric bereavement care; written resources for bereaved parents: http://www.bereavementservices.org
- Carter, BS, Levetown M, Friebert, SE. Palliative Care for Infants, Children and Adolescents: A Practical Handbook. American Academy of Hospice and Palliative Medicine;2011.
- O'Neill Hunt M. Pediatric Palliative Care Consultant: Guidelines for Effective Management of Symptoms. HospiScript Services;2014.
- Wolfe J. Easing distress when death is near. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care.* Philadelphia, PA: Elsevier Saunders, 368-384;2011.
- Wrede-Seaman, L. (2005). Pediatric Pain and Symptom Management Algorithm. Intellicard.

- Children's Project on Palliative/Hospice Services (ChiPPS): https://www.nhpco.org/pediatric

Domain 8: Ethical and Legal Aspects of Care

Advance Care Planning:

- National Healthcare Decisions Day: https://www.nhdd.org/
- Aging with Dignity: Decision-making resources for Adults (Five Wishes), Teens (Voicing My Choices) and Children (My Wishes): https://www.agingwithdignity.org
- American Bar Association Commission on Law and Aging: https://www.americanbar.org/groups/law_aging.html
- National POLST Paradigm: http://polst.org/
- Prepare for Your Care: https://prepareforyourcare.org/welcome
- The Conversation Project: https://theconversationproject.org/
- CaringInfo: http://www.caringinfo.org/

Ethics:

- Center for Practical Bioethics: https://www.practicalbioethics.org/
- Blueprint for 21st Century Nursing Ethics: Johns Hopkins Berman Institute of Bioethics. 2014: http://www.bioethicsinstitute.org/nursing-ethics-summit-report
- The Hastings Center: Bioethics Research Institute: http://www.thehastingscenter.org/our-issues/chronic-conditions-and-end-of-life-care/

Capacity Assessment of Older Persons:

Physicians:

- Appelbaum PS, Grisso T. *Assessing Patients' Capacities to Consent to Treatment. N Engl J Med.* 1988 Dec 22;319(25):1635-8. Erratum in: *N Engl J Med.* 1989 Mar 16;320(11):748.
- Dastidar JG, Odden A. How do I determine if my patient has decision-making capacity? *The Hospitalist*. 2011 August;2011(8) https://www.the-hospitalist.org/hospitalist/article/124731/how-do-i-determine-if-my-patient-has-decision-making-capacity
- Merel, S. *Decisional Capacity*. https://depts.washington.edu/uwmedres/patientcare/objectives/hospitalist/Decisional_capacity.pdf
- PennState College of Medicine. *Assessing Decision Making Capacity.* https://sites.psu.edu/humanities/files/2016/09/Assessing-Decision-Making-Capacity-9-2016-2174ob8.pdf

Lawyers:

- American Bar Association Commission on Law and Aging and American Psychological Association. *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers.* http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf

Judges:

- American Bar Association Commission on Law and Aging, American Psychological Association, National College of Probate Judges. *Judicial Determination of Capacity of Older Adults in Guardianship Proceedings: A Handbook for Judges.* https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_judges_capacity_longer_version.authcheckdam.pdf

Psychologists:

- American Bar Association Commission on Law and Aging and American Psychological Association. *Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists.* http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Pediatrics:

- American Academy of Pediatrics, Resilience Curriculum: Resilience in the face of grief and loss: https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/hospice-palliative-care/Pages/Resilience-Curriculum.aspx
- Children's Mercy Center for Bioethics: https://www.childrensmercy.org/Bioethics/
- Courageous Parents' Network: decision-making resources for parents and health care professionals for children with serious illness, including resources in Spanish: https://courageousparentsnetwork.org/
- Perinatal Hospice & Palliative Care: resources for both parents and health care professionals making decisions regarding serious illness during pregnancy: http://www.perinatalhospice.org/
- American Academy of Pediatrics: https://www.aap.org/en-us/Pages/Default.aspx
- Treuman Katz Center for Pediatric Bioethics: http://www.seattlechildrens.org/research/initiatives/bioethics/

Position and Policy Statements:

- American Academy of Hospice and Palliative Medicine. *Position Statement – Withholding and Withdrawing Non-Beneficial Medical Interventions.* Glenview, IL: American Academy of Hospice and Palliative Medicine;2017. http://aahpm.org/positions/withholding-nonbeneficial-interventions
- American Academy of Hospice and Palliative Medicine. *Position Statement – Statement on Artificial Nutrition and Hydration at End of Life.* Glenview, IL: American Academy of Hospice and Palliative Medicine;2013. http://aahpm.org/positions/anh

- American Academy of Hospice and Palliative Medicine. *Position Statement – Statement on Palliative Care Research*. Glenview, IL: American Academy of Hospice and Palliative Medicine;2014. http://aahpm.org/positions/research-ethics
- American Academy of Hospice and Palliative Medicine. *Position Statement -Statement on Palliative Sedation*. Glenview, IL: American Academy of Hospice and Palliative Medicine;2014. http://aahpm.org/positions/palliative-sedation
- American Academy of Hospice and Palliative Medicine. *Position Statement – Statement on Physician-Assisted Dying*. Glenview, IL: American Academy of Hospice and Palliative Medicine;2016. http://aahpm.org/positions/pad
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Informed Consent in Decision-Making in Pediatric Practice*. Elk Grove, IL: American Academy of Pediatrics;2016. http://pediatrics.aappublications.org/content/138/2/e20161485
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Honoring Do-Not-Attempt-Resuscitation Requests in Schools.* Elk Grove, IL: American Academy of Pediatrics;2010. Reaffirmed 2016. http://pediatrics.aappublications.org/content/125/5/1073
- American Academy of Pediatrics Committee on Bioethics. *Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations.* Elk Grove, IL: American Academy of Pediatrics;2013. http://pediatrics.aappublications.org/content/132/5/966
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Ethical Controversies in Organ Donation after Circulatory Death.* Elk Grove, IL: American Academy of Pediatrics;2013. Reaffirmed 2017. http://pediatrics.aappublications.org/content/131/5/1021
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Physician Refusal to Provide Information or Treatment on the Basis of Claims of Conscience*. Elk Grove, IL: American Academy of Pediatrics;2009, Reaffirmed 2014. http://pediatrics.aappublications.org/content/124/6/1689
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Institutional Ethics Committees.* Elk Grove, IL: American Academy of Pediatrics;2001, Reaffirmed 2014. http://pediatrics.aappublications.org/content/107/1/205
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Forgoing Medically Provided Nutrition and Hydration in Children.* Elk Grove, IL: American Academy of Pediatrics;2009, Reaffirmed 2014. http://pediatrics.aappublications.org/content/124/2/813
- American Academy of Pediatrics Committee on Bioethics. *Policy Statement – Communicating with Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information.* Elk Grove, IL: American Academy of Pediatrics;2008, Reaffirmed 2017. http://pediatrics.aappublications.org/content/121/5/e1441
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Appendix III: Contributors

We would like to extend our appreciation to the additional individuals and organizations who provided their time and expertise about different aspects of the NCP Guidelines.

Subject Matter Experts

The following subject matter experts provided topic-specific input to the NCP Writing Workgroup:

Domain 3: Psychological and Psychiatric Aspects of Care

- Susan Block, MD, Dana-Farber Cancer Institute
- Kenneth J. Doka, MDiv, PhD, The College of New Rochelle
- Frances Eichholz Heller, LMSW, ACHP-SW, NY Presbyterian, Columbia University Medical Center
- Elizabeth Goy, MA, PhD, Rebecca S. Allen, PhD, ABPP, Brian D. Carpenter, PhD, Veronica L. Shead, PhD, Debbie DiGilio, MPH, American Psychological Association Working Group on End of Life Issues and Care
- Shibani Ray-Mazumder, ScD, PhD, New York State Psychological Association Palliative Care Psychology Task Force
- Christina Puchalski, MD, MS, FACP, FAAHPM, George Washington University Institute for Spirituality and Health

Domain 6: Cultural Aspects of Care

- Brenda Gonzalez, Agrace Hospice & Palliative Care
- Maichou Lor, PhD, RN, Postdoctoral Research Fellow (Nursing), Columbia University

Domain 8: Ethical and Legal Aspects of Care

- Charlie Sabatino, JD, American Bar Association Commission on Law and Aging
- Timothy W. Kirk, PhD, MJHS Hospice & Palliative Care

Practice Examples

The following palliative care and hospice programs contributed their experience to inform the Practice Examples:

- Advocate Children's Hospital, Park Ridge, IL
- Akron Children's Hospital, Akron, OH
- Aspire Health, Nashville, TN
- Blue Shield of California, San Francisco, CA

- Bluegrass Navigators, Lexington, KY
- Center to Advance Palliative Care, New York, NY
- Dana-Farber Cancer Institute/Harvard Medical School, Boston, MA
- Emory Palliative Care Center, Atlanta, GA
- Fairview Health Services, Minneapolis, MN
- Four Seasons, Flat Rock, NC
- Gallup Indian Health Services, Gallup, NM
- Hometown Health Centers, Schenectady, NY
- JourneyCare, Barrington, IL
- Lehigh Valley Health Network OACIS Palliative Medicine, Allentown, PA
- Memorial Herman Physician Network and Symptom Management Consultants, Houston, TX
- Mount Sinai Health System, New York, NY
- NYU School of Medicine, Bellevue Hospital, New York, NY
- OSF HealthCare, Peoria, IL
- Palliative Medicine & Supportive Care at Northwestern Medicine – Lake Forest Hospital, Lake Forest, IL
- Presbyterian Healthcare Services, Albuquerque, NM
- ProHEALTH Care, Lake Success, NY
- Providence Little Company of Mary Medical Center, San Pedro, CA
- Providence St Joseph Medical Center Burbank, Burbank, CA
- Resolution Care, Eureka, CA
- Sharp HealthCare, San Diego, CA
- Sutter Health, Sutter Care at Home, Fairfield, CA
- Texas Children's Hospital, Houston, TX
- Trinity Health, Livonia, MI
- University of Alabama at Birmingham, School of Nursing, Birmingham, AL
- University of California San Francisco, San Francisco, CA
- VITAS Healthcare, Miami, FL

Appendix IV: Scoping Review

The NCP Guidelines includes a selected bibliography of articles identified in a scoping review designed to identify resources to support the recommendations and conclusions in this document. Concurrently with the review of this document a systematic review to accompany the NCP Guidelines was completed.

As a result, the bibliography in this document is in no way comprehensive. It is a list of selected citations from a variety of journals organized by domain and topic. In addition to the eight domains, the literature review focused on:

- Pediatric palliative care
- Bereavement and grief

The literature review also focused on the six key themes:

1. Comprehensive assessment
2. Caregiving
3. Care coordination
4. Care transitions
5. Culture
6. Communication

Both qualitative and quantitative studies are included, as well as published consensus statements, expert opinions, and statements from professional organizations.

Scoping Review Methodology

This systematic review used *Academic Search Complete, AgeLine, Alt. HealthWatch, CINAHL Complete, Health Source: Consumer Edition; Health Source: Nursing/Academic Edition, MEDLINE, PsychArticles, Psychology and Behavioral Science Collection, PsychInfo,* and *Social Work Abstracts* databases to search for evidence-based literature across the eight domains as listed within the *Clinical Practice Guidelines for Quality Palliative Care, 3rd edition.*[1]

This database search was limited to peer-reviewed journal articles published between January 1, 2007 and September 17, 2017. All searches were conducted using the following search terms in exact string order: "palliative care or end of life care or terminal care or dying or advanced illness or serious illness" and "united states or us." A total of 21,533 articles were identified across all eight domains and the three additional searches using the search terms defined below.

Domain 1: Structure and Processes of Care

The initial search on the structure and processes of care was conducted using various search term iterations to gather literature related to cross-cutting themes within this domain, including: "structure," "culture," "access to care," "education," "interdisciplinary," "finance," "quality," "workforce," "triggers," "population health," "communication," and "education." Upon removal of duplicate articles, a total of 2,436 separate titles and abstracts were retrieved for further review.

A subsequent search for domain, structure and process of care, was conducted using the following search terms in exact string order: "palliative care or end of life care or terminal care or dying or advanced illness or serious illness" and "united states." Various search term iterations were used to gather literature related to cross-cutting themes within this domain, which include: "rural," "urban," "interdisciplinary," and "pediatric." Upon removal of duplicate articles and screening of titles and abstracts, a total of 129 separate articles were retrieved for inclusion.

Domain 2: Physical Aspects of Care

The physical aspects of care search included the following search terms to gather literature related to cross-cutting themes within the domain, including: "cultur*[1]," "symptom," "communication," "pain," "activities of daily living or ADLs," "illness or disease or syndrome or condition," "dementia," "heart failure," "pulmonary," "cancer," "ALS," "Parkinson's," "stroke," "kidney," "liver," "frailty," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,522 separate titles and abstracts were retrieved for further review.

Domain 3: Psychological and Psychiatric Aspects of Care

An initial search on psychological and psychiatric aspects of palliative care was conducted using various search term iterations to gather literature related to cross-cutting themes within this domain, including: "cultur*[1]," "depression," "communication," "dementia," "delirium," "anxiety," "hopelessness," "behavioral disturbances," "substance use disorder," "PTSD or post-traumatic stress disorder," "post-illness psychosis," "dual diagnosis," "psychiatric," "grief or bereavement," "aid in dying or assisted suicide or euthanasia or hasten death," "suicide," "disability," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,336 separate titles and abstracts were retrieved for further review.

Domain 4: Social Aspects of Care

The social aspects of care literature search included the following cross-cutting terms relevant to this domain, including: "psychosocial," "cultur*," "communication," "family systems theory," "social determinants of care or social determinants of health," "loneliness," "social work*," "empathy," "motivational interviewing," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "social work" to broaden the search by finding words that start with the same root respectively (eg, social worker, social working). Upon removal of duplicate articles, a total of 1,715 separate titles and abstracts were retrieved for further review.

Domain 5: Spiritual, Religious, and Existential Aspects of Care

The first search related to content in the spiritual aspects of care domain included selected search terms, including: "spiritual," "cultur*," "communication," "religious or religion or religiosity," "existential," "beliefs," "values," "chaplain or clergy or spiritual caregiver," "assessment," "care goals," and "care

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[1] Where indicated, an asterisk symbol was placed at the end of the search term to broaden the search by finding words that start with the same root (eg, cultural, culture, cultures, social worker).

plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,393 separate titles and abstracts were retrieved for further review.

A subsequent search was conducted to capture other topics relevant to the domain content: "chaplain," "chaplaincy," and "spiritual care." Upon removal of duplicate articles, a total of 348 separate titles and abstracts were retrieved for further review.

Domain 6: Cultural Aspects of Care

An initial search on the cultural aspects of care was conducted using the following search terms: "cultural," "cultur*," "communication," "intersectionality," "transcultural," "cultural humility," "culturally inclusive," "radical respect," "competence," "disparities," "race or racial or race or ethnicity," "socioeconomic status," "gender identity or sex," "sexual orientation," "sexuality," "interpreters or medical interpreters," "immigrant," "cultural brokers," "language," "literacy," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 3,103 separate titles and abstracts were retrieved for further review. An additional 16 articles were identified after a hand-checked review of references by the writing dyad following the initial database search.

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

An initial search specific to Domain 7 was conducted to gather literature related to cross-cutting themes within this domain, including: "hospice," "cultur*," "communication," "eligibility," "comfort measures," "prognosis or prognostication," "hope," "life closure," "terminal illness," "terminal sedation or palliative sedation," "advance care planning or advanced directive," "POLST or physician orders for life sustaining treatment," "aid in dying or assisted suicide or euthanasia or hasten death," "funeral," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,739 separate titles and abstracts were retrieved for further review.

Domain 8: Ethical and Legal Aspects of Care

The search related to ethical and legal aspects of care included the following search terms: "ethics or ethical principles," "cultur*," "communication," "legal," "decisional capacity," "cognitively impaired," "consent," "shared decision making," "safety or risks," "disability," "futile care," "advanced care planning," "aid in dying or assisted suicide or euthanasia or hasten death," "assessment," "care goals," and "care plan." An asterisk symbol was placed at the end of "cultur" to broaden the search by finding words that start with the same root respectively (eg, cultures, cultural). Upon removal of duplicate articles, a total of 2,336 separate titles and abstracts were retrieved for further review.

Additional Searches

Additional searches were conducted to retrieve articles within the following content areas: pediatrics, care transitions and coordination of care, and grief, bereavement and survivorship. These searches were conducted using the same databases and inclusion criteria as in the aforementioned eight domains.

Pediatrics

The pediatrics search focused on the following content areas: "pediatrics," "neonatal," "grief," and "care coordination." Upon removal of duplicate articles, a total of 118 separate titles and abstracts were retrieved for further review.

Care Transitions and Coordination of Care

The literature search related to care transitions and coordination of care focused specifically on these two content areas within the context of palliative care: "care transitions" and "care coordination." Upon removal of duplicate articles, a total of 261 separate titles and abstracts were retrieved for further review.

Grief, Bereavement, and Survivorship

An initial search on grief, bereavement, and survivorship was conducted to explore the differences between grief and bereavement and review the literature related to survivorship. The following terms were included: "grief," "bereavement," and "survivorship." Upon removal of duplicate articles, a total of 1,097 separate titles and abstracts were retrieved for further review.

Review and Inclusion Process

A three-stage review process was used to determine whether or not articles were included in the final bibliography. During the first-stage, all titles and abstracts were reviewed for relevancy based on the article title. During the second stage, abstracts of the remaining articles were read. At the third-stage, writers requested articles to review to determine if the article was applicable to the domain content.

Domain 1: Structure and Processes of Care

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Endnote

[1] National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 3rd edition; 2013.

Appendix V: Endorsing and Supporting Organizations

The National Coalition for Hospice and Palliative Care and the National Consensus Project for Quality Palliative Care would like to thank the following organizations who provided endorsement and support for the 4th edition of the NCP Guidelines.

Endorsing Organizations

Academy of Integrative Pain Management

Academy of Neonatal Nursing

Accountable Care Learning Collaborative

Accreditation Commission for Health Care

Aging Life Care Association

American Academy of Home Care Medicine

American Academy of Hospice and Palliative Medicine

American Academy of Nursing

American Academy of Pediatrics

American Association of Colleges of Nursing

American Association of Critical Care Nurses

American Association of Neuroscience Nurses

American Association of Nurse Practitioners

American Board of Internal Medicine

American Cancer Society

American Case Management Association

American College of Surgeons

American Health Care Association

American Heart Association/American Stroke Association

American Holistic Nurses Association

American Medical Group Association

American Nephrology Nurses Association

American Nurses Association

American Psychiatric Nurses Association

Argentum

Ariadne Labs

Association for Clinical Pastoral Education

Association of Professional Chaplains

Association of Rehabilitation Nurses

Blue Shield of California

California State University Institute for Palliative Care

Cambia Health Foundation

Cambia Health Solutions

Catholic Health Association of the United States

Center for Practical Bioethics

Center to Advance Palliative Care

Coalition for Compassionate Care of California

Coalition to Transform Advanced Care

College of Pastoral Supervision and Psychotherapy

Community Health Accreditation Partner

Discern Health

ElevatingHOME & Visiting Nurse Associations of America

Emergency Nurses Association

End of Life Nursing Education Consortium

Excellus BlueCross BlueShield

Family Caregiver Alliance

Gerontological Advanced Practice Nurses Association

HealthCare Chaplaincy Network

Horizon Healthcare Services, Inc.

Hospice and Palliative Nurses Association

Infusion Nurses Society

Institute for Healthcare Improvement

International Transplant Nurses Society

LeadingAge

Long-Term Quality Alliance

National Alliance for Caregiving

National Association of Catholic Chaplains

National Association of Clinical Nurse Specialists

National Association of Home Care and Hospice

National Association of Pediatric Nurse Practitioners

National Association of Social Workers

National Consumer Voice for Quality Long-Term Care

National Hospice and Palliative Care Organization

National PACE Association

National Palliative Care Research Center

National Partnership for Women and Families

National Patient Advocate Foundation

National Pediatric Hospice and Palliative Care Collaborative

National POLST Paradigm

Neshama: Association of Jewish Chaplains

Northwell Health

Nurses Organization of Veterans Affairs

Oncology Nurses Society

Physician Assistants in Hospice and Palliative Medicine

Respecting Choices

Sigma Theta Tau International Nursing Honor Society

Social Work Hospice & Palliative Care Network

Society of Palliative Care Pharmacists

Society for Social Work Leadership in Health Care

Supportive Care Coalition

The Conversation Project

The National Association of Directors of Nursing Administration in Long Term Care

Supporting Organizations*

Alzheimer's Association

American Association of Colleges of Pharmacy

American Geriatrics Society

American Society of Hematology

Anthem, Inc.

LEAD Coalition

National Association of Accountable Care Organizations

National League for Nursing

The Joint Commission

**Supporting organizations are ones who are supporting the NCP Guidelines by disseminating to their respective membership and/or stakeholders; and are unable to provide an official endorsement.*

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To the NCP leadership organizations:

The National Coalition for Hospice and Palliative Care also would like to acknowledge the **16 national organizations** who provided the leadership for the National Consensus Project for Quality Palliative Care:

American Academy of Home Care Medicine
www.aahcm.org

American Academy of Hospice and Palliative Medicine
www.aahpm.org

American Health Care Association
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American Medical Group Association
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