Optimizing Care in the Seriously Ill: Using the National Guidelines in Palliative Care

Objectives

1. Define palliative care.
2. Explain how the 4th edition of the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (NCP Guidelines) was developed.
3. Describe the eight domains of the NCP Guidelines and what's new in the 4th edition.
4. Identify strategies to implement the NCP Guidelines within your health care team and organization.

What is Palliative Care?

Palliative Care Definition

- Interdisciplinary care delivery system designed for patients, their families and caregivers
- Beneficial at any stage of a serious illness
- Anticipates, prevents, and manages physical, psychological, social, and spiritual suffering to optimize quality of life
- Delivered in any care setting through the collaboration of many types of care providers
- Improves quality of life for both the patient and the family through early integration into the care plan

- National Consensus Project for Quality Palliative Care

Key Concepts

- Person-and family-centered approach to care
- Inclusive of all people living with serious illness, regardless of setting, diagnosis, age or prognosis
- A responsibility of all clinicians and disciplines caring for people living with serious illness

Serious Illness

A health condition that carries a high risk of mortality <u>and</u> either negatively impacts a person's daily function <u>or</u> quality of life <u>or</u> excessively strains their caregiver.*

*Kelley, AS, Bollens-Lund, E. Identifying the population with serious illness: the "denominator" challenge. Journal of Palliative Medicine. Volume: 21 Issue S2: March 1, 2018.

Community is Person-Centric

"Community" is defined:

- by the person living with serious illness
- as a lens through which their needs are assessed

- National Consensus Project
Strategic Directions Summit
June 2017

Guidelines Background & Process

Why Clinical Practice Guidelines?

✓Guidelines improve care and safety for patients and families:

- Defines structures and processes of care
- Sets expectations for providers
- Guides clinical decision making
- Promotes standardization
- Creates a foundation for accountability

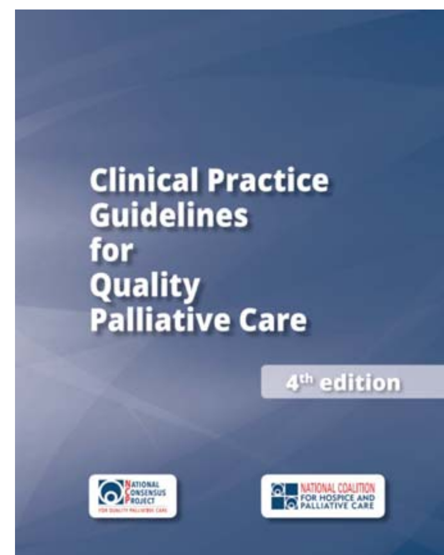
✓Guidelines provide the essential elements for standards, policies and best practices

National Consensus Project for Quality Palliative Care (NCP)

- Began in 2001 to define and improve the delivery of palliative care
- Stakeholder involvement expanded over the last decade
- Three prior editions of the NCP Guidelines published: 2004, 2009, 2013
- National Coalition for Hospice and Palliative Care serves as organization home of NCP

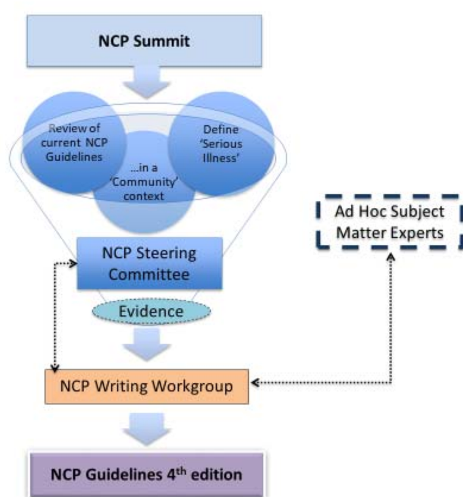
The 4th edition

- For all people with serious illness, regardless of setting, diagnosis, prognosis, or age
- Funded by the Gordon and Betty Moore Foundation
- Published by the National Coalition for Hospice and Palliative Care
- NCP leadership consisted of 16 national organizations



NCP Leadership Organizations

National Consensus Project Process (2017-18)



- **Development**:
  - Steering Committee and Writing Workgroup formed
  - NCP Strategic Directions Stakeholder Summit held
  - Writing > reviews > revisions > approvals > consensus achieved
- **Systematic review of research evidence**:
  - Completed by the RAND Evidence-based Practice Center
- **Endorsements**:
  - Received from more than 80 national organizations
- **Publication**: **October 31, 2018**

4th edition: Domains & Content

Domains of Palliative Care

Domain 1: Structure and Processes of Care

Domain 2: Physical Aspects of Care

Domain 3: Psychological and Psychiatric Aspects of Care

Domain 4: Social Aspects of Care

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

Domain 6: Cultural Aspects of Care

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

Domain 8: Ethical and Legal Aspects of Care

Key Themes: the 6 C's

Each domain addresses:

- Comprehensive assessment
- Care coordination
- Care transitions
- Caregiver needs
- Cultural inclusion
- Communication

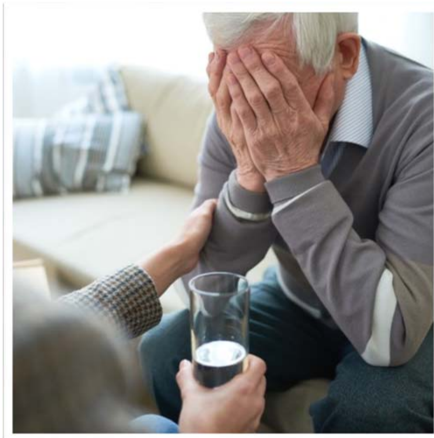
Domain 1: Structure and Processes of Care

- 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)
- Begins with a comprehensive assessment and emphasizes:
  - Patient and family engagement
  - Communication
  - Care coordination
  - Continuity of care across health care settings

Domain 2: Physical Aspects of Care

- Begins with understanding patient goals in the context of physical, functional, emotional, and spiritual
- Focuses on relieving symptoms and improving or maintaining functional status and quality of life
- Emphasizes symptom management that encompasses pharmacological, non-pharmacological, interventional, behavioral, and complementary treatments
- Is accomplished through collaboration between all professionals involved in the patients' care across all care settings

Domain 3: Psychological and Psychiatric Aspects of Care



- IDT addresses psychological and psychiatric aspects of care in the context of serious illness
- IDT conducts comprehensive developmentally and culturally sensitive mental status screenings
- Social worker facilitates mental health assessment and treatment in all care settings
- IDT communicates to the patient and family the implications of psychological and psychiatric aspects of care

Domain 4: Social Aspects of Care

- Addresses environmental and social factors that affect patients and their families
- Social determinants of health have a strong influence on care outcomes
- IDT partners with the patient and family to identify strengths and address needs
- Social worker is essential to the IDT

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

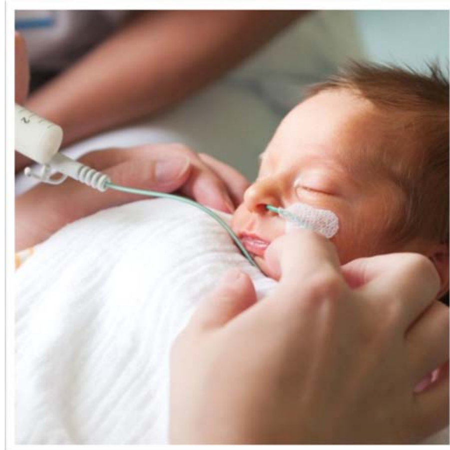
- Spirituality is recognized as a fundamental aspect of palliative care
- Dynamic aspect through which individuals seek meaning, purpose, and transcendence, and experience relationships
- Expressed through beliefs, values, traditions, and practices
- IDT serves in a manner that respects
  - all spiritual beliefs and practices, and
  - when patients and families decline to discuss their beliefs or accept support

Domain 6: Cultural Aspects of Care

- First step is assessing and respecting values, beliefs and traditions
- Care plans incorporate culturally sensitive resources and strategies
- Respectful acknowledgment and culturally sensitive support for grieving practices is provided
- IDT members continually expand awareness of their own biases and perceptions

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

- Highlights care provided to patients and their families near the end of life,
- Particular emphasis on the days leading up to and just after the death of the patient.
- Comprehensive assessment and management of physical, social, spiritual, psychological, and cultural aspects of care are critically important near death
- IDT provides developmentally appropriate education to patient, family and others



Domain 7: Care of the Patient Nearing the End of Life (continued)

- Interdisciplinary model of hospice care is recognized as the best care for patients nearing the end of life
- Early access to hospice support should be facilitated whenever possible to optimize care outcomes
- Palliative care teams, hospice providers and other healthcare organizations must work together to find solutions for all patients and families in their final months of life

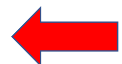
Domain 8: Ethical and Legal Aspects of Care

- IDT applies ethical principles to the care of patients with serious illness, including honoring patient preferences, and decisions made by surrogates
- 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
  - Evolving treatments with legal ramifications (eg, medical marijuana)

4th edition: Publication

Anatomy of a Domain: Example 1

Domain 1



Bleed tabs for easy access

Domain 1: Structure and Processes of Care

Expanded introductions

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

Temporal organization

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.

Words bolded in **red** are defined in the Glossary

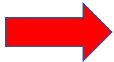
Criteria:

Numbered items

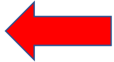
1.1.1 The IDT provides care focused on individual physical, functional, psychological, social, spiritual, and cultural needs.

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

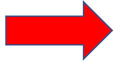
Anatomy of a Domain: Example 2



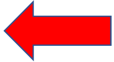
Clinical implications



Operational implications



Application for ALL clinicians



Key research evidence overview

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

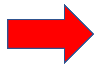
All clinicians need expertise in the assessment of patient symptom burden, functional status, and quality of life, and in the development of a palliative treatment plan that is consistent with patient and family needs and preferences. Clinicians need the skills to identify and treat symptoms associated 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).

Anatomy of a Domain: Example 3



Diverse practice examples

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.

Additional Content

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.

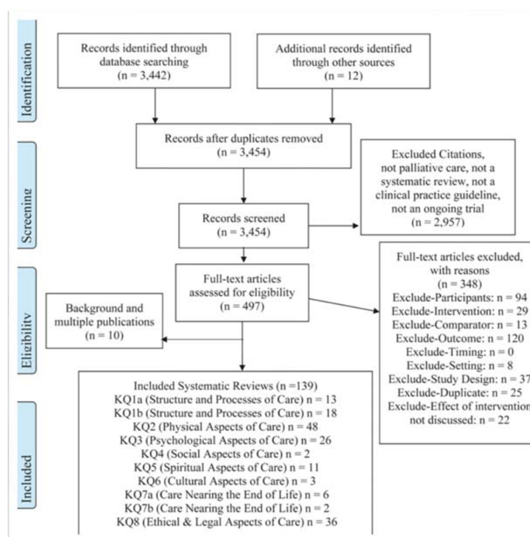
Appendix II: Tools and Resources

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

Systematic Review of Research Evidence

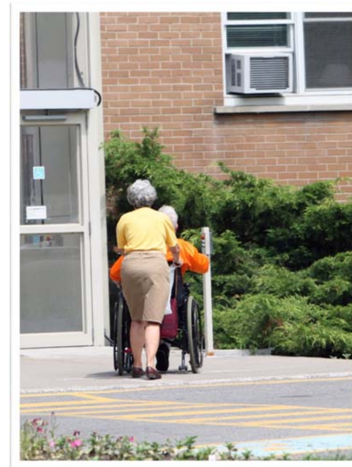
- Conducted by Rand Evidence-based Practice Center with Technical Expert Panel (TEP)
- Complete findings published: *Journal of Pain and Symptom Management*
  - https://www.jpsmjournal.com/article/S0885-3924(18)30468-8/fulltext
- Funded by:
  - Gordon and Betty Moore Foundation
  - Gary and Mary West Foundation
  - The John A. Hartford Foundation
  - Stupski Foundation



Practice Examples

Practice Example: Long-Term Care Setting

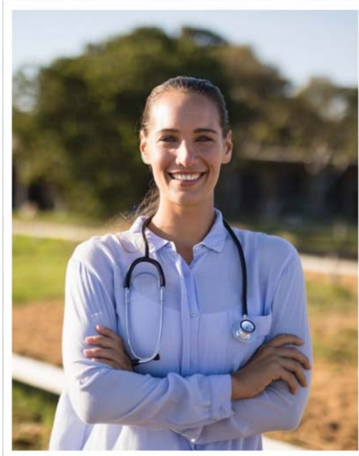
- A long-term care setting is incorporating palliative care
- Physician assistant and social worker lead efforts to improve advance care planning and completion of formal directives.
- Varying levels of decision-making capacity pose a challenge to completing advance directives
- Staff need help determining capacity
- Facility develops a consultative relationship with a hospital-based palliative care team and ethics consult service



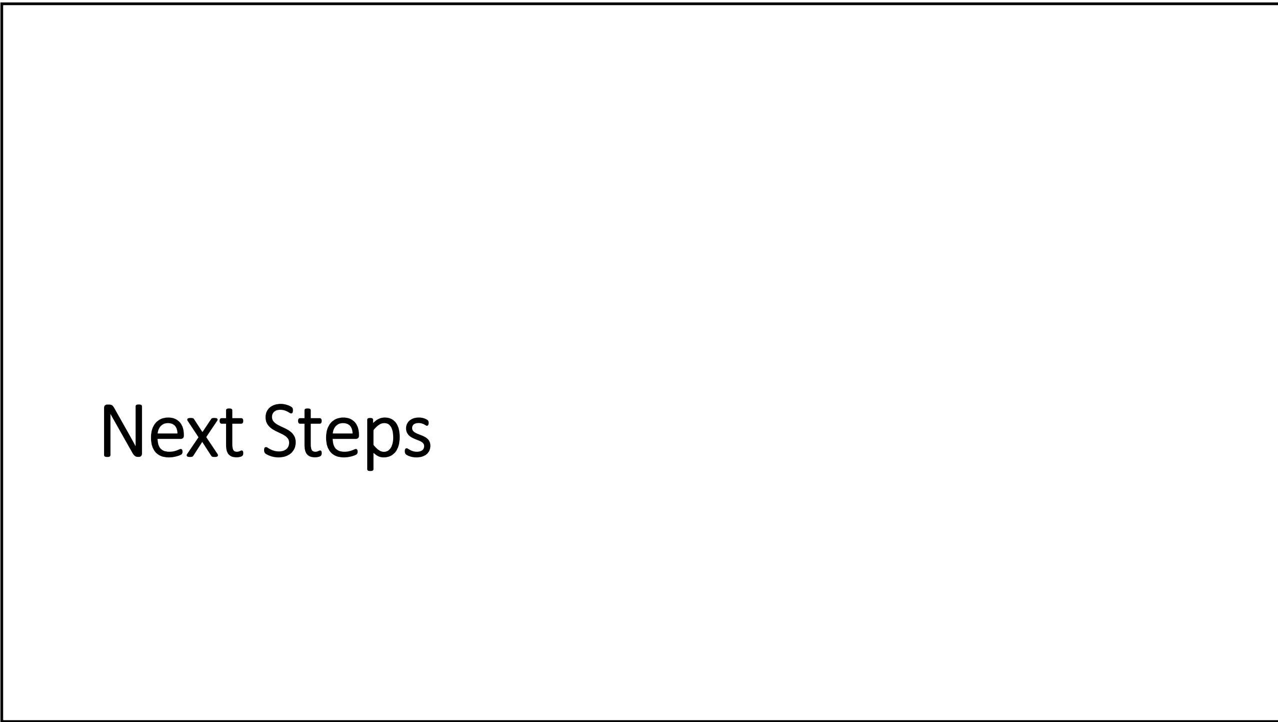
Practice Example: Community Hospital

- Staff at a community hospital identify a trend re: after hours and weekend utilization of the ED with seriously ill children following a hospitalization
- Local hospice has a large home-based pediatric palliative and hospice program, with just one board-certified hospice and palliative medicine pediatrician.
- Hospital's pediatric service partners with a large community pediatric practice and the hospice pediatric physician, to implement a collaborative QI initiative.

Practice Example: Rural Palliative Care



- A rural palliative care program provides care in patients' homes
- Staff is often alone on visits
- Team members stressed with ethical issues (ie requests for physician aid-in-dying, family conflicts)
- Program develops an online ethics forum for staff education
- Provides educational podcasts for team members
- Leadership facilitates dual visits of the practitioners and social workers to facilitate greater support


Next Steps

Read the Guidelines

Available at:

www.nationalcoalitionhpc.org/ncp

PDF

E-PUB

ONLINE

PURCHASE

Implement the Guidelines

1. Share the NCP Guidelines with your team and colleagues
2. Assess strengths, gaps and opportunities in your practice setting to apply the NCP Guidelines
3. Develop a plan to improve care for your patients with serious illness and their families/caregivers
4. Begin with easily attainable goals, and plan to grow and scale
5. Celebrate achievements

Communication and Education Resources

Available at www.nationalcoalitionhpc.org/ncp

- NCP in the News: published articles
- Press Release
- FAQs
- Blog Post
- Ready-made PPT w/ speaker notes
- On-demand webinar and handout
- NCP Stakeholder Summit Report
- About and History of the NCP

For More Information

Visit: www.nationalcoalitionhpc.org/ncp
Follow: @coalitionhpc (#NCPGuidelines)
Contact: info@nationalcoalitionhpc.org