

Clinical Practice Guidelines for Quality Palliative Care

4th edition



Publisher:

National Coalition for Hospice and Palliative Care

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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.

Foreword

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

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:

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>.

- 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 existing 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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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.

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- Association of Professional Chaplains www.professionalchaplains.org
- Center to Advance Palliative Care www.capc.org
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Endnotes

- 1 Kelley AS, Bollens-Lund, E. Identifying the population with serious illness: the “denominator” challenge. *J Palliat Med*. Volume: 21 Issue S2: March 1, 2018.
- 2 Smith A, McCarthy E, Weber E, et al. Half of Older Americans Seen in Emergency Department in Last Month of Life; Most Admitted to Hospital, and Many Die There. *Health Aff (Project Hope)*. 2012;31(6):1277-1285. doi:10.1377/hlthaff.2011.0922.
- 3 IOM (Institute of Medicine). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press. <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>. Published 2015. Accessed January 31, 2018.
- 4 IOM (Institute of Medicine). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press. <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>. Published 2015. Accessed January 31, 2018.

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- 5 Centers for Medicare and Medicaid Services, Department of Health and Human Services. Hospice care. Code of Federal Register. 79 FR 50509, August 22, 2014. https://www.ecfr.gov/cgi-bin/text-idx?SID=95c732ed603d39aed3682d6371ca27ea&mc=true&node=se42.3.418_13&rgn=div8. Accessed April 25, 2018.
- 6 Center to Advance Palliative Care. Get palliative care. <https://getpalliativecare.org/>. Accessed April 26, 2018.
- 7 National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America. https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf Published March 2018. Accessed March 30, 2018.
- 8 National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America. https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf Published March 2018. Accessed March 30, 2018.
- 9 IOM (Institute of Medicine). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press. <https://www.nap.edu/read/18748/chapter/1#ii> Published 2015. Accessed January 31, 2018.
- 10 Puchalski CM, Ferrell B. *Making health care whole: integrating spirituality into patient care*. West Conshohocken, PA: Templeton Press; 2010.

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.

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- 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.

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- 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.

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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

Domain 1: Structure and Processes of Care

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:

Domain 2: Physical Aspects of Care

- 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.

Domain 2: Physical Aspects of Care

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.

Domain 3: Psychological and Psychiatric Aspects of Care

- 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

Domain 3: Psychological and Psychiatric Aspects of Care

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

Domain 4: Social Aspects of Care

- 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, identifying 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

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- 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

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

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.

Domain 6: Cultural Aspects of Care

- 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

Domain 6: Cultural Aspects of Care

- 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
- Dietitians 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

Domain 6: Cultural Aspects of Care

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:
- Ensuring frequent telephone and in-person contact with patient and family caregivers in the days before death
 - Supporting notification of distant family and friends, as desired by the patient and family caregivers
 - 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)
 - Identifying signs and symptoms of approaching death, and what can be expected before and after the patient dies
 - Talking about approaching death with patients and families
 - 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.*

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

- 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.

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

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. Forgoing 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

Domain 8: Ethical and Legal Aspects of Care

- 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 statutes 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.

Domain 8: Ethical and Legal Aspects of Care

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 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.

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

Endnotes

- 1 Sam, DL, Berry, JW. Acculturation: when individuals and groups of different backgrounds meet. *Perspect Psychol Sci*, 2010;5(4): 472-481.
- 2 Activities of daily living. Accessed April 16, 2018, from Centers for Medicare and Medicaid Services website, https://www.cms.gov/research-statistics-data-and-systems/research/mcbs/downloads/2008_appendix_b.pdf
- 3 POLST and advance care planning. *National POLST Paradigm*. Available at: <http://polst.org/polst-advance-care-planning/> Accessed June 9, 2018.
- 4 Holley CK, Mast BT. The impact of anticipatory grief on caregiver burden in dementia caregivers. *Gerontologist*. 2009;49(3):388-396. doi:10.1093/geront/gnp061.

- 5 Entwistle V, Carter S, Cribb A, McCaffery K. Supporting patient autonomy: The Importance of clinician-patient relationships. *J Gen Intern Med.* 2010;25(7):741-745. doi:10.1007/s11606-010-1292-2.
- 6 Bhanji SM. Health Care Ethics. *J Clinic Res Bioeth.* 2013;4:142.
- 7 Bereavement. (n.d.). Accessed April 16, 2018, from Psychology Today website, <https://www.psychologytoday.com/us/conditions/bereavement>
- 8 McDonald K. Evaluating the state of quality-improvement science through evidence synthesis: Insights from the closing the quality gap series. *Perm J.* 2013;17(4):52-61. doi:10.7812/tpp/13-010.
- 9 McDonald, KM., Sundaram V., Bravata DM., Lewis R., Lin N., Kraft S., et. al. (2007). Closing the quality gap: A Critical analysis of quality improvement strategies, technical review 9. (eds K.G., Shojania, K.M. McDonald, R.M. Wachter, D.K. Owens). Prepared by the Stanford University-UCSF Evidence-based Practice Center under contract 290-02-0017. AHRQ Publication No. 04(07)-0051-7. Rockville, MD: Agency for Healthcare Research and Quality.
- 10 Improving care transitions. Health Affairs Health Policy Brief, September 13, 2012. doi:10.1377/hpb20120913.327236.
- 11 Feinberg L. Assessing family caregiver needs: Policy and practice considerations. (Fact Sheet 258). Washington DC: AARP Public Policy Institute.
- 12 Centers for Disease Control and Prevention. Cognitive impairment: a call for action, now! Retrieved from: https://www.cdc.gov/aging/pdf/cognitive_impairment/cogimp_poilicy_final.pdf
- 13 Given BA, Reinhard SC. Caregiving at the end of life: The challenges for family caregivers. *Generations* 2017;41:50–57.
- 14 Okon TR. Overview of comprehensive patient assessment in palliative care. Accessed April 23, 2018 from <https://www.uptodate.com/contents/overview-of-comprehensive-patient-assessment-in-palliative-care>
- 15 Kamal A, Hanson L, Casarett D et al. The quality imperative for palliative care. *J Pain Symptom Manage.* 2015;49(2):243-253. doi:10.1016/j.jpainsymman.2014.06.008.
- 16 Foronda C, Baptiste D, Reinholdt M, Ousman K. Cultural humility: A concept analysis. *J Transcult Nurs.* 2015;27(3):210-217. doi:10.1177/1043659615592677.
- 17 Kepple A, Azzam P, Gopalan P, Arnold R. Decision-making capacity at the end of life. *Prog Palliat Care.* 2014;23(3):133-136. doi:10.1179/1743291x14y.0000000109.
- 18 Clark J, Fasciano K. Young adult palliative care. *Am J Hosp Palliat Care.* 2013;32(1):101-111. doi:10.1177/1049909113510394.
- 19 Huxtable R. Get out of jail free? The doctrine of double effect in English law. *Palliat Med* 2004;18: 62-8. Accessed May 11, 2018 http://journals.sagepub.com/doi/abs/10.1191/0269216304pm855oa?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub%3Dpubmed&
- 20 Nelson-Becker H. *Spirituality, Religion, and Aging.* SAGE; 2018.
- 21 Institute for Patient-and Family-Centered Care. Patient- and family-centered care. Accessed April 23, 2018 <http://www.ipfcc.org/bestpractices/sustainable-partnerships/background/pfcc-defined.html>
- 22 Care for the Family Caregiver: A Place to Start. The White House Conference on Aging March 2010 Edition. Accessed April 23, 2018 from http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf
- 23 Acquaviva K. LGBTQ-inclusive hospice and palliative care. New York, NY: Harrington Park Press; 2017.

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- 24 Sexual orientation and gender identity definitions | Human Rights Campaign. Human Rights Campaign. 2018. Available at: <https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions>. Accessed April 23, 2018.
- 25 Zisook S, Shear K. Grief and bereavement: What psychiatrists need to know. *World Psychiatry*. 2009;8(2):67-74. doi:10.1002/j.2051-5545.2009.tb00217.x.
- 26 Heart M. The historical trauma response among natives and its relationship with substance abuse: A Lakota illustration. *J Psychoactive Drugs*. 2003;35(1):7-13. doi:10.1080/02791072.2003.10399988.
- 27 Hospice Care. National Hospice and Palliative Care Organization. 2018. Available at: <https://www.nhpco.org/about/hospice-care>. Accessed April 23, 2018.
- 28 Definitions. Centers for Medicare and Medicaid Services. CMS.gov. 2018. Available at: https://www.cms.gov/research-statistics-data-and-systems/research/mcbs/downloads/2008_appendix_b.pdf. Accessed April 23, 2018.
- 29 Youngwerth J, Twaddle M. Cultures of interdisciplinary teams: How to foster good dynamics. *J Palliat Med*. 2011;14:650-654. Accessed September 10, 2018.
- 30 Hill Collins P, Bilge S. Intersectionality. Malden, MA: Polity Press; 2016.
- 31 Medicaid and Long-Term Services and Supports: A Primer. The Henry J Kaiser Family Foundation. 2018. Available at: <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/>. Accessed April 23, 2018.
- 32 Considerations regarding withholding/withdrawing life-sustaining treatment. Center for Practical Bioethics. 2015. Available at: <https://www.practicalbioethics.org/files/ethics-consortium-guidelines/Withholding-Withdrawing-Life-Sustaining-Treatment.pdf>. Accessed April 23, 2018.
- 33 Morrison EE. *Ethics in Health Administration: A Practical Approach for Decision Makers*. Burlington, MA: Jones and Bartlett Publishers; 2006.
- 34 Dying in America: improving quality and honoring individual preferences near the end of life. <https://www.nap.edu>. 2015. Available at: <https://www.nap.edu/read/18748/chapter/1>. Accessed April 23, 2018.
- 35 Dying in America: improving quality and honoring individual preferences near the end of life. <https://www.nap.edu>. 2015. Available at: <https://www.nap.edu/read/18748/chapter/1>. Accessed April 23, 2018.
- 36 Mehnert A. Clinical psychology in palliative care. In Cherny N, Fallon M, Kaasa S, Portenoy R, Currow D. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press; 2015.
- 37 Fairman N, Irwin S. Palliative care psychiatry: Update on an emerging dimension of psychiatric practice. *Curr Psychiatry Rep*. 2013;15(7). doi:10.1007/s11920-013-0374-3.
- 38 Koenig H, King DE, Carson VB. *Handbook of Religion and Mental Health*. 2nd ed. New York: Oxford University Press; 2012.
- 39 Kelley AS, Bollens-Lund, E. Identifying the population with serious illness: the “denominator” challenge. *J Palliat Med*. 2018; 21(S2). <https://www.liebertpub.com/doi/full/10.1089/jpm.2017.0548>, Published March 2, 2018. Accessed September 5, 2018.
- 40 Legare F, Witteman H. Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Aff*. 2013;32(2):276-284. doi:10.1377/hlthaff.2012.1078.

- 41 About social determinants of health. World Health Organization. 2011. Available at: http://www.who.int/social_determinants/sdh_definition/en/. Accessed April 23, 2018.
- 42 Puchalski C, Ferrell B, Virani R et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliat Med.* 2009;12(10):885-904. doi:10.1089/jpm.2009.0142.
- 43 Puchalski C, Ferrell B, Virani R et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliat Med.* 2009;12(10):885-904. doi:10.1089/jpm.2009.0142.
- 44 Caldeira S, Carvalho E, Vieira M. Spiritual Distress-Proposing a New Definition and Defining Characteristics. *Int J Nurs Knowl.* 2013;24(2):77-84. doi:10.1111/j.2047-3095.2013.01234.x.
- 45 Puchalski C, Ferrell B, Virani R et al. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *J Palliat Med.* 2009;12(10):885-904. doi:10.1089/jpm.2009.0142.
- 46 Puchalski C, Ferrell B, Virani R et al. Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *J Palliat Med.* 2009;12(10):885-904. doi:10.1089/jpm.2009.0142.
- 47 Brant J. Holistic total pain management in palliative care: Cultural and global considerations. *Palliat Med Hosp Care Open J.* 2017;SE(1):S32-S38. doi:10.17140/pmhcoj-se-1-108.

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/>
- Dy SM, Kiley SB, Ast K, Lupu D, Norton SA, McMillan SC, Herr K, Rotella JD, Casarett DJ. *Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. J Pain Symptom Manage.* 2015;49(4):773-781. doi:10.1016/j.jpainsymman.2015.01.012.
- Institute for Healthcare Improvement – Plan-Do-Study-Act (PDSA) Worksheet <http://www.ihl.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/>

Pediatrics:

- Chrastek J. *Pediatric palliative care in the community.* In Dahlin, C., Coyne, P. J., & Ferrell, B. R. (Eds.). *Advanced practice palliative nursing.* New York, NY: Oxford University Press, 587-596;2016.

- Widger K, Sutradhar R, Rapoport A, Vadeboncoer C, Zelcer S, Kassam A, ..., & Gupta S. Predictors of specialized pediatric palliative care involvement and impact on patterns of end-of-life care in children with cancer. *J Clin Oncol*, 2018; Jan 22, e-pub ahead of print. doi:10.1200/JCO.2017.75.6312.
- Davis KG. Integrating palliative care into the school and community. *Pediatric Clinics of North America*, 2016;63(5):899-911.
- Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, & Friebert SE. Pediatric palliative care in the community. *CA Cancer J Clin*, 2018;65(4):316-333.
- 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>

Appendix II: Tools and Resources

- 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.
- Collins JJ, Devine TD, Dick GS, et al. The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. *J Pain Symptom Manage*, 2002;23(1):10-16.
- Krechel SW, Bildner J. CRIES: A new neonatal postoperative pain measurement score: initial testing of validity and reliability. *Pediatr Anesth*, 1995;5:53-61.
- Lawrence J, Alcock D, McGrath P, Kay J, MacMurray SB, Dulberg C. The development of a tool to assess neonatal pain. *Neonatal Net*, 1993;12(6):59-66.
- Hummel P, Puchalski M, Creech SD, Weiss MGI. 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.anesthesiarianimazione.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.
- Collins JJ, Berde CB, Frost JA. Pain Assessment and management. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 284-299;2011.

- Davies D. Respiratory symptoms. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 300-310;2011.
- Friedrichsdorf SJ, Drake R, Webster ML. Gastrointestinal symptoms. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 311-334;2011.
- Goldsmith M, Ortiz-Rubio P, Staveski, S, Chan M, Shaw RJ. Delirium. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 251-265;2011.
- 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.
- Haskamp, AC, Lafond DA. Pediatric oncology. In Dahlin, C., Coyne, P. J., & Ferrell, B. R. (Eds.). *Advanced practice palliative nursing*. New York, NY: Oxford University Press, 575-586;2016. ****Includes symptom management**
- 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.
- Herbert A, Seton C, Gamble A. Sleep and insomnia. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 272-283;2011.
- Hesselgrave J, Hockenberry M. Fatigue. In Wolfe, J., Hinds, P. S., & Sourkes, B. M. (Eds.). *The textbook of interdisciplinary pediatric palliative care*. Philadelphia, PA: Elsevier Saunders, 266-271;2011.
- Holley LM, Kometiani MK, Friebe S. Expressive therapy and complementary approaches in palliative care. In Kobler, K., & Limbo, R. (Eds.). *Conversations in perinatal, neonatal, and pediatric palliative care*. Pittsburgh, PA: Hospice and Palliative Nurses Association, 87-108;2017.
- Puchalski ML, Johnson, TS. Infant pain. In Kobler, K., & Limbo, R. (Eds.). *Conversations in perinatal, neonatal, and pediatric palliative care*. Pittsburgh, PA: Hospice and Palliative Nurses Association, 63-8;2017.
- Pieper L, Zernikow B, Drake R, Frosch M, Printz M, Wager J. Dyspnea in children with life-threatening and life-limiting complex chronic conditions. *J Palliat Med*, Jan 9, e-pub ahead of print. doi: 10.1089/jpm.2017.0240.

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.psych-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/>

- Duncan J, Kobler K. Communication in pediatrics. In Dahlin, C., Coyne, P. J., & Ferrell, B. R. (Eds.). *Advanced practice palliative nursing*. New York, NY: Oxford University Press, 597-608;2016.

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.

- De Andrade Alvarenga W, de Carvalho EC, Caldeira S, Vieira M, Nascimento LC. The possibilities and challenges in providing pediatric spiritual care. *J Child Health Care*, 2017;21(4):435-445.
- Ferrell B, Wittenberg E, Battista V, Walker G. Exploring the spiritual needs of families with seriously ill children. *Int J Palliat Nurs*, 2016;22(8): 388-394.
- 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-\(1\)](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>

Appendix II: Tools and Resources

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>
- American Academy of Pediatrics Committee on Bioethics. *Guidelines on Forgoing Life-sustaining Medical Treatment*. Elk Grove, IL: American Academy of Pediatrics;2017. <http://pediatrics.aappublications.org/content/140/3/e20171905>

Appendix II: Tools and Resources

- American Academy of Pediatrics Committee on Fetus and Newborn. *Noninitiation or Withdrawal of Intensive Care for High-Risk Newborns*. Elk Grove, IL: American Academy of Pediatrics;2007. Reaffirmed 2014. <http://pediatrics.aappublications.org/content/119/2/401.full?sid=6cdfa1d6-8fd4-48fc-81a1-7d637f568d5b>
- American Medical Association. *Code of Medical Ethics' Opinions Related to End-of-Life Care*. AMA Journal of Ethics. <https://journalofethics.ama-assn.org/article/ama-code-medical-ethics-opinions-related-end-life-care/2018-08>
- American Nurses Association. *Position Statement – The Ethical Responsibility to Manage Pain and the Suffering It Causes*. Silver Spring: MD: American Nurses Association. 2018. <https://www.nursingworld.org/~495e9b/globalassets/docs/ana/ethics/theethicalresponsibilitytomanagepainandthesufferingitcauses2018.pdf>
- American Nurses Association. *Position Statement – Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions*. Washington, DC: American Nurses Association;2012. <https://www.nursingworld.org/~4ad4a8/globalassets/docs/ana/nursing-care-and-do-not-resuscitate-dnr-and-allow-natural-death-decisions.pdf>
- American Nurses Association. *Position Statement – Euthanasia, Assisted Suicide, and Aid in Dying*. Washington, DC: American Nurses Association;2013. https://www.nursingworld.org/~4ae33e/globalassets/docs/ana/euthanasia-assisted-suicideaid-in-dying_ps042513.pdf
- American Nurses Association. *Position Statement – Code of Ethics for Nurses*. Washington, DC: American Nurses Association;2015. <http://www.nursingworld.org/codeofethics>
- American Nurses Association. *Position Statement – Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life*. Washington, DC: American Nurses Association;2016. <https://www.nursingworld.org/~4af078/globalassets/docs/ana/ethics/endoflife-positionstatement.pdf>
- American Nurses Association. *Position Statement – The Nurse's Role in Ethics and Human Rights: Protecting and Promoting Individual Worth, Dignity, and Human Rights in Practice Settings*. Washington, DC: American Nurses Association;2016. <https://www.nursingworld.org/~4ad4a8/globalassets/docs/ana/nursesrole-ethicshumanrights-positionstatement.pdf>
- American Nurses Association. *Position Statement – Therapeutic Use of Marijuana and Related Cannabinoids*. Washington, DC: American Nurses Association;2016. <https://www.nursingworld.org/~49a8c8/globalassets/practiceandpolicy/ethics/therapeutic-use-of-marijuana-and-related-cannabinoids-position-statement.pdf>
- American Nurses Association. *Position Statement – Nutrition and Hydration at the End of Life*;2017. <https://www.nursingworld.org/~4ad4a8/globalassets/docs/ana/nutrition-and-hydration-at-end-of-life.pdf>
- American Psychological Association. *Resolution on Palliative Care and End-of-life Issues and Justification*. Washington, DC: American Psychological Association;2017. <http://www.apa.org/about/policy/palliative-care-eol.aspx>
- American Society of Health System Pharmacists. *ASHP Guidelines on the Pharmacist's Role in Palliative and Hospice Care*. American Journal of Health-System Pharmacists;2016. <http://www.ajhp.org/content/73/17/1351.long?sso-checked=true>

- Hospice and Palliative Nurses Association. *Position Statement – Artificial Nutrition and Hydration in Advanced Illness*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2011. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – Role of Palliative Care in Organ and Tissue Donation*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2013. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – The Use of Medical Marijuana*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2014. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – The Role of Hospice and Palliative Nurses in Research*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2016. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – Withholding and/or Withdrawing Life-Sustaining Therapies*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2016. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – Palliative Sedation*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2016. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – Physician Assisted Death/ Physician Assisted Suicide*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2017. <https://advancingexpertcare.org/position-statements/>
- Hospice and Palliative Nurses Association. *Position Statement – The Ethics of the Use of Opioids in Palliative Nursing*. Pittsburgh, PA: Hospice and Palliative Nurses Association;2017. <https://advancingexpertcare.org/position-statements/>
- National Association of Neonatal Nurses. *Position Statement – Palliative and End-of-Life Care for Newborns and Infants*. Chicago, IL: National Association of Neonatal Nurses;2015. http://nann.org/uploads/About/PositionPDFS/1.4.5_Palliative%20and%20End%20of%20Life%20Care%20for%20Newborns%20and%20Infants.pdf
- National Association of Neonatal Nurses. *Position Statement – NICU Nurse Involvement in Ethical Decisions (Treatment of Critically Ill Newborns)*. Chicago, IL: National Association of Neonatal Nurses;2016. http://nann.org/uploads/3067_NICU_Nurse_Involvement_in_Ethical_Decisions.pdf
- National Association for Social Workers Standards for Palliative & End of Life Care. <https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3d&portalid=0>
- National Hospice and Palliative Care Organization. *Position Statement – Commentary and Position Statement on Artificial Nutrition and Hydration*. Alexandria, VA: National Hospice and Palliative Care Organization;2010. https://www.nhpco.org/sites/default/files/public/ANH_Statement_Commentary.pdf

Appendix II: Tools and Resources

- National Hospice and Palliative Care Organization. *Position Statement – Commentary and Position Statement on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients*. Alexandria, VA: National Hospice and Palliative Care Organization;2010. https://www.nhpco.org/sites/default/files/public/JPSM/NHPCO_Pall-Sedation-Ther_JPSM_May2010.pdf
- National Hospice and Palliative Care Organization. *Position Statement – Hospice and Palliative Care: Ethical Marketing Practices*. Alexandria, VA: National Hospice and Palliative Care Organization;2011. https://www.nhpco.org/sites/default/files/public/NHPCO_Ethical_Marketing_Statement_June11.pdf

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

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- Shibani Ray-Mazumder, ScD, PhD, New York State Psychological Association Palliative Care Psychology Task Force
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Domain 6: Cultural Aspects of Care

- Brenda Gonzalez, Agrace Hospice & Palliative Care
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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:

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

Appendix III: Contributors

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- 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,"

Appendix IV: Scoping Review

"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

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.

Appendix IV: Scoping Review

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

Access

- Artnak KE, McGraw RM, Stanley VF. Health care accessibility for chronic illness management and end-of-life care: A view from rural America. *J Law Med Ethics*. 2011;39(2):140-155.
- Fishman J, O'Dwyer P, Lu HL, Henderson H, Asch DA, Casarett DJ. Race, treatment preferences, and hospice enrollment: Eligibility criteria may exclude patients with the greatest care needs. *Cancer*. 2009;115(3):689-697.
- Hoffman HC, Dickinson GE. Characteristics of prison hospice programs in the United States. *Am J Hosp Palliat Care*. 2011;28(4):245-252.
- Jones BW. The need for increased access to pediatric hospice and palliative care. *Dimens Crit Care Nurs*. 2011;30(5):231-235.
- Keim-Malpass J, Mitchell E, Blackhall L, DeGuzman P. Evaluating stakeholder-identified barriers in accessing palliative care at an NCI-designated cancer center with a rural catchment area. *J Palliat Med*. 2015;18(7):634-637. doi:10.1089/jpm.2015.0032.
- Lyckholm JJ, Coyne PJ, Kreutzer KO, Ramakrishnan V, Smith TJ. Barriers to effective palliative care for low-income patients in the late stages of cancer: A report of a study and strategies for defining and conquering the barriers. *Nurs Clin North Am*. 2010;45(3):399-409.

- Meier DE. Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly*. 2011;89(3):343-380.
- Menzel PT. The cultural moral right to a basic minimum of accessible health care. *Kennedy Inst Ethics J*. 2011;21(1):79-119.
- Morrison RS, Augustin R, Souvanna P, Meier DE. America's care of serious illness: A state-by-state report card on access to palliative care in our nation's hospitals. *J Palliat Med*. 2011;14(10):1094-1096.
- Nyatanga B. The pursuit of cultural competence: Service accessibility and acceptability. *Int J Palliat Nurs*. 2011;17(5):212-215.
- Pesut B, Beswick F, Robinson CA, Bottorff JL. Philosophizing social justice in rural palliative care: Hayek's moral stone? *Nurs Philos*. 2012;13(1):46-55.
- Rowett D, Ravenscroft PJ, Hardy J, Currow DC. Using national health policies to improve access to palliative care medications in the community. *J Pain Symptom Manage*. 2009;37(3):395-402.
- Vassal P, Le Coz P, Herve C, Matillon Y, Chapuis F. Is the principle of equal access for all applied in practice to palliative care for the elderly? *J Palliat Med*. 2009;12(12):1089.

Communication

- Anderson W, Puntillo K, Boyle D et al. ICU bedside nurses' involvement in palliative care communication: A multicenter survey. *J Pain Symptom Manage*. 2016;51(3):589-596.e2. doi:10.1016/j.jpainsymman.2015.11.003.
- Au DH, Udris EM, Engelberg RA, et al. A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest*. 2012;141(3):726-735.
- Boyd D, Merkh K, Rutledge D, Randall V. Nurses' perceptions and experiences with end-of-life communication and care. *Oncol Nurs Forum*. 2011;38(3):229-239.
- Casarett D, Pickard A, Fishman JM, et al. Can metaphors improve communication with seriously ill patients? *J Palliat Med*. 2010;13(3):255-260.
- Chuang E, Lamkin R, Hope A, Kim G, Burg J, Gong M. "I Just Felt Like I Was Stuck in the Middle": Physician assistants' experiences communicating with terminally ill patients and their families in the acute care setting. *J Pain Symptom Manage*. 2017;54(1):27-34. doi:10.1016/j.jpainsymman.2017.03.011.
- Eggly S, Albrecht T, Kelly K, Prigerson H, Sheldon L, Studts J. The role of the clinician in cancer clinical communication. *J Health Commun*. 2009;14(sup1):66-75. doi:10.1080/10810730902806778.
- Eneanya N, Goff S, Martinez T et al. Shared decision-making in end-stage renal disease: A protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients. *BMC Palliat Care*. 2015;14(1). doi:10.1186/s12904-015-0027-x.
- Finley E, Casarett DJ. Making difficult discussion easier: Using prognosis to facilitate transitions to hospice. *CA Cancer J Clin*. 2009;59(4):250-263.
- Goldsmith J, Ferrell B, Wittenberg-Lyles E, Ragan S. Palliative care communication in oncology nursing. *Clin J Oncol Nurs*. 2013;17(2):163-167. doi:10.1188/13.cjon.163-167.
- Gordon N, O'Riordan D, Dracup K, De Marco T, Pantilat S. Let us talk about it: Heart failure patients' preferences toward discussions about prognosis, advance care planning, and spiritual support. *J Palliat Med*. 2017;20(1):79-83. doi:10.1089/jpm.2016.0097.

- Gramling R, Norton S, Ladwig S et al. Direct observation of prognosis communication in palliative care: A descriptive study. *J Pain Symptom Manage*. 2013;45(2):202-212. doi:10.1016/j.jpainsymman.2012.02.004.
- Hanson, Associate Editor L. Communication is our procedure. *J Palliat Med*. 2011;14(10):1084-1085. doi:10.1089/jpm.2011.9647.
- Jackson V, Jacobsen J, Greer J, Pirl W, Temel J, Back A. The cultivation of prognostic awareness through the provision of early palliative care in ambulatory setting: A communication guide. *J Palliat Med*. 2013;16(8):894-900. doi:10.1089/jpm.2012.0547.
- Kelley AS, Back AL, Arnold RM, et al. Geritalk: Communication skills training for geriatric and palliative medicine fellows. *J Am Geriatr Soc*. 2012;60(2):332-337.
- Kissane DW, Bylund CL, Banerjee SC, et al. Communication skills training for oncology professionals. *J Clin Oncol*. 2012;30(11):1242-1247.
- Krimshtein NS, Luhrs CA, Puntillo K, et al. Training nurses for interdisciplinary communication with families in the intensive care unit: An Intervention. *J Palliat Med*. 2011:1325-1332.
- Litzelman D, Inui T, Schmitt-Wendholt K et al. Clarifying values and preferences for care near the end of life: The role of a new lay workforce. *J Community Health*. 2017;42(5):926-934. doi:10.1007/s10900-017-0336-5.
- Mack JW, Paulk ME, Vinswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med*. 2010;170(17):1533-1540.
- Malloy P, Virani R, Kelly K, Munevar C. Beyond bad news: Communication skills of nurses in palliative care. *J Hosp Palliat Nurs*. 2010;12(3):166-174.
- Miner TJ. Communication skills in palliative surgery: Skill and effort are key. *Surg Clin of North Am*. 2011;91(2):355-366.
- Morris D, Johnson K, Ammarell N, Arnold R, Tulsy J, Steinhauer K. What is your understanding of your illness? A communication tool to explore patients' perspectives of living with advanced illness. *J Gen Intern Med*. 2012;27(11):1460-1466. doi:10.1007/s11606-012-2109-2.
- Morrison RS, Dietrich J, Ladwig S, et al. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff*. 2011;30(3):454-463.
- Ozanne EM, Partridge A, Moy B, Ellis KJ, Sepucha KR. Doctor-patient communication about advance directives in metastatic breast cancer. *J Palliat Med*. 2009;12(6):547-553.
- Pekmezaris R, Walia R, Nouryan C, et al. The impact of an end-of-life communication skills intervention on physicians-in-training. *Gerontol Geriatr Educ*. 2011;32(2):152-163.
- Pollak K, Childers J, Arnold R. Applying motivational interviewing techniques to palliative care communication. *J Palliat Med*. 2011;14(5):587-592. doi:10.1089/jpm.2010.0495.
- Sharma R. Cross-cultural communication and use of the family meeting in palliative care. *Am J Hosp Palliat Care*. 2011;28(6):437.
- Silva M, Genoff M, Zaballa A, Stabler S, Gany F, Diamond L. Interpreting in palliative care: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *J Clin Oncol*. 2014;32(31_suppl):123-123. doi:10.1200/jco.2014.32.31_suppl.123.

- Slort W, Schweitzer BP, Blankenstein AH, et al. Perceived barriers and facilitators for general practitioner-patient communication in palliative care: A systematic review. *Palliat Med*. 2011;25(6):613-629.
- Smith-Stoner M. Webcasting in home and hospice care services: Virtual communication in home care. *Home Healthc Nurse*. 2011;29(6):337-341.
- Szmulowicz E, el-Jawahri A, Chiappetta L, Kamdar M, Block S. Improving residents' end-of-life communication skills with a short retreat: A randomized controlled trial. *J Palliat Med*. 2010;13(4):439-452.
- Trice ED, Prigerson HG. Communication in end-stage cancer: Review of the literature and future research. *J Health Commun*. 2009;14:95-108.
- Truog RD. Translating research on communication in the intensive care unit into effective educational strategies. *Crit Care Med*. 2010;38(3):976-977.
- Wagner GJ, Riopelle D, Steckart J, Lorenz KA, Rosenfeld KE. Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *J Pain Symptom Manage*. 2010;29:527-534.
- Wittenberg E, Ferrell BR, Goldsmith J et al. (Eds.). Textbook of palliative care communication. New York: Oxford University Press.

Culture

- Arthur D. Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective. *J Soc Work End Life Palliat Care*. 2015;11(2):178-201. doi:10.1080/15524256.2015.1074141.
- Barnato A, Anthony D, Skinner J, Gallagher P, Fisher E. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med*. 2009;24(6):695-701. doi:10.1007/s11606-009-0952-6.
- Dillon P, Basu A. African Americans and hospice care: A culture-centered exploration of enrollment disparities. *Health Commun*. 2016;31(11):1385-1394. doi:10.1080/10410236.2015.1072886.
- Drisdom, S. Barriers to using palliative care: Insight into African American culture. *Clin J Oncol Nurs*. 2013;17(4):376-380.
- Fink R, Oman K, Youngwerth J, Bryant L. A palliative care needs assessment of rural hospitals. *J Palliat Med*. 2013;16(6):638-644. doi:10.1089/jpm.2012.0574.
- Hazin, R. and C. A. Giles. Is there a color line in death? An examination of end-of-life care in the African American community. *J Nat Med Assoc*. 2009; 103(7):609-13.
- Isaacson M, Lynch A. culturally relevant palliative and end-of-life care for U.S. indigenous populations: An integrative review. *J Transcult Nurs*. 2017:104365961772098. doi:10.1177/1043659617720980.
- LoPresti M, Dement F, Gold H. End-of-life care for people with cancer from ethnic minority groups. *Am J Hosp Palliat Care*. 2014;33(3):291-305. doi:10.1177/1049909114565658.
- Lynch S. Hospice and Palliative Care Access Issues in Rural Areas. *Am J Hosp Palliat Care*. 2012;30(2):172-177. doi:10.1177/1049909112444592.
- Mitchell B, Mitchell L. Review of the literature on cultural competence and end-of-life treatment decisions: The role of the hospitalist. *J Nat Med Assoc*. 2009;101(9):920-926. doi:10.1016/s0027-9684(15)31040-3.

Appendix IV: Scoping Review

- Shreve, S. Hospice and palliative care by the VA, beyond the VA. *Generations*. 2010;34(2), 49–56.
- Smith A, Sudore R, Pérez-Stable E. Palliative care for Latino patients and their families. *JAMA*. 2009;301(10):1047. doi:10.1001/jama.2009.308.
- Vail W, Niyogi A, Henderson N, Wennerstrom A. Bringing it all back home: Understanding the medical difficulties encountered by newly released prisoners in New Orleans, Louisiana - a qualitative study. *Health Soc Care Community*. 2017;25(4):1448-1458. doi:10.1111/hsc.12445.
- Yennurajalingam S, Noguera A, Parsons H et al. A multicenter survey of Hispanic caregiver preferences for patient decision control in the United States and Latin America. *Palliat Med*. 2013;27(7):692-698. doi:10.1177/0269216313486953.

Decision-Making

- Bakitas M, Kryworuchko J, Matlock DD, Volandes AE. Palliative medicine and decision science: The critical need for a shared agenda to foster informed patient choice in serious illness. *J Palliat Med*. 2011;14(10):1109-1116.
- Baumrucker SJ, Stolick M, Morris GM, et al. A cognitively impaired patient without a surrogate: Who makes the decision? *Am J Hosp Palliat Care*. 2011;28(8):583-587.
- Berger JT. Patients' concerns for family burden: A nonconforming preference in standards for surrogate decision making. *J Clin Ethics*. 2009;20(2):158-161.
- Bomba P, Morrissey M, Leven D. Key role of social work in effective communication and conflict resolution process: Medical orders for life-sustaining treatment (MOLST) program in New York and shared medical decision making at the end of life. *J Soc Work End Life Palliat Care*. 2011;7(1):56-82. doi:10.1080/15524256.2011.548047.
- Eskew S, Meyers C. Religious belief and surrogate medical decision making. *J Clin Ethics*. 2009;20(2):192-200.
- Gramling R, Sanders M, Ladwig S, Norton S, Epstein R, Alexander S. Goal communication in palliative care decision-making consultations. *J Pain Symptom Manage*. 2015;50(5):701-706. doi:10.1016/j.jpainsymman.2015.05.007.
- Hammes BJ, Rooney BL, Gundrum JD, Hickman SE, Hager N. The POLST program: A retrospective review of the demographics of use and outcomes in one community where advance directives are prevalent. *J Palliat Med*. 2012;15(1):77-85.
- Kapp MB. Medical decision-making for incapacitated elders: A "therapeutic interests" standard. *Int J Law Psychiatry*. 2010;33(5-6):369-374.
- Karasz A, Sacajiu G, Kogan M, Watkins L. The rational choice model in family decision making at the end of life. *J Clin Ethics*. 2010;21(3):189-200.
- Kwon YC, Shin DW, Lee JH, et al. Impact of perception of socioeconomic burden on advocacy for patient autonomy in end-of-life decision making: A study of societal attitudes. *Palliat Med*. 2009;23(1):87-94.
- Mack JM, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: Predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol*. Mar 2010;28(7):1203-1208.
- Mahon MM. Advanced care decision making: Asking the right people the right questions. *J Psychosoc Nurs Ment Health Serv*. 2010;48(7):13-19.

- Moorman SM. Older adults' preferences for independent or delegated end-of-life medical decision making. *J Aging Health*. 2011;23(1):135-157.
- Newport K, Patel S, Lyckholm L, Bobb B, Coyne P, Smith T. The "PSOST": Providers' signout for scope of treatment. *J Palliat Med*. 2010;13(9):1055-1058. doi:10.1089/jpm.2010.0103.
- Romo R, Allison T, Smith A, Wallhagen M. Sense of control in end-of-life decision-making. *J Am Geriatr Soc*. 2016;65(3):e70-e75. doi:10.1111/jgs.14711.
- Sauler M, Siegel MD. The past, present, and future of advance directives as a guide to end-of-life decision making. *Chest*. 2012;141(1):9-10.
- Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010;362(13):1211-1218.
- Waldrop D, Meeker M, Kutner J. The developmental transition from living with to dying from cancer: Hospice decision making. *J Psychosoc Oncol*. 2015;33(5):576-598. doi:10.1080/07347332.2015.1067282.

Education

Nurse

- End of Life Nursing Education Consortium (ELNEC). *History, Statewide Effort and Recommendations for the Future – Advancing Palliative Nursing Care*. Long Beach, CA: Archstone Foundation;2012.
- Ferrell BR, Virani R, Paice JA, Malloy P, Dahlin C. Statewide efforts to improve palliative care in critical care settings. *Critical Care Nurse*. 2010;30(6):40-45.
- Forrest C, Derrick C. Interdisciplinary education in end-of-life care: creating new opportunities for social work, nursing, and clinical pastoral education students. *J Soc Work End Life Palliat Care*. 2010;6(1-2):91-116.
- Institute of Medicine. *The Future of Nursing: Leading Change, Advancing Health*. Washington, DC: The National Academies Press; 2011. <http://www.nationalacademies.org/hmd/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health.aspx>. Accessed September 1, 2012.
- Kain V, Gardner G, Yates P. Neonatal palliative care attitude scale: Development of an instrument to measure the barriers to and facilitators of palliative care in neonatal nursing. *Pediatrics*. 2009;123(2):e207-e213.
- Lee SM, Coakley EE, Blakeney B, Brandt LK, Rideout ML, Dahlin C. The national AgeWISE pilot. *J Nurse Admin*. 2012;42(7/8):356-360.
- Lee SM, Coakley EE, Dahlin C, Carleton PF. An evidence-based nurse residency program in geropalliative care. *J Contin Educ Nurs*. 2009;40(12):536-542.
- Lewis DY. Incorporating national priorities into the curriculum. *J Prof Nur*. 2012;28(2):105-109.
- Marshall V. Benefits of hospice and palliative care certification. *Home Healthc Nurs*. 2009;27(8):463-457.
- Moules NJ, Johnstone H. Commendations, conversations, and life-changing realizations: Teaching and practicing family nursing. *J Fam Nurs*. 2010;16(2):146-160.
- Schreiner LS, Pimple C, Wolf Bordonaro GP. Palliative care for children: Preparing undergraduate nursing students. *Nurse Educator*. 2009;34(4):162-165.
- Smith-Stoner M. Using high-fidelity simulation to educate nursing students about end-of-life care. *Nurs Educ Perspect*. 2009;30(2):115-120.

Appendix IV: Scoping Review

Physician

- Ahmed NN, Farnie M, Dyer CB. The effect of geriatric and palliative medicine education on the knowledge and attitudes of internal medicine residents. *J Am Geriatr Soc.* 2011;59(1):143-147.
- American Academy of Hospice and Palliative Medicine. Position Statement - Requirements for the Successful Development of Academic Palliative Medicine Programs. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2010.
- Baker M, Wrubel J, Rabow MW. Professional development and the informal curriculum in end-of-life care. *J Cancer Educ.* 2011;26(3):444-450.
- Billings ME, Engelberg R, Curtis JR, Block S, Sullivan AM. Determinants of medical students' perceived preparation to perform end-of-life care, quality of end-of-life care education, and attitudes toward end-of-life care. *J Palliat Med.* 2010;13(3):319-326.
- Bruera E, Billings JA, Lupu D, Ritchie CS. AAHPM position paper: Requirements for the successful development of academic palliative care programs. *J Pain Symptom Manage.* 2010;39(4):743-755.
- Buss MK, Lessen DS, Sullivan AA, VonRoenn J, Arnold RM, Block SD. Hematology/Oncology fellows' training in palliative care: Results of a national survey. *Cancer.* 2011;117(18):4304-4311.
- Dickens DS. Building competence in pediatric end-of-life care. *J Palliat Med.* 2009;12(7):617- 622.
- Dunn GP. Principles and core competencies of surgical palliative care: An overview. *Otolaryngol Clin North Am.* 2009;42(1):1-13.
- Irwin SA, Montross LP, Bhat RG, Nelesen RA, von Gunten CF. Psychiatry resident education in palliative care: Opportunities, desired training, and outcomes of a targeted educational intervention. *Psychosomatics.* 2011;52(6):530-536.
- Klaristenfeld DD, Harrington DT, Miner TJ. Teaching palliative care and end-of-life issues: A core curriculum for surgical residents. *Ann Surg Oncol.* 2007;14(6):1801-1806.
- Lamba S, Pound A, Rella JG, Compton S. Emergency medicine resident education in palliative care: A needs assessment. *J Palliat Med.* 2012;15(5):516-520.
- Marco CA, Lu DW, Stettner E, Sokolove PE, Ufberg JW, Noeller TP. Ethics curriculum for emergency medicine graduate medical education. *J Emerg Med.* 2011;40(5):550-556.
- Morrison LJ, Block SD, HPM Competencies Project Phase III Workgroup. Hospice and palliative medicine competencies project: Toolkit of assessment methods. 2010. <http://aahpm.org/uploads/education/competencies/Toolkit%20Intro%202014.pdf>. Accessed September 7, 2012.
- Morrison LJ, Block SD, HPM Competencies Project Workgroup. Hospice and palliative medicine core competencies, version 2.3. 2009. <http://aahpm.org/uploads/education/competencies/Competencies%20v.%202.3.pdf>. Accessed September 7, 2012.
- Morrison LJ, Block SD, HPM Competencies Project Workgroup. Measurable outcomes for hospice and palliative medicine (HPM) competencies, version 2.3. 2009. <http://aahpm.org/uploads/education/competencies/Outcomes%20v.%202.3.pdf>. Accessed September 7, 2012.
- Morrison RS. Bringing palliative care to scale in our nation's medical schools. *J Palliat Med.* 2010;13(3):233-234.

Social Work

- Altilio T, Gardia G, Otis-Green S. Social work practice in palliative and end-of-life care: A report from the summit. *J Soc Work End Life Palliat Care*. 2008;3(4):68-86. doi:10.1080/15524250802003513.
- Simons K, Park-Lee E. Social work students' comfort with end-of-life care. *J Soc Work End Life Palliat Care*. 2009;5(1-2):34-48.

Pharmacist

- American Society of Health-System Pharmacist. Palliative care/pain management PGY2 accredited residencies. <https://accred.ashp.org/aps/pages/directory/residencyProgramSearch.aspx>. Accessed July 5th, 2017.
- Society of Palliative Care Pharmacists (SPCP). <http://www.palliativepharmacist.org/>. Accessed July 5, 2017.

Interdisciplinary Education

- Atayee RS, Lockman K, Brock C, Abazia DT, Brooks TL, Pawasauskas J, Edmonds KP, Herndon CM. Multicentered study evaluating pharmacy students' perception of palliative care and clinical reasoning using script concordance testing. *Am J Hosp Palliat Care*. 2018 Jan 1:1049909118772845. doi: 10.1177/1049909118772845. [Epub ahead of print] PubMed PMID: 29690782.
- Dickinson GE. End-of-life and palliative care education in US pharmacy schools. *Am J Hosp Palliat Care*. 2012. doi:10.1177/1049909112457011.
- Dugan Day M. Interdisciplinary hospice team processes and multidimensional pain: A qualitative study. *J Soc Work End Life Palliat Care*. 2012;8(1):53-76. doi:10.1080/15524256.2011.650673.
- Grant M, Elk R, Ferrell B, Morrison RS, von Gunten CF. Current status of palliative care--clinical implementation, education, and research. *CA Cancer J Clin*. 2009;59(5):327-335.
- Kobayashi R, McAllister C. Hospice core professions' view on interdisciplinary teams: A qualitative investigation. *J Soc Work End Life Palliat Care*. 2016;12(3):214-230. doi:10.1080/15524256.2016.1201565.
- Mackereth P, Carter A, Parkin S, et al. Complementary therapists' training and cancer care: A multi-site study. *Eur J Oncol Nurs*. 2009;13(5):330-335.
- Meredith PJ. Has undergraduate education prepared occupational therapy students for possible practice in palliative care? *Aust Occup Ther J*. 2010;57(4):224-232.
- Otis-Green S, Ferrell B, Spolum M, et al. An overview of the ACE Project-advocating for clinical excellence: Transdisciplinary palliative care education. *J Cancer Educ*. 2009;24(2):120-126.
- Parker Oliver D, Demiris G, Wittenberg-Lyles E, Porock D, Collier J, Arthur A. Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *Am J Hosp Palliat Care*. 2010;27(7):465-473. doi:10.1177/1049909110362402.
- Porter-Williamson K, Parker M, Babbott S, Steffen P, Stites S. A model to improve value: The interdisciplinary palliative care services agreement. *J Palliat Med*. 2009;12(7):609-615.

Appendix IV: Scoping Review

- Powazki R, Walsh D, Shrotriya S. A prospective study of the clinical content of palliative medicine interdisciplinary team meetings. *Am J Hosp Palliat Care*. 2014;32(8):789-796. doi:10.1177/1049909114546886.
- Rivers KO, Perkins RA, Carson CP. Perceptions of speech-pathology and audiology students concerning death and dying: A preliminary study. *Int J Lang Commun Disorders*. 2009;44(1):98.
- Rodriguez E, A Johnson G, Culbertson T, Grant W. An educational program for spiritual care providers on end of life care in the critical care setting. *J Interprof Care*. 2011;25(5):375-377.
- Wittenberg-Lyles E, Parker Oliver D, Demiris G, Baldwin P. The ACTive intervention in hospice interdisciplinary team meetings: Exploring family caregiver and hospice team communication. *J Comput Mediat Commun*. 2010;15(3):465-481. doi:10.1111/j.1083-6101.2010.01502.x.
- Wittenberg-Lyles E, Parker Oliver D, Demiris G, Regehr K. Interdisciplinary collaboration in hospice team meetings. *J Interprof Care*. 2010;24(3):264-273.
- Youngwerth J, Twaddle M. Cultures of interdisciplinary teams: How to foster good dynamics. *J Palliat Med*. 2011;14(5):650-654. doi:10.1089/jpm.2010.0395.

Finances and Cost

- Association of Professional Chaplains. Standards of Practice for Professional Chaplains. 2015. http://www.professionalchaplains.org/professional_standards.
- Baily MA. Futility, autonomy, and cost in end-of-life care. *J Law Med Ethics*. 2011;39(2):172-182.
- Carlson MJ, Herrin QD, Epstein C, et al. Impact of hospice disenrollment in health care use and Medicare expenditures for patients with cancer. *J Clin Oncol*. 2010;28:4371-4375.
- Dussel V, Bona K, Heath JA, Hilden JM, Weeks JC, Wolfe J. Unmeasured costs of a child's death: Perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost a child to cancer. *J Clin Oncol*. 2011;29(9):1007-1013.
- Iglehart JK. A new era of for-profit: Hospice care -- The Medicare Benefit. *N Engl J Med*. 2009;360(26):2701-2703.
- Jennings B, Morrissey M. Health care costs in end-of-life and palliative care: The quest for ethical reform. *J Soc Work End Life Palliat Care*. 2011;7(4):300-317. doi:10.1080/15524256.2011.623458.
- Kaplan RM. Variation between end-of-life health care costs in Los Angeles and San Diego: Why are they so different? *J Palliat Med*. 2011;14(2):215-220.
- Kovner CT, Lusk E, Selander NM. 'Affordable' death in the United States: An action plan based on lessons learned from the Nursing Economic\$ special issue. *Nurs Econ*. 2012;30(3):179-184.
- Lupu D. Estimates of current hospice and palliative medicine workforce shortage. *J Pain Symptom Manage*. 2010;40:899-911.
- Morrison RS, Penrod JD, Cassel JB, et al. Palliative care leadership centers' outcomes groups: Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med*. 2008;168:1783-1790.
- Penrod J, Deb P, Dellenbaugh C et al. Hospital-based palliative care consultation: Effects on hospital cost. *J Palliat Med*. 2010;13(8):973-979. doi:10.1089/jpm.2010.0038.

- Radwin LE, Ananian L, Cabral HJ, Keeley A, Currier PF. Effects of a patient/family-centered practice of change on the quality and cost of intensive care: Research protocol. *J Adv Nurs*. 2011;67(1):215-224.
- Rothrock JF. 40 days and 40 nights. A guide to accelerating the crisis in healthcare financing. *Headache*. 2009;49(2):328-329.
- Schneiderman LJ. Rationing just medical care. *Am J Bioeth*. 2011;11(7):7-14.
- Schroeder SA. Personal reflections on the high cost of American medical care: many causes but few politically sustainable solutions. *Arch Intern Med*. 2011;171(8):722-727.
- Sherman DW, Cheon J. Palliative care: A paradigm of care responsive to the demands for health care reform in America. *Nurs Econ*. 2012;30(3):153-162, 166.
- Taylor D. Effect of hospice on Medicare and informal care costs: The United States experience. *J Pain Symptom Manage*. 2009;38:110-114.
- Weissman DE, Meier DE, Morrison RS. Center to advance palliative care - Palliative care clinical care and customer satisfaction metrics consensus recommendations. *J Palliat Med*. 2010;3(2):179-184.

Hospice

- Furman CD, Doukas DJ, Reichel W. Unlocking the closed door: Arguments for open access hospice. *American J Hosp Palliat Med*. 2010;27(1):86-90.
- National Hospice and Palliative Care Organization. *Standards of Practice for Hospice Programs*. Alexandria, VA: National Hospice and Palliative Care Organization; 2010.
- Rhodes R, Mitchell S, Miller S, Connor S, Teno J. Bereaved family members' evaluation of hospice care: What factors influence overall satisfaction with services? *J Pain Symptom Manage*. 2008;35(4):365-371. doi:10.1016/j.jpainsymman.2007.12.004.
- Sanders S, Mackin ML, Reyes J, et al. Implementing evidence-based practices: Considerations for the hospice setting. *Am J Hosp Palliat Care*. 2010;27(6):369-376.
- Silveira MJ, Connor SR, Goold SD, McMahon LF, Feudtner C. Community supply of hospice: Does wealth play a role? *J Pain Symptom Manage*. 2011;42(1):76-82.
- Teno J, Casarett D, Spence C, Connor S. It is "Too Late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage*. 2012;43(4):732-738. doi:10.1016/j.jpainsymman.2011.05.012.

Palliative Care

- Aldridge M, Hasselaar J, Garralda E et al. Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliat Med*. 2015;30(3):224-239. doi:10.1177/0269216315606645.
- Bischoff K, O'Riordan D, Marks A, Sudore R, Pantilat S. Care planning for inpatients referred for palliative care consultation. *JAMA Intern Med*. 2018;178(1):48. doi:10.1001/jamainternmed.2017.6313.
- Cassel JB, Hager MA, Clark RR, et al. Concentrating hospital-wide deaths in a palliative care unit: The effect on place of death and system-wide mortality. *J Palliat Med*. 2010;13(4):371-374.
- Dobrof J, Heyman JC, Greenberg RM. Building on community assets to improve palliative and end-of-life care. *J Soc Work End Life Palliat Care*. 2011;7(1):5-13.

Appendix IV: Scoping Review

- Feudtner C, Kang T, Hexem K, et al. Patients receiving pediatric palliative care consultations: A prospective multicenter cohort study. *Pediatrics*. 2011;127(6):1094-1010.
- Fromme EK, Smith MD, Bascom PB, Kenworthy-Heinige T, Lyons KS, Tolle SW. Incorporating routine survival prediction in a U.S. hospital-based palliative care service. *J Palliat Med*. 2010;13(12):1439-1444.
- Gade G, Venohr I, Conner D et al. Impact of an inpatient palliative care team: A randomized controlled trial. *J Palliat Med*. 2008;11(2):180-190. doi:10.1089/jpm.2007.0055.
- Gidwani R, Nevedal A, Patel M et al. The appropriate provision of primary versus specialist palliative care to cancer patients: Oncologists' perspectives. *J Palliat Med*. 2017;20(4):395-403. doi:10.1089/jpm.2016.0399.
- Hauser J, Sileo M, Araneta N, et al. Navigation and palliative care. *Cancer*. 2011; 117: 3583–3589 doi:10.1002/cncr.26266.
- Kayser K, DeMarco R, Stokes C, DeSanto-Madeya S, Higgins P. Delivering palliative care to patients and caregivers in inner-city communities: Challenges and opportunities. *Palliat Support Care*. 2013;12(05):369-378. doi:10.1017/s1478951513000230.
- Kelley A, Morrison R. Palliative care for the seriously ill. *N Engl J Med*. 2015;373(8):747-755. doi:10.1056/nejmra1404684.
- Klick JC, Hauer J. Pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care*. 2010;40(6):120-151.
- Krakauer R, Spettell CM, Wade MJ. Opportunities to improve the quality of care for advanced illness. *Health Aff (Millwood)*. 2009;28:1357-1359.
- Meier DE, Back AL, Berman A, et al. A national strategy for palliative care. *Health Aff (Millwood)* 2017;36:1265–1273.
- Meier DE, Casarett DJ, von Gunten CF, Smith WJ, Storey CP. Palliative medicine: Politics and policy. *J Palliat Med*. 2010;13(2):141-146.
- Meier DE, Issacs SL, Hughes RG. *Palliative Care Transforming the Care of Serious Illness*. New York: Jossey Bass; 2010.
- Norton S, Powers B, Schmitt M et al. Navigating tensions: Integrating palliative care consultation services into an academic medical center setting. *J Pain Symptom Manage*. 2011;42(5):680-690. doi:10.1016/j.jpainsymman.2011.02.010.
- Rodriguez K, Barnato A, Arnold R. Perceptions and utilization of palliative care services in acute care hospitals. *J Palliat Med*. 2007;10(1):99-110. doi:10.1089/jpm.2006.0155.
- Rogers SK, Gomez CF, Carpenter P, et al. Quality of life for children with life-limiting and life-threatening illnesses: Description and evaluation of a regional, collaborative model for pediatric palliative care. *Am J Hosp Palliat Care*. 2011;28(3):161-170.
- Schenker Y, Rabow M, Crowley-Makota M et al. Organizational factors influencing specialty palliative care utilization at academic cancer centers. *J Clin Oncol*. 2016;34(26_suppl):109-109. doi:10.1200/jco.2016.34.26_suppl.109.
- Silver J, Raj V, Fu J, Wisotzky E, Smith S, Kirch R. Cancer rehabilitation and palliative care: critical components in the delivery of high-quality oncology services. *Support Care Cancer*. 2015;23(12):3633-3643. doi:10.1007/s00520-015-2916-1.

Trachsel M, Irwin S, Biller-Andorno N, Hoff P, Riese F. Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psych*. 2016;16(1). doi:10.1186/s12888-016-0970-y.

Populations

Geriatrics

American Geriatrics Society and American Academy of Hospice and Palliative Medicine. Report of the geriatrics-hospice and palliative medicine work group: American geriatrics society and american academy of hospice and palliative medicine leadership collaboration. *J Am Geriatr Soc*. 2012;60(3):583-587.

Barford KL, D'Olimpio JT. Symptom management in geriatric oncology: Practical treatment considerations and current challenges. *Curr Treat Options Oncol*. 2008;9(2-3):204-214.

Gilbertson-White S, Aouizerat BE, Jahan T, Miaskowski C. A review of the literature on multiple symptoms, their predictors, and associated outcomes in patients with advanced cancer. *Palliat Support Care*. 2011;9(1):81-102.

Holley AP, Gorawara-Bhat R, Dale W, Hemmerich J, Cox-Hayley D. Palliative access through care at home: Experiences with an urban, geriatric home palliative care program. *J Am Geriatr Soc*. 2009;57(10):1925-1931.

Lange JW, Mager D, Greiner PA, Saracino K. The ELDER project: Educational model and three-year outcomes of a community-based geriatric education initiative. *Gerontol Geriatr Educ*. 2011;32(2):164-181.

Liao S, Jayawardena KM, Bufalini E, Wigglesworth A. Elder mistreatment reporting: Differences in the threshold of reporting between hospice and palliative care. *J Palliat Med*. Jan 2009;12(1):64-70.

Lynch MT, Dahlin C, Bakitas MK. Bowel obstruction and delirium: Managing difficult symptoms at end of life. *Clin J Oncol Nurs*. 2012;16(4):391-398.

McCormack WC. An AAHPM and AGS leadership collaboration: The Geriatrics - Hospice and Palliative Medicine Work Group. *J Pain Symptom Manage*. 2012;43(3):e1-2.

Powers B, Norton S, Schmitt M, Quill T, Metzger M. Meaning and practice of palliative care for hospitalized older adults with life limiting illnesses. *J Aging Res*. 2011;2011:1-8. doi:10.4061/2011/406164.

Rao SS, Go JT. Update on the management of constipation in the elderly: New treatment options. *Clin Interv Aging*. 2010;5:163-171.

Pediatrics

Armstrong-Dailey A, Zarbock S. *Hospice Care for Children*. 3rd ed. New York, NY: Oxford University Press; 2009.

Bona K, Bates J, Wolfe J. Massachusetts' pediatric palliative care network: Successful implementation of a novel state-funded pediatric palliative care program. *J Palliat Med*. Nov 2011;14(11):1217-1223.

Christenson K, Lybrand S, Hubbard C, Hubble R, Ahsens L, Black P. Including the perspective of the adolescent in palliative care preferences. *J Pediatr Health Care*. 2010;24(5):286-291. doi:10.1016/j.pedhc.2009.07.001.

- Doorenbos A, Lindhorst T, Starks H, Aisenberg E, Curtis J, Hays R. Palliative care in the pediatric ICU: Challenges and opportunities for family-centered practice. *J Soc Work End Life Palliat Care*. 2012;8(4):297-315. doi:10.1080/15524256.2012.732461.
- 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. doi:10.1089/jpm.2016.0138.
- Fitchett G, Lyndes K, Cadge W, Berlinger N, Flanagan E, Misasi J. The role of professional chaplains on pediatric palliative care teams: Perspectives from physicians and chaplains. *J Palliat Med*. 2011;14(6):704-707. doi:10.1089/jpm.2010.0523.
- Gilmer M, Foster T, Bell C, Mulder J, Carter B. Parental perceptions of care of children at end of life. *Am J Hosp Palliat Care*. 2012;30(1):53-58. doi:10.1177/1049909112440836.
- Hexem KR, Mollen CJ, Carroll K, Lanctot DA, Feudtner C. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *J Palliat Med*. 2011;14(1):39-44.
- Jonas D, Bogetz J. Identifying the deliberate prevention and intervention strategies of pediatric palliative care teams supporting providers during times of staff distress. *J Palliat Med*. 2016;19(6):679-683. doi:10.1089/jpm.2015.0425.
- Jones BW. The need for increased access to pediatric hospice and palliative care. *Dimens Crit Care Nurs*. 2011;30(5):231-235.
- Kars MC, Grypdonck MH, vanDelden JJ. Being a parent of a child with cancer throughout the end-of-life course. *Oncol Nurs Forum*. 2011;38(4):E260-E271.
- Knapp CA, Thompson LA, Vogel WB, Madden VL, Shenkman EA. Developing a pediatric care program: Addressing the lack of baseline expenditure information. *Am J Hosp Palliat Care*. 2009;26(1):40-46.
- Liben S, Papadatou D, Wolfe J. Paediatric palliative care: Challenges and emerging ideas. *The Lancet*. 2008;371(9615):852-864. doi:10.1016/s0140-6736(07)61203-3.
- Lyndes K, 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. doi:10.1080/08854726.2012.667332.
- National Hospice and Palliative Care Organization. *Standards of Practice for Pediatric Palliative Care and Hospice*. Alexandria, VA: National Hospice and Palliative Care Organization; 2009.
- Pritchard S, Cuvelier G, Harlos M, Barr R. Palliative care in adolescents and young adults with cancer. *Cancer*. 2011;117(10 Supplement):2323-2328.
- Tamburro R, Shaffer M, Hahnen N, Felker P, Ceneviva G. Care goals and decisions for children referred to a pediatric palliative care program. *J Palliat Med*. 2011;14(5):607-613. doi:10.1089/jpm.2010.0450.
- Uncan J, Spengler E, Wolfe J. Providing pediatric palliative care. *MCN Am J Matern Child Nurs*. 2007;32(5):279-287.
- Weaver M, Heinze K, Bell C et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliat Med*. 2015;30(3):212-223. doi:10.1177/0269216315583446.
- Weidner, NJ, Cameron, M, Lee, RC, McBride, J, Mathias, EJ, Byczkowski, TL. End-of-life care for the dying child: What matters most to parents. *J Palliat Care*. 2011;27(4):279-286.

Wool C, Côté-Arsenault D, Perry Black B, Denney-Koelsch E, Kim S, Kavanaugh K. Provision of services in perinatal palliative care: A multicenter survey in the United States. *J Palliat Med*. 2016;19(3):279-285. doi:10.1089/jpm.2015.0266.

Professional Educational Resources

Hospice

National Hospice and Palliative Care Organization. *Hospice Volunteer Program Resource Manual*. Alexandria, VA: National Hospice and Palliative Care Organization; 2015.

National Hospice and Palliative Care Organization. *Community Outreach Tools and Resources*. Alexandria, VA: National Hospice and Palliative Care Organization; 2009. <https://www.nhpco.org/resources/outreach-tools>

National Hospice and Palliative Care Organization. *Hospice COPs, Tools and Tips*. Alexandria, VA: National Hospice and Palliative Care Organization; 2009.

National Hospice and Palliative Care Organization. *Essential Guide to Hospice Management*. Alexandria, VA: National Hospice and Palliative Care Organization; 2011.

National Hospice and Palliative Care Organization. *Hospice Care: A Physician's Guide (REVISED)*. Alexandria, VA: National Hospice and Palliative Care Organization; 2011.

National Hospice and Palliative Care Organization. *Certification and Recertification of Hospice Terminal Illness (REVISED)*. Alexandria, VA: National Hospice and Palliative Care Organization; 2011.

Medicine

American Academy of Hospice and Palliative Medicine. *Compensation and Benefits Survey: 2010 Report*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2010.

Chamberlain BH. Hospice Medical Director Billing Guide. 2011; <http://connect.aahpm.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=e56ff2d7-2764-49e1-97a5-5a2bc596129b> Accessed December 17, 2012.

O'Mahony S, Gerhart J, Grosse J, Abrams I, Levy M. Posttraumatic stress symptoms in palliative care professionals seeking mindfulness training: Prevalence and vulnerability. *Palliat Med*. 2015;30(2):189-192. doi:10.1177/0269216315596459.

Quill T, Holloway RG, Shah MS, Caprio TV, Storey Jr. CP. *Primer of Palliative Care* 5th ed. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2010.

Quill T. *Primer Workbook*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2010. *Hospice Medical Director Manual*. Glenview, IL: American Academy of Hospice and Palliative Medicine; 2011.

UNIPAC QR: *A Quick Reference Guide to the UNIPAC Self-Study Program*. Glenview, IL: American Academy Hospice and Palliative Medicine; 2009.

Nursing

Core Curriculum for the Advanced Practice Hospice and Palliative Registered Nurse. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2012.

Appendix IV: Scoping Review

- Core Curriculum for the Hospice and Palliative Administrator*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.
- Core Curriculum for the Long-Term Care Nurse*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2012.
- Core Curriculum for the Licensed Practical/Vocational Nurse*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.
- Dahlin C. *The Hospice and Palliative Advanced Practice Registered Nurse Professional Practice Guide*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2017.
- Dahlin, C, Coyne P, Ferrell, B. *Advanced Practice Palliative Nursing*. New York, NY: Oxford University Press; 2016.
- Hospice and Palliative Nurses Association. *Competencies for the Generalist Hospice and Palliative Nurse*. 2nd ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2012.
- Martinez H, Berry, P. *Core Curriculum for the Hospice and Palliative Registered Nurse*. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2015.
- Study Guide for the Generalist Hospice and Palliative Nurse*. 3rd ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2009.
- Study Guide For The Licensed Practical/Vocational Hospice And Palliative Nurse*. Revised ed. Pittsburgh, PA: Hospice and Palliative Nurses Association; 2010.

Social Work

- Association of Oncology Social Work. AOSW Standards of Practice in Oncology Social Work 2012; <https://www.aosw.org/professional-development/standards-of-practice/> Accessed December 17, 2012.
- Association of Pediatric Oncology Social Workers. The Association of Pediatric Oncology Social Workers Standards of Practice. 2009; www.aposw.org/docs/StandardsOfPractice.pdf
- Collaboration of City of Hope, Association of Oncology Social Work, Association of Pediatric Oncology Social Workers. ExCEL in Social Work: Excellence in Cancer Education and Leadership <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4339672/>
- Gardner D, Gerbino S, Walls J, Chachkes E, Doherty M. Mentoring the next generation of social workers in palliative and end-of-life care: The Zelda foster studies program. *J Soc Work End Life Palliat Care*. 2015;11(2):107-131. doi:10.1080/15524256.2015.1074142.
- Institute Social Work Policy. Hospice social work: Linking policy, practice, and research. A report from the March 25, 2010 symposium. 2010; www.socialworkpolicy.org/wp-content/uploads/2010/09/SWPIHospice-Report-FINAL.pdf Accessed December 17, 2012.
- Social Work Hospice & Palliative Care Network. Home page. The first social work organization in end of-life and palliative care. Resources for hospice and palliative social workers. <http://www.swhpn.org>.
- National Association of Social Workers. *Encyclopedia of Social Work*. 20th ed. Washington, DC: NASW Press; 2008.
- National Association of Social Workers. Social workers in hospice and palliative care: Occupational profile. 2010; <https://www.socialworkers.org/LinkClick.aspx?fileticket=k77-Y1kmG-E%3d&portalid=0> Accessed December 17, 2012.

Quality and Outcomes

- Altilio T, Otis-Green S, Dahlin C. Applying the national quality forum preferred practices for palliative care and hospice care: A social work perspective. *J Soc Work End Life Palliat Care*. 2008;4(1):3-16. doi:10.1080/15524250802071999.
- Beckstrand RL, Hadley KH, Luthy KE, Macintosh JL. Critical care nurses' suggestions to improve end-of-life care obstacles: Minimal change over 17 years. *Dimens Crit Care Nurs*. 2017;36, 264-270.
- Bernacki R, Ko D, Higgins P et al. Improving access to palliative care through an innovative quality improvement initiative: An opportunity for pay-for-performance. *J Palliat Med*. 2012;15(2):192-199. doi:10.1089/jpm.2011.0301.
- Boucher N, White S, Keith D. A framework for improving chronic critical illness care. *Med Care*. 2016;54(1):5-8. doi:10.1097/mlr.0000000000000460.
- Boyer R, McPherson ML, Deshpande G, Smith SW. Improving medication error reporting in hospice care. *Am J Hosp Palliat Care*. 2009;26(5):361-367.
- Carlson MD, Barry C, Schlesinger M, et al. Quality of palliative care at US hospices: Results of a national survey. *Med Care*. Sep 2011;49(9):803-809.
- Carpenter J, McDarby M, Smith D, Johnson M, Thorpe J, Ersek M. Associations between timing of palliative care consults and family evaluation of care for veterans who die in a hospice/palliative care unit. *J Palliat Med*. 2017;20(7):745-751. doi:10.1089/jpm.2016.0477.
- Casarett D, Johnson M, Smith D, Richardson D. The optimal delivery of palliative care: A national comparison of the outcomes of consultation teams vs inpatient units. *Arch Intern Med*. Apr 11 2011;171(7):649-655.
- Casarett D, Pickard A, Bailey F et al. A nationwide VA palliative care quality measure: The family assessment of treatment at the end of life. *J Palliat Med*. 2008;11(1):68-75. doi:10.1089/jpm.2007.0104.
- De Roo ML, Leemans K, Claessen SJ, et al; EURO IMPACT. Quality indicators for palliative care: Update of a systematic review. *J Pain Symptom Manage*. 2013;46(4):556-572.
- Dobrof J, Heyman J, Greenberg R. Building on community assets to improve palliative and end-of-life care. *J Soc Work End Life Palliat Care*. 2011;7(1):5-13. doi:10.1080/15524256.2011.548044.
- Fawole O, Dy S, Wilson R et al. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. *J Gen Intern Med*. 2012;28(4):570-577. doi:10.1007/s11606-012-2204-4.
- Fink R, Oman K, Youngwerth J, Bryant L. A palliative care needs assessment of rural hospitals. *J Palliat Med*. 2013;16(6):638-644. doi:10.1089/jpm.2012.0574.
- Gramling R, Stanek S, Ladwig S et al. Feeling heard and understood: A patient-reported quality measure for the inpatient palliative care setting. *J Pain Symptom Manage*. 2016;51(2):150-154. doi:10.1016/j.jpainsymman.2015.10.018.
- Hanson LC, Rowe C, Wessell K, et al. Measuring palliative care quality for seriously ill hospitalized patients. *J Palliat Med*. 2012;15 (7):798-804.
- Hanson LC, Schenck AP, Rokoske FS, et al. Hospices' preparation and practices for quality measurement. *J Pain Symptom Manage*. 2010;39(1):1-8.

Appendix IV: Scoping Review

- Johnson KS, Elbert-Avila K, Kuchibhatla M, Tulsy JA. Characteristics and outcomes of hospice enrollees with dementia discharged alive. *J Am Geriatr Soc*. 2012.
- Kamal AH, Bull J, Stinson C, et al. Collecting data on quality is feasible in community-based palliative care. *J Pain Symptom Manage*. 2011;42(5):663-667.
- McMillan SC, Small BJ, Haley WE. Improving hospice outcomes through systematic assessment: A clinical trial. *Cancer Nurs*. 2011;34(2):89-97.
- Penrod JD, Pronovost PJ, Livote EE, et al. Meeting standards of high-quality intensive care unit palliative care: Clinical performance and predictors. *Crit Care Med*. 2012;40(4):1105-1112.
- Penrod J, Cortez T, Luhrs C. Use of a report card to implement a network-based palliative care program. *J Palliat Med*. 2007;10(4):858-860. doi:10.1089/jpm.2007.0026.
- Schenck AP, Rokoske FS, Durham DD, Cagle JG, Hanson LC. The PEACE Project: Identification of quality measures for hospice and palliative care. *J Palliat Med*. 2010;13(12):1451-1459.
- Schulman-Green D, Cherlin E, Pace KB, Hennessy M, Crocker PA, Bradley EH. Experiences of participation in a collaborative to develop performance measures for hospice care. *Jt Comm J Qual Patient Saf*. 2011;37(1):38-44.
- Seow H, Snyder C, Mularski R et al. A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage*. 2009;38(6):903-912. doi:10.1016/j.jpainsymman.2009.04.024.
- Seow H, Snyder C, Shugarman L et al. Developing quality indicators for cancer end-of-life care. *Cancer*. 2009;115(17):3820-3829. doi:10.1002/cncr.24439.
- Smith D, Caragian N, Kazlo E, Bernstein J, Richardson D, Casarett D. Can we make reports of end-of-life care quality more consumer-focused? Results of a nationwide quality measurement program. *J Palliat Med*. 2011;14(3):301-307.
- Sudore R, Casarett D, Smith D, Richardson D, Ersek M. Family involvement at the end-of-life and receipt of quality care. *J Pain Symptom Manage*. 2014;48(6):1108-1116. doi:10.1016/j.jpainsymman.2014.04.001.
- Temkin-Greener H, Li Q, Li Y, Segelman M, Mukamel D. End-of-life care in nursing homes: From care processes to quality. *J Palliat Med*. 2016;19(12):1304-1311. doi:10.1089/jpm.2016.0093.
- Teno JM, Gozalo PL, Lee IC, et al. Does hospice improve quality of care for persons dying from dementia? *J Am Geriatr Soc*. 2011;59(8):1531-1536.
- Twaddle M, Maxwell T, Cassel J et al. Palliative care benchmarks from academic medical centers. *J Palliat Med*. 2007;10(1):86-98. doi:10.1089/jpm.2006.0048.
- Walling AM, Asch SM, Lorenz KA, et al. The quality of care provided to hospitalized patients at the end of life. *Arch Intern Med*. 2010;170(12):1057-1063.
- Zimmerman S, Cohen L, van der Steen J et al. Measuring end-of-life care and outcomes in residential care/assisted living and nursing homes. *J Pain Symptom Manage*. 2015;49(4):666-679. doi:10.1016/j.jpainsymman.2014.08.009.

Quality of Life

- Allen L, Gheorghiade M, Reid KJ, et al. Identifying patients hospitalized with heart failure at risk for unfavorable future quality of life. *Circ Cardiovasc Qual Outcomes*. 2011;4(4):379-381.

- Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. *J Clin Oncol*. 2010;28(3):445-452.
- Baumrucker SJ, Stolick M, Carter GT, et al. Death, dying, and statistics: Quality measures versus quality of life. *Am J Hosp Palliat Care*. 2010;27(7):494-499.
- Black B, Herr K, Fine P, et al. The relationships among pain, nonpain symptoms, and quality of life measures in older adults with cancer receiving hospice care. *Pain Med*. 2011;12(6):880-889.
- Blinderman C, Homel P, Billings JA, Tennstadt S, Portenoy R. Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2009;38(1):115-123.
- Cartwright JC, Miller L, Volpin M. Hospice in assisted living: Promoting good quality care at end of life. *Gerontol*. 2009;49(4):508-516.
- Chandran D, Corbin J, Shillam C. An ecological understanding of caregiver experiences in palliative care. *J Soc Work End Life Palliat Care*. 2016;12(1-2):162-182. doi:10.1080/15524256.2016.1156602.
- Choi YK. The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients. *J Music Ther*. 2010;47(1):53-69.
- Dean-Clower E, Doherty-Gilman AM, Keshaviah A, et al. Acupuncture as palliative therapy for physical symptoms and quality of life for advanced cancer patients. *Integr Cancer Ther*. 2010;9(2):158-167.
- Guo Q, Jacelon C. An integrative review of dignity in end-of-life care. *Palliat Med*. 2014;28(7):931-940. doi:10.1177/0269216314528399.
- Hermann CP, Looney SW. Determinants of quality of life in patients near the end of life: A longitudinal perspective. *Oncol Nurs Forum*. 2011;38(1):23-31.
- Jacobsen J, Kvale E, Rabow M et al. Helping patients with serious illness live well through the promotion of adaptive coping: A report from the improving outpatient palliative care (IPAL-OP) initiative. *J Palliat Med*. 2014;17(4):463-468. doi:10.1089/jpm.2013.0254.
- Kamper R, Van Cleve L, Savedra M. Children with advanced cancer: Responses to a spiritual quality of life interview. *J Spec Pediatr Nurs*. 2010;15(4):301-306.
- Kelemen A, Cagle J, Groninger H. Screening for intimacy concerns in a palliative care population: Findings from a pilot study. *J Palliat Med*. 2016;19(10):1102-1105. doi:10.1089/jpm.2016.0092.
- Oechsle K, Jensen W, Schmidt T, et al. Physical activity, quality of life, and the interest in physical exercise programs in patients undergoing palliative chemotherapy. *Support Care Cancer*. 2011;19(5):613-619.
- Pizzo P. Thoughts about dying in America: Enhancing the impact of one's life journey and legacy by also planning for the end of life: Table 1. *Proceedings of the National Academy of Sciences*. 2016;113(46):12908-12912. doi:10.1073/pnas.1614266113.
- Puchalski C, Vitillo R, Hull S, Reller N. Improving the spiritual dimension of whole person care: Reaching national and international consensus. *J Palliat Med*. 2014;17(6):642-656. doi:10.1089/jpm.2014.9427.
- Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: Is care changing? *J Clin Oncol*. 2008;26(10):1717-1723.

Appendix IV: Scoping Review

Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol*. 2010;28(29):4457-4464.

Research

- Henry B, Scales DC. Ethical challenges in conducting research on dying patients and those at high risk of dying. *Account Res*. 2012;19(1):1-12.
- Knapp CA. Research in pediatric palliative care: Closing the gap between what is and what is not known. *Am J Hosp Palliat Care*. 2009;26(5):392-398.
- LeBlanc TW, Wheeler JL, Abernethy AP. Research in end-of-life settings: an ethical inquiry. *J Pain Palliat Care Pharmacother*. 2010;24(3):244-250.
- Loke SS, Rau KM. Differences between inpatient hospice care and in-hospital nonhospice care for cancer patients. *Cancer Nurs*. 2011;34(3):E21-26.
- Morrison RS, Meier DE. The national palliative care research and the center to advance palliative care: A partnership to improve care. *J Pediatr Hematol Oncol*. 2011;33(2):S126-131.
- National Institute for Nursing Research (NINR). *Executive Summary -The Science of Compassion Future Directions in End-of-Life and Palliative Care Summit*. 2011; Bethesda, MD. <https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/science-of-compassion-executive-summary.pdf>
- Quest TE, Asplin BR, Cairns CB, Hwang U, Pines JM. Research priorities for palliative and end-of-life care in the emergency setting. *Acad Emerg Med*. 2011;18(6):e70-76.
- Spice R, Palacios M, Biondo PD, Hagen NA. Design and implementation of an online course on research methods in palliative care: lessons learned. *J Palliat Med*. 2011;14(4):413-419.
- Sullivan AM, Gadmar NM, Block EM. The project on death in America: A report on scholars' progress. *J Palliat Med*. 2009;12(2):155-159.
- Wheeler JL, Greene A, Tieman J, Abernethy AP. Key characteristics of palliative care studies reported in the specialized literature. *J Pain Symptom Manage*. 2012;43(987-992).

Settings of Care

Emergency Department

- Allen M. A Child dies in the emergency department: Development of a program to support bereaved families and staff. *Clin Nurse Spech*. 2009;23(3):96.
- Chan GK. Trajectories of approaching death in the emergency department: Clinician narratives of patient transitions to the end of life. *J Pain Symptom Manage*. 2011;42(6):864-881.
- Grudzen CR, Hwang U, Cohen JA, Fischman M, Morrison RS. Characteristics of emergency department patients who receive a palliative care consultation. *J Palliat Med*. 2012;15(4):396-399.
- Grudzen CR, Richardson LD, Morrison M, Cho E, Morrison RS. Palliative care needs of seriously ill, older adults presenting to the emergency department. *Acad Emerg Med*. 2010;17(11):1253-1257.
- Lamba S, Nagurka R, Zielinski A, Scott S. Palliative care provision in the emergency department: Barriers reported by emergency physicians. *J Palliat Med*. 2013;16(2):143-147. doi:10.1089/jpm.2012.0402.

- Lawson B, Burge F, McIntyre P, Field S, Maxwell D. Can the introduction of an integrated service model to and existing palliative care service impact emergency department visits among enrolled patients. *J Palliat Med*. 2009;12(3):245-252.
- Pines JM, Asplin BR. Conference proceedings-Improving the quality and efficiency of emergency care across the continuum: A systems approach. *Acad Emerg Med*. 2011;18(6):655-661.
- Quest TE, Marco CA, Derse AR. Hospice and palliative medicine: A new subspecialty, new opportunities. *Ann Emerg Med*. 2009;54(1):94-102.
- Rady MY, Verheijde JL, McGregor JL. Scientific, legal, and ethical challenges of end-of-life organ procurement in emergency medicine. *Resuscitation*. 2010;81(9):1069-1078.
- Rondreau D, Schmidt T. Treating cancer patients who are near the end of life in the Emergency department. *Emerg Med Clin North Am*. 2009;27(2):341-354.
- Smith A, Schonberg M, Fisher J, et al. Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. *J Pain Symptom Manage*. 2010;39:972-981.
- Smith AK, Fisher J, Schonberg MA, et al. Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department. *Ann Emerg Med*. 2009;54(1):86-93.

Intensive Care Unit

- Brennan CW, Prince-Paul M, Wiencek CA. Providing a “good death” for oncology patients during the final hours of life in the intensive care unit. *AACN Adv Crit Care*. 2011;22(4):379-396.
- Cooper Z, Rivara FP, Wang J, MacKenzie EJ, Jurkovich GJ. Withdrawal of life-sustaining therapy in injured patients: Variations between trauma centers and nontrauma centers. *J Trauma*. 2009;66(5):1327-1335.
- Delgado-Guay MO, Parsons HA, Li Z, Palmer LJ, Bruera E. Symptom distress, interventions, and outcomes of intensive care unit cancer patients referred to a palliative care consult team. *Cancer*. 2009;115(2):437-445.
- Gardiner C, Cobb M, Gott M, Ingleton C. Barriers to providing palliative care for older people in acute hospitals. *Age Ageing*. 2011;40(2):233-238.
- Lamba S, Murphy P, McVicker S, Harris Smith J, Mosenthal A. Changing end-of-life care practice for liver transplant service patients: Structured palliative care interventions in the surgical intensive care unit. *J Pain Symptom Manage*. 2012;44(4):508-519.
- LeGrand SB, Walsh D. Comfort measures: Practical care of the dying cancer patient. *Am J Palliat Care*. 2010;27(7):488-493.
- Lewis-Newby M, Curtis JR, Martin DP, Engelberg RA. Measuring family satisfaction with care and quality of dying in the intensive care unit: Does patient age matter? *J Palliat Med*. 2011;14(12):1284-1290.
- Lin CY, Arnold RM, Lave JR, Angus DC, Barnato AE. Acute care practices relevant to quality end-of-life care: A survey of Pennsylvania hospitals. *Qual Saf Health Care*. 2010;19(6):e12.
- Luce JM. A history of resolving conflicts over end-of-life care in intensive care units in the United States. *Crit Care Med*. 2010;38(8):1623-1629.
- Luce JM. End-of-life decision making in the intensive care unit. *Am J Respir Crit Care*. 2010;182(1):6-11.

Appendix IV: Scoping Review

- McCormick AJ, Curtis JR, Stowell-Weiss P, Toms CE, R. Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *J Palliat Med*. 2010;13(3):297-304.
- Meert KL, Schim SM, Briller SH. Parental bereavement needs in the pediatric intensive care unit: Review of available measures. *J Palliat Med*. 2011;14(8):951-964.
- Mehta S. The intensive care unit continuum of care: easing death. *Crit Care Med*. 2012;40(2):700-701.
- Mosenthal AC, Weissman DE, Curtis JR, et al. Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Unit (IPAL-ICU) project advisory board and the center to advance palliative care. *Crit Care Med*. 2012;40(4):1199-1206.
- Nelson JE, Hope AA. Integration of palliative care in chronic critical illness management. *Respiratory Care*. 2012;57(6):1004-1012.
- Nelson JE, Puntillo K, Pronovost PJ, et al. In their own words: Patients and families define high-quality palliative care in the intensive care unit. *Crit Care Med*. 2010;38(3):808-818.
- Penrod JD, Luhrs CA, Livote EE, Cortez TB, Kwak J. Implementation and evaluation of a network-based pilot program to improve palliative care in the intensive care unit. *J Pain Symptom Manage*. 2011;42(5):668-671.
- Placencia FX, McCullough LB. The history of ethical decision making in neonatal intensive care. *J of Inten Care Med*. 2011;26(6):368-384.
- Rhondali W, Hui D, Kim SH, et al. Association between patient-reported symptoms and nurses' clinical impressions in cancer patients admitted to an acute palliative care unit. *J Palliat Med*. 2012;15(3):301-307.
- Rice EM, Betcher DK. Palliative care in an acute care hospital: from pilot to consultation service. *Medsurg Nurs*. 2010;19(2):107-112.
- Schenker Y, Tiver GA, Hong SY, White DB. Association between physicians' beliefs and the option of comfort care for critically ill patients. *Int Care Med*. 2012. doi:10.1007/s00134-012-2671-4.
- Sharma G, Freeman J, Zhang D, Goodwin JS. Continuity of care and intensive care unit use at the end of life. *Arch Intern Med*. 2009;169(1):81-86.
- Sihra L, Harris M, O'Reardon C. Using the improving palliative care in the intensive care unit (IPAL-ICU) project to promote palliative care. *J Pain Symptom Manage*. 2011;42(5):672-675.
- Williams BA, Sudore RL, Greifinger RB, Morrison RS. Balancing punishment and compassion for seriously ill prisoners. *Ann Intern Med*. 2011;155(2):122-126.

Long-Term Care

- Bern-Klug M. *Transforming Palliative Care in Nursing Homes*. New York, NY: Columbia University Press; 2010.
- Carlson M, Lim B, Meier D. Strategies and innovative models for delivering palliative care in nursing homes. *JAMDA*. 2011;12(2):91-98. doi:10.1016/j.jamda.2010.07.016.
- Cartwright JC, Miller L, Volpin M. Hospice in assisted living: Promoting good quality care at end of life. *Gerontologist*. 2009;49(4):508-516.
- Dellefield ME, Ferrini R. Promoting excellence in end-of-life care: Lessons learned from a cohort of nursing home residents with advanced Huntington disease. *J of Neurosci Nurs*. 2011;43(4):186-192.

- Duncan JG, Bott MJ, Thompson SA, Gajewski BJ. Symptom occurrence and associated clinical factors in nursing home residents with cancer. *Res Nurs Health*. 2009;32(4):453-464.
- Grabowski DC, Mitchell SL. Family oversight and the quality of nursing home care for residents with advanced dementia. *Med Care*. 2009;47(5):568-574.
- Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. A comparison of methods to communicate treatment preferences in nursing facilities: Traditional practices versus the physician orders for life-sustaining treatment program. *J Am Geriatr Soc*. 2010;58(7):1241-1248.
- Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2010;58(12):2284-2291.
- Kortes-Miller K, Habjan S, Kelley ML, Fortier M. Development of a palliative care education program in rural long-term care facilities. *J Palliat Care*. 2007;23(3):154-162.
- Lepore MJ, Miller SC, Gazalo P. Hospice use among urban Black and White U.S. nursing home decedents in 2005. *Gerontologist*. 2011;51(2):251-260.
- Miller SC, Lima A, Gonzalo FL, Mor V. The growth of hospice in U.S. nursing homes. *J Am Geriatr Soc*. 2010;58(8):1481-1488.
- Mukamel DB, Caprio T, Ahn R, et al. End-of-life quality-of-care measures for nursing homes: Place of death and hospice. *J Palliat Med*. 2012;15(4):438-446.
- Rich SE, Williams CS, Zimmerman S. Concordance of family and staff member reports about end of life in assisted living and nursing homes. *Gerontologist*. 2010;50(1):112-120.
- Stevenson D, Bramson J. Hospice care in the nursing home setting: A review of the literature. *J Pain Symptom Manage*. 2009;38(3):440-451.
- Teno JM, Gozalo P, Mitchell SL, Bynum JP, Dosa D, Mor V. Terminal hospitalizations of nursing home residents: Does facility increasing the rate of do not resuscitate orders reduce them? *J Pain Symptom Manage*. 2011;41(6):1040-1047.
- Tilden VP, Thompson SA, Gajewski BJ, Bott MJ. End-of-life care in nursing homes: The high cost of staff turnover. *Nurs Econ*. 2012;30(3):163-166.
- Unroe K, Cagle J, Lane K, Callahan C, Miller S. Nursing home staff palliative care knowledge and practices: Results of a large survey of frontline workers. *J Pain Symptom Manage*. 2015;50(5):622-629. doi:10.1016/j.jpainsymman.2015.06.006.
- Waldrop DP, Kirkendall A. Comfort measures: A qualitative study of nursing home-based end-of-life care. *J Palliat Med*. 2009;12(8):719-724.
- Welch LC, Miller SC, Martin EW, Nanda A. Referral and timing of referral to hospice care in nursing homes: The significant role of staff members. *Gerontologist*. 2008;48(4):477-484.

Outpatient

- Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA*. 2009;302(7):741-749.
- Bakitas MK, Bishop MF, Caron P, Stephens L. Developing successful models of cancer palliative care services. *Semin Oncol Nurs*. 2010;26(4):266-284.
- Bekelman DB, Nowels CT, Allen LA, Shakar S, Kutner JS, Matlock DD. Outpatient palliative care for chronic heart failure: a case series. *J Palliat Med*. 2011;14(7):815-821.

- Bekelman D, Rabin B, Nowels C et al. Barriers and Facilitators to Scaling Up Outpatient Palliative Care. *J Palliat Med*. 2016;19(4):456-459. doi:10.1089/jpm.2015.0280.
- Davies PS, Prince-Paul M. Palliative care in the outpatient cancer center. *J Hosp Palliat Nurs*. 2012;14(8):506-513.
- Glare P, Semple D, Stabler S, Salts L. Palliative care in the outpatient setting: Evaluation of a practical set of referral criteria. *J Oncol Pract*. 2011;7(6):366-370.
- Hui D, Elsayem A, De la Cruz M, et al. Availability and integration of palliative care at US Cancer Centers. *JAMA*. 2012;303(11):1054-1061.
- Jenko M, Adams J, Johnson C, Thompson J, Bailey D. Facilitating palliative care referrals in the intensive care unit. *Dim Crit Care Nurs*. 2015;34(6):329-339. doi:10.1097/dcc.000000000000143.
- Khan L, Kwong J, Nguyen J, et al. Comparing baseline symptom severity and demographics over two time periods in an outpatient palliative radiotherapy clinic. *Supp Care Cancer*. 2012;20(3):549-555.
- Kwon J, Hui D, Chisholm G, Hong W, Nguyen L, Bruera E. Experience of barriers to pain management in patients receiving outpatient palliative care. *J Palliat Med*. 2013;16(8):908-914. doi:10.1089/jpm.2012.0610.
- Morita T, Fujimoto K, Namba M, et al. Palliative care needs of cancer outpatients receiving chemotherapy: An audit of a clinical screening project. *Supp Care Cancer*. 2008;16(1):101-107.
- Muir JC, Daly F, Davis MS, Weinberg R, Heintz JS. Integrating palliative care into the outpatient, private practice oncology setting. *J Pain Palliat Manage*. 2010;40(1):126-135.
- Owens D EK, Burson S, Green M, McGoodwin W, Isaac M. Primary palliative care clinic pilot project demonstrates benefits of a nurse practitioner-directed clinic providing primary and palliative care. *J Am Acad Nurse Pract*. 2012;24(1):52-58.
- Prince-Paul M, Burant C, Saltzman J, Teston L, Matthews C. The effects of integrating an advance practice palliative care nurse in a community oncology setting center: A pilot study. *J Support Oncol*. 2010;8(1):21-27.
- Rabow MW, Smith AK, Braun AL, Weissman DE. Outpatient palliative care services. *Arch Intern Med*. 2010 170(7):654-655.
- Singer A, Ash T, Ochotorena C et al. A systematic review of family meeting tools in palliative and intensive care settings. *Am J Hosp Palliat Care*. 2016;33(8):797-806. doi:10.1177/1049909115594353.
- Smith TJ, Temin S, Alesi ER, et. al. American society of clinical oncology provisional clinical opinion: The integration of palliative care into standard oncology care. *J Clin Onc*. 2012;30(8):880-887.
- Temel J, Greer J, Muzikansky A, et al. Early palliative care for patients with metastatic non-small cell lung cancer. *N Engl J Med*. 2010;363:733-742.
- Truog R, Campbell M, Curtis J et al. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. *Crit Care Med*. 2008;36(3):953-963. doi:10.1097/ccm.0b013e3181659096.

Technology

- Demiris G, Oliver D, Courtney K, Day M. Telehospice tools for caregivers. *Clin Gerontol*. 2007;31(1):43-57. doi:10.1300/j018v31n01_04.
- Holland D, Vanderboom C, Ingram C et al. The feasibility of using technology to enhance the transition of palliative care for rural patients. *CIN*. 2014;32(6):257-266. doi:10.1097/cin.0000000000000066.
- Riggs A, Breuer B, Dhingra L, Chen J, Portenoy R, Knotkova H. Hospice enrollment after referral to community-based, specialist palliative care: Impact of telephonic outreach. *J Pain Symptom Manage*. 2017;54(2):219-225. doi:10.1016/j.jpainsymman.2017.03.007.
- Volandes A, Ariza M, Abbo E, Paasche-Orlow M. Overcoming educational barriers for advance care planning with Latinos with video images. *J Palliat Med*. 2008;11(5):700-706. doi:10.1089/jpm.2007.0172.

Volunteers

- Berry P, Planalp S. Ethical issues for hospice volunteers. *Am J Hosp Palliat Care*. 2008;25(6):458-462.
- Brown MV. How they cope: A qualitative study of the coping skills of hospice volunteers. *Am J Hosp Palliat Med*. 2011;28(6):398-402.
- Brown MV. The stresses of hospice volunteer work. *Am J Hosp Palliat Care*. May 2011;28(3):188-192.
- Coyne E. How volunteer services can improve and advance palliative care programs. *J Hosp Palliat Nurs*. 2017; 19(2), 166-169. doi:10.1097/NJH.0000000000000325.
- MacLeod A, Skinner MW, Low E. Supporting hospice volunteers and caregivers through community-based participatory research. *Health Soc Care Community*. 2012;20(2):190-198.
- Planalp S, Trost M. Reasons for starting and continuing to volunteer for hospice. *Am J Hosp Palliat Med*. 2009;26(4):288-294.
- Savery CA, Egbert N. Hospice volunteer as patient advocate: A trait approach. *Palliat Support Care*. 2010;8(2):159-167.
- Wittenberg-Lyles E, Schneider G, Oliver DP. Results from the national hospice volunteer training survey. *J Palliat Med*. 2010;13(3):261-265.

Domain 2: Physical Aspects of Care

Illness/Conditions

Cancer

- Aktas A, Walsh D, Galang M et al. Underrecognition of malnutrition in advance cancer: The role of the dietitian and clinical practice variations. *Am J Hosp Palliat Care*. 2016;34(6):547-555. doi:10.1177/1049909116639969.
- Azvolinsky A. Ask early and often: Offering better palliative care. *J Natl Cancer Inst*. 2015;108(1):djv420. doi:10.1093/jnci/djv420.
- Beach P, White B. Applying the evidence to help caregivers torn in two. *Nursing*. 2015;45(6):30-37. doi:10.1097/01.nurse.0000464983.54444.80.

- Benzo R, Siemion W, Novotny P et al. Factors to inform clinicians about the end of life in severe chronic Obstructive pulmonary disease. *J Pain Symptom Manage*. 2013;46(4):491-499.e4. doi:10.1016/j.jpainsymman.2012.10.283.
- Campbell M, Templin T, Walch J. Patients who are near death are frequently unable to self-report dyspnea. *J Palliat Med*. 2009;12(10):881-884. doi:10.1089/jpm.2009.0082.
- Chih M, DuBenske L, Hawkins R et al. Communicating advanced cancer patients' symptoms via the Internet: A pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood. *Palliat Med*. 2012;27(6):533-543. doi:10.1177/0269216312457213.
- de la Cruz M, Yennu S, Liu D, Wu J, Reddy A, Bruera E. Increased symptom expression among patients with delirium admitted to an acute palliative care unit. *J Palliat Med*. 2017;20(6):638-641. doi:10.1089/jpm.2016.0315.
- Dowell D, Haegerich T, Chou R. CDC guideline for prescribing opioids for chronic pain—United States, 2016. *JAMA*. 2016;315(15):1624. doi:10.1001/jama.2016.1464.
- DuBenske L, Gustafson D, Namkoong K et al. CHESS improves cancer caregivers' burden and mood: Results of an eHealth RCT. *Health Psycho*. 2014;33(10):1261-1272. doi:10.1037/a0034216.
- Dy S, Roy J, Ott G et al. Tell U: A web-based tool for improving communication among patients, families, and providers in hospice and palliative care through systematic data specification, collection, and use. *J Pain Symptom Manage*. 2011;42(4):526-534. doi:10.1016/j.jpainsymman.2010.12.006.
- El-Jawahri A, Traeger L, Park E et al. Associations among prognostic understanding, quality of life, and mood in patients with advanced cancer. *Cancer*. 2013;120(2):278-285. doi:10.1002/cncr.28369.
- Gidwani R, Nevedal A, Patel M et al. The appropriate provision of primary versus specialist palliative care to cancer patients: Oncologists' perspectives. *J Palliat Med*. 2017;20(4):395-403. doi:10.1089/jpm.2016.0399.
- Harrington S, Smith T. The role of chemotherapy at the end of life. *JAMA*. 2008;299(22):2667. doi:10.1001/jama.299.22.2667.
- Harris P. Review: Palliative care improves quality of life and symptom burden but does not affect mortality at 1 to 3 months. *Ann Int Med*. 2017;166(6):JC31. doi:10.7326/acpjc-2017-166-6-031.
- Jackson V, Jacobsen J, Greer J, Pirl W, Temel J, Back A. The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: A communication guide. *J Palliat Med*. 2013;16(8):894-900. doi:10.1089/jpm.2012.0547.
- JC Weeks, JW Mack, D Schrag. Talking with patients about dying. *N Engl J Med*. 2013, (368): 480– 481.
- Lagman R, Rivera N, Walsh D, LeGrand S, Davis M. Acute inpatient palliative medicine in a cancer center: Clinical problems and medical interventions—A prospective study. *Am J Hosp Palliat Care*. 2007;24(1):20-28. doi:10.1177/1049909106295292.
- Meier DE, Back AL, Berman A, et al. A national strategy for palliative care. *Health Aff (Millwood)* 2017;36:1265–1273.
- Mohan D, Alexander S, Garrigues S, Arnold R, Barnato A. Communication practices in physician decision-making for an unstable critically ill patient with end-stage cancer. *J Palliat Med*. 2010;13(8):949-956. doi:10.1089/jpm.2010.0053.

- Moroni M, Bolognesi D, Muciarelli P, Abernethy A, Biasco G. Investment of palliative medicine in bridging the gap with academia: A call to action. *Eur J Cancer*. 2011;47(4):491-495. doi:10.1016/j.ejca.2010.12.014.
- Okimasa S, Saito Y, Okuda H et al. Assessment of cancer pain in a patient with communication difficulties: A case report. *J Med Case Rep*. 2016;10(1). doi:10.1186/s13256-016-0935-2.
- Parker S, Clayton J, Hancock K et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage*. 2007;34(1):81-93. doi:10.1016/j.jpainsymman.2006.09.035.
- Pollak K, Childers J, Arnold R. Applying motivational interviewing techniques to palliative care communication. *J Palliat Med*. 2011;14(5):587-592. doi:10.1089/jpm.2010.0495.
- Rak A, Raina R, Suh T et al. Palliative care for patients with end-stage renal disease: Approach to treatment that aims to improve quality of life and relieve suffering for patients (and families) with chronic illnesses. *Clin Kidney J*. 2016;sfw105. doi:10.1093/ckj/sfw105.
- Rocque G, Mullvain J, Eickhoff J, Cleary J, Campbell T. Integrating palliative care into the oncology clinic: A joint management approach. *Palliat Med*. 2015;30(5):510-512. doi:10.1177/0269216315601947.
- Schenker Y, Arnold R, Bauman J, Heron D, Johnson J. An enhanced role for palliative care in the multidisciplinary approach to high-risk head and neck cancer. *Cancer*. 2015;122(3):340-343. doi:10.1002/cncr.29754.
- Schulman-Green D, Ercolano E, Jeon S, Dixon J. Validation of the knowledge of care options instrument to measure knowledge of curative, palliative, and hospice care. *J Palliat Med*. 2012;15(10):1091-1099. doi:10.1089/jpm.2011.0514.S.
- Shin J, Temel J. Integrating palliative care. *Curr Opin Pulm Med*. 2013;1. doi:10.1097/mcp.0b013e3283620e76.
- Silver J, Smith S, Wisotzky E, Raj V, Fu J, Kirch R. Response to editorial by Richard Crevenna, MD, regarding "cancer rehabilitation and palliative care: Critical components in the delivery of high-quality oncology services" by Silver et al. *Supp Care Cancer*. 2015;23(12):3409-3410. doi:10.1007/s00520-015-2917-0.
- Steinhauser K, Arnold R, Olsen M et al. Comparing three life-limiting diseases: Does diagnosis matter or is sick, sick? *J Pain Symptom Manage*. 2011;42(3):331-341. doi:10.1016/j.jpainsymman.2010.11.006.
- Twaddle M, Maxwell T, Cassel J et al. Palliative care benchmarks from academic medical centers. *J Palliat Med*. 2007;10(1):86-98. doi:10.1089/jpm.2006.0048.
- Wittenberg-Lyles E, Goldsmith J, Ragan S. The shift to early palliative care. *Clin J Oncol Nurs*. 2011;15:304-10.
- Yates P. What can we do to improve the coordination of care for cancer patients? *Cancer Nursing*. 2015;38(3):248-249. doi:10.1097/ncc.0000000000000253.

Dementia

- Dowding D, Lichtner V, Allcock N et al. Using sense-making theory to aid understanding of the recognition assessment and management of pain in patients with dementia in acute hospital settings. *Int J Nurs Stud*. 2016;53:152-162. doi:10.1016/j.ijnurstu.2015.08.009.

Appendix IV: Scoping Review

- Grabowski DC, Mitchell SL. Family oversight and the quality of nursing home care for residents with advanced dementia. *Medical Care*. 2009;47(5):568-574.
- Hasson F, Kernohan WG, McLaughlin M, et al. An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliat Med*. 2010;24(7):731-736.
- Hsu A, Kao H. The clinical course of advanced dementia. *N Engl J Med*. 2010;362(4):363-365.
- Johnson KS, Elbert-Avila K, Kuchibhatla M, Tulsy JA. Characteristics and outcomes of hospice enrollees with dementia discharged alive. *J Am Geriatr Soc*. 2012.
- Kaldjian LC, Shinkunas L, Bern-Klug M, Schultz SK. Dementia, goals of care, and personhood: A study of surrogate decision makers' beliefs and values. *Am J Hosp Palliat Care*. 2010;27(6):387-397.
- Kiely DK, Givens JL, Shaffer ML, Teno JM, Mitchell SL. Hospice use and outcomes in nursing home residents with advanced dementia. *J Am Geriatr Soc*. 2010;58(12):2284-2291.
- Kong E, Evans L, Guevara J. Non-pharmacological intervention for agitation in dementia: A systematic review and meta-analysis. *Aging Ment Heal*. 2009;13(4):512-520.
- Long CO. Palliative care for advanced dementia: Approaches that work. *J Geron Nurs*. 2009;35(11):19-24.
- McCarty CE, Volicer L. Hospice access for individuals with dementia. *Am J Alzheimers Dis Other Demen*. 2009;24(6):476-485.
- Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med*. 2009;361(16):1529-1538.
- Murray TM, Sach GA, Shega JW. The symptom experience of community-dwelling persons with dementia: Self and caregiver report and comparison with standardized symptom assessment measures. *Am J Geriatr Psychiatry*. 2012;20(4):298-305.
- Nakanishi M, Nakashima T, Shindo Y et al. An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper. *Int Psychogeriatr*. 2015;27(09):1551-1561. doi:10.1017/s1041610215000150.
- Palecek EJ, Teno JM, Casarett DJ, Hanson LC, Rhodes RL, Mitchell SL. Comfort feeding only: A proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc*. 2010;5(3):580-584.
- Teno JM, Gozalo PL, Lee IC, et al. Does hospice improve quality of care for persons dying from dementia? *J Am Geriatr Soc*. 2011;59(8):1531-1536.

Heart Failure

- Allen L, Gheorghiade M, Reid KJ, et al. Identifying patients hospitalized with heart failure at risk for unfavorable future quality of life. *Circ Cardiovasc Qual Outcomes*. 2011;4(4):379-381.
- Allen LA, Stevenson LW, Grady KL, et al. American Heart Association Council on Quality of Care and Outcomes Research, Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Cardiovascular Radiology and Intervention, and Council on Cardiovascular Surgery and Anesthesia. Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation*. 2012;125:1928-1952. doi:10.1161/CIR.0b013e31824f2173.
- Bakitas M, Dionne-Odom J, Pamboukian S et al. Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: results of the ENABLE CHF-PC pilot clinical trial. *BMC Palliat Care*. 2017;16(1). doi:10.1186/s12904-017-0226-8.

- Bekelman D, Rabin B, Nowels C et al. Barriers and facilitators to scaling up outpatient palliative care. *J Palliat Med*. 2016;19(4):456-459. doi:10.1089/jpm.2015.0280.
- Bekelman DB, Rumsfeld JA, Havranek EP, et al. Symptom burden, depression, and spiritual well-being: A comparison of heart failure and advanced cancer patients. *J Gen Intern Med*. 2009;24(5):592-598.
- Doorenbos A, Levy W, Curtis J, Dougherty C. An intervention to enhance goals-of-care communication between heart failure patients and heart failure providers. *J Pain Symptom Manage*. 2016;52(3):353-360. doi:10.1016/j.jpainsymman.2016.03.018.
- Goodlin S, Trupp R, Bernhardt P, Grady K, Dracup K. Development and evaluation of the "Advanced Heart Failure Clinical Competence Survey": A tool to assess knowledge of heart failure care and self-assessed competence. *Patient Educ Couns*. 2007;67(1-2):3-10. doi:10.1016/j.pec.2007.01.013.
- Goodlin S. Palliative care in congestive heart failure. *J Am Coll Cardiol*. 2009;54:386-396.
- Hupcey JE, Penrod J, Fenstermacher K. A model of palliative care for heart failure. *Am J Hosp Palliat Care*. 2009;29(5):399-404.
- Johnson M, Bland J, Gahbauer E et al. Breathlessness in elderly adults during the last year of life sufficient to restrict activity: Prevalence, pattern, and associated factors. *J Am Geriatr Soc*. 2016;64(1):73-80. doi:10.1111/jgs.13865.
- Martin DE. Palliation of dyspnea in patients with heart failure. *Dimen Crit Care Nurs*. 2011;30(3):144-149.
- Martin-Pfitzenmeyer I, Gauthier S, Bailly M, et al. Prognostic factors in stage D heart failure in the very elderly. *Gerontology*. 2009;55(6):719-726.
- McClung JA. End of life care in the Treatment of Advanced Heart Failure in the Elderly. *Curr Cardiol Rev*. 2012. doi:10.1097/CRD.0b013e31826d23ea.
- Naghi JJ, Philip KJ, Phan A, Cleenewerck L, Schwarz E. The effects of spirituality and religion on outcomes in patients with chronic heart failure. *J Relig Health*. 2010.
- Pantilat SZ, O'Riordan DL, Dibble SL, Landefeld CS. Longitudinal assessment of symptom severity among hospitalized elders diagnosed with cancer, heart failure, and chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2012;43(5):866-873.
- Richard Conti C. Access to quality cardiovascular care. *Clin Cardiol*. 2010;33(2):60-61.
- Ryan M, Farrelly M. Living with an unfixable heart: a qualitative study exploring the experience of living with advanced heart failure. *Eur J Cardiovasc Nurs*. 2009;8(3):223-231.
- Samala RV, Navas V, Saluke E, Ciocon JO. Heart failure in frail, older patients: we can do 'MORE'. *Cleve Clin J Med*. 2011;78(12):837-845.
- Silver M. Depression and heart failure: A overview of what we know and don't know. *Cleve Clin J Med*. 2010;77(S3):S7-S11.
- Smith D. Development of an end-of-life care pathway for patients with advanced heart failure in a community setting. *Int J Palliat Nurs*. 2012;18(6):293-300.
- Swetz KM, Freeman MR, AbouEzzeddine OF, et al. Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy. *Mayo Clinic Proceedings*. 2011;86(6):493-500.

Appendix IV: Scoping Review

Wingate S, Bain KT, Goodlin SJ. Availability of data when heart failure patients are admitted to hospice. *Congest Heart Fail*. 2011;17(6):303-308.

Pulmonary Conditions

Au DH, Udris EM, Engelberg RA, et al. A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest*. 2012;141(3):726-735.

Blanchette CM, Berry SR, Lane SJ. Advances in chronic obstructive pulmonary disease among older adults. *Curr Opin Pulm Med*. 2011;17(2):84-89.

Blinderman C, Homel P, Billings JA, Tennstadt S, Portenoy R. Symptom distress and quality of life in patients with advanced chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2009;38(1):115-123.

Braus N, Campbell T, Kwekkeboom K et al. Prospective study of a proactive palliative care rounding intervention in a medical ICU. *Intensive Care*. 2015;42(1):54-62. doi:10.1007/s00134-015-4098-1.

Brown MV. How they cope: A qualitative study of the coping skills of hospice volunteers. *Am J Hosp Palliat Care*. 2011;28(6):398-402.

Brown MV. The stresses of hospice volunteer work. *Am J Hosp Palliat Care*. 2011;28(3):188-192.

Cohen LM, Ruthazer R, Germain MJ. Increasing hospice services for elderly patients maintained with hemodialysis. *J Palliat Med*. 2010;13(7):847-854.

Dellon EP, Shores MD, Nelson KI, Wolfe J, Noah TL, Hanson LC. Family caregiver perspectives on symptoms and treatments for patients dying from complications of cystic fibrosis. *J Pain Symptom Manage*. 2010;40(6):829-837.

Ford DW, Koch KA, Ray DE, Selecky PA. Palliative and end-of-life care in lung cancer: Diagnosis and management of lung cancer, 3rd ed: American College of Chest Physicians evidence-based clinical practice guidelines. *Chest*. 2013;143:e498S-e512S.

Gysels M, Higginson IJ. The experience of breathlessness: The social course of chronic obstructive pulmonary disease. *J Pain Symptom Manage*. 2010;39(3):555-563.

Hayes D, Jr., Anstead MI, Warner RT, Kuhn RJ, Ballard HO. Inhaled morphine for palliation of dyspnea in end-stage cystic fibrosis. *Am J Health Syst Pharm*. 2010;67(9):737-740.

Jacobsen J, Kvale E, Rabow M et al. Helping patients with serious illness live well through the promotion of adaptive coping: A report from the Improving Outpatient Palliative Care (IPAL-OP) Initiative. *J Palliat Med*. 2014;17(4):463-468. doi:10.1089/jpm.2013.0254.

Janssen DJ, Engelberg RA, Wouters EF, Curtis JR. Advance care planning for patients with COPD: Past, present and future. *Patient Educ Couns*. 2012;86(1):19-24.

Joshi M, Joshi A, Bartter T. Symptom burden in chronic obstructive pulmonary disease and cancer. *Curr Opin Pulm Med*. 2012;18(2):97-103.

Kitzing B, Torzillo PJ, Allman KC. Resolution of hepatopulmonary syndrome after methadone withdrawal as demonstrated by right to left shunt study. *Clin Nucl Med*. 2011;36(2):152-153.

Kozak LE, Kayles L, McCarty R, Walkinshaw C, Congdon S, Kleinberger J. Use of complementary and alternative medicine (CAM) by Washington state hospices. *Am J Hosp Palliat Care*. 2008-2009;25(6):463-468.

Kuschner W, Gruenewald D, Clum N, Beal A, Ezeji-Okoye S. Implementation of ICU palliative care guidelines and procedures. *Chest*. 2009;135(1):26-32. doi:10.1378/chest.08-1685.

- Kuschner WG. Palliative care for pulmonary patients. *Am J Respir Crit Care Med*. 2011;183(3):416-417.
- Lewis D, Scullion J. Palliative and end-of-life care for patients with idiopathic pulmonary fibrosis: Challenges and dilemmas. *Int J Palliat Nurs*. 2012;18(7):331-337.
- Lowton K. 'A bed in the middle of nowhere': parents' meanings of place of death for adults with cystic fibrosis. *Soc Sci Med*. 2009;69(7):1056-1062.
- Mahler DA, Selecky PA, Harrod CG, et al. American College of Chest Physicians consensus statement on the management of dyspnea in patients with advanced lung or heart disease. *Chest*. 2010;137(3):674-691.
- Patel K, Janssen DJ, Curtis JR. Advance care planning in COPD. *Respirology*. 2012;17(1):72-78.
- Planalp S, Trost M. Motivations of hospice volunteers. *Am J Hosp Palliat Care*. 2009;26(3):188-192.
- Planalp S, Trost M. Reasons for starting and continuing to volunteer for hospice. *Am J Hosp Palliat Care*. 2009;26(4):288-294.
- Rich S, Gruber-Baldini A. Differences in services provided by hospices based on home health agency certificate status. *Med Care*. 2009;47(1):9-14.
- Savery CA, Egbert N. Hospice volunteer as patient advocate: A trait approach. *Palliat Support Care*. 2010;8(2):159-167.
- Wittenberg-Lyles E, Parker Oliver D, Demiris G, Regehr K. Interdisciplinary collaboration in hospice team meetings. *J Interprof Care*. 2010;24(3):264-273.
- Wittenberg-Lyles E, Schneider G, Oliver DP. Results from the national hospice volunteer training survey. *J Palliat Med*. 2010;13(3):261-265.

Other

- Braun LT, Grady KL, Kutner JS d, et al; American Heart Association Advocacy Coordinating Committee. Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association/American Stroke Association. *Circulation*. 2016;134:e198–e225. doi:10.1161/CIR.0000000000000438.
- Brownlee A, Palovcak M. The role of augmentative communication devices in the medical management of ALS. *NeuroRehab*. 2007; 22: 445-450.
- Chang T, Sawhney R, Monto A et al. Implementation of a multidisciplinary treatment team for hepatocellular cancer at a Veterans Affairs Medical Center improves survival. *HPB (Oxford)*. 2008;10(6):405-411. doi:10.1080/13651820802356572.
- Connolly S, Galvin M, Hardiman O. End-of-life management in patients with amyotrophic lateral sclerosis. *Lancet Neurol*. 2015;14(4):435-442. doi:10.1016/s1474-4422(14)70221-2.
- Connor K, Cheng E, Siebens H, et al. Study protocol of "CHAPS": A randomized controlled trial protocol of care coordination for health promotion and activities in Parkinson's disease to improve the quality of care for individuals with Parkinson's disease. *BMC Neuro*. 2015;15(1). doi:10.1186/s12883-015-0506-y.
- Dy S, Feldman D. Palliative care and rehabilitation for stroke survivors: Managing symptoms and burden, maximizing function. *J Gen Intern Med*. 2012;27(7):760-762. doi:10.1007/s11606-012-2054-0.

Appendix IV: Scoping Review

Holloway RG, Arnold RM, Creutzfeldt CJ, et al. American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology. Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association. *Stroke*. 2014;45(6):1887- 916. doi:10.1161/STR.0000000000000015.

Physical Aspects

Johnson R, Gustin J. Acute renal failure requiring renal placement therapy in the intensive care unit: Impact on the prognostic assessment for shared decision making. *J Palliat Med*. 2011;14(7):883-889. doi:10.1089/jpm.2010.0452.

Keefer P, Lehmann K, Shanley M et al. Single-center experience providing palliative care to pediatric patients with end-stage renal disease. *J Palliat Med*. 2017;20(8):845-849. doi:10.1089/jpm.2016.0353.

Marin B, Beghi E, Vial C et al. Evaluation of the application of the European guidelines for the diagnosis and clinical care of amyotrophic lateral sclerosis (ALS) patients in six French ALS centres. *Eur J Neurol*. 2016;23(4):787-795. doi:10.1111/ene.12941.

Mitsumoto H, Rabkin J. Palliative care for patients with amyotrophic lateral sclerosis. *JAMA*. 2007;298(2):207. doi:10.1001/jama.298.2.207.

Nedjat-Haiem F, Carrion I, Gonzalez K et al. Implementing an advance care planning intervention in community settings with older Latinos: A feasibility study. *J Palliat Med*. 2017;20(9):984-993. doi:10.1089/jpm.2016.0504.

Radunovic A, Mitsumoto H, Leigh PN: Clinical care of patients with amyotrophic lateral sclerosis. *Lancet Neurol*. 2007, 6: 913-925.

Roeland E, Cain J, Onderdonk C, Kerr K, Mitchell W, Thornberry K. When open-ended questions don't work: The role of palliative paternalism in difficult medical decisions. *J Palliat Care*. 2014;17:415–20.

Weisbord S, Bossola M, Fried L et al. Cultural comparison of symptoms in patients on maintenance hemodialysis. *Hemodial Int*. 2008;12(4):434-440. doi:10.1111/j.1542-4758.2008.00307.x.

Symptoms

General

Barbosa M, Bennett M, Verissimo R, Carvalho D. Cross-cultural psychometric assessment of the Leeds Assessment of Neuropathic Symptoms and Signs (LANSS) Pain Scale in the Portuguese population. *Pain Pract*. 2013;14(7):620-624. doi:10.1111/papr.12118.

Berry-Cabán C, Crespo H. Cultural competency as a skill for health care providers. *Hisp Health Care Int*. 2008;6(3):115-121. doi:10.1891/1540-4153.6.3.115.

Brown M, Lobb J, Novak-Tibbitt R, Rowe W. American pain foundation position statement on access to pain care. *J Pain Palliat Care Pharmacother*. 2011;25(2):165-170. doi:10.3109/15360288.2010.525602.

Chuang E, Lamkin R, Hope A, Kim G, Burg J, Gong M. "I Just Felt Like I Was Stuck in the Middle": Physician assistants' experiences communicating with terminally ill patients and their families in the acute care setting. *J Pain Symptom Manage*. 2017;54(1):27-34. doi:10.1016/j.jpainsymman.2017.03.011.

- Feldman R, Berman N, Reid M et al. Improving symptom management in hemodialysis patients: Identifying barriers and future directions. *J Palliat Med.* 2013;16(12):1528-1533. doi:10.1089/jpm.2013.0176.
- Hanson L, Scheunemann L, Zimmerman S, Rokoske F, Schenck A. The PEACE project review of clinical instruments for hospice and palliative care. *J Palliat Med.* 2010;13(10):1253-1260. doi:10.1089/jpm.2010.0194.
- Hanson L. Communication is our procedure. *J Palliat Med.* 2011;14(10):1084-1085. doi:10.1089/jpm.2011.9647.
- Hodge F, Itty T, Cadogan M, Martinez F. "Weaving balance into life": Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians. *J Cancer Surviv.* 2011;6(2):182-188. doi:10.1007/s11764-011-0209-3.
- Institute of Medicine. IOM calls for transformation of attitudes toward pain and its prevention and management. *J Pain Palliat Care Pharmacother.* 2012;26(1):40-43. doi:10.3109/15360288.2011.650362.
- Jarabek B, Jama A, Cha S, Ruegg S, Moynihan T, McDonald F. Use of a palliative care order set to improve resident comfort with symptom management in palliative care. *Palliat Med.* 2008;22(4):343-349. doi:10.1177/0269216308090169.
- Johnson M, Bland J, Gahbauer E et al. Breathlessness in elderly adults during the last year of life sufficient to restrict activity: Prevalence, pattern, and associated factors. *J Am Geriatr Soc.* 2016;64(1):73-80. doi:10.1111/jgs.13865.
- Kirk T. Managing pain, managing ethics. *Pain Manage Nurs.* 2007;8(1):25-34. doi:10.1016/j.pmn.2006.12.004.
- Krouse R. Lessons learned from a collaborative meeting to construct a palliative care protocol. *J Pain Symptom Manage.* 2007;34(1):S60-S62. doi:10.1016/j.jpainsymman.2007.04.006.
- Lagman R, Rivera N, Walsh D, LeGrand S, Davis M. Acute inpatient palliative medicine in a cancer center: Clinical problems and medical interventions—A prospective study. *Am J Hosp Palliat Care.* 2007;24(1):20-28. doi:10.1177/1049909106295292.
- Lopez I, Ramirez R, Guarnaccia P, Canino G, Bird H. Ataques de nervios and somatic complaints among island and mainland Puerto Rican children. *CNS Neurosci Ther.* 2010;17(3):158-166. doi:10.1111/j.1755-5949.2010.00137.x.
- Mausbach B, Harvey P, Goldman S, Jeste D, Patterson T. Development of a brief scale of everyday functioning in persons with serious mental illness. *Schizophr Bull.* 2006;33(6):1364-1372. doi:10.1093/schbul/sbm014.
- Meier DE, Back AL, Berman A, et al. A national strategy for palliative care. *Health Aff (Millwood)* 2017;36:1265–1273.
- Oliver D, Wittenberg-Lyles E, Demiris G, Washington K, Porock D, Day M. Barriers to pain management: Caregiver perceptions and pain talk by hospice interdisciplinary teams. *J Pain Symptom Manage.* 2008;36(4):374-382. doi:10.1016/j.jpainsymman.2007.11.005.
- Ray D, Karlekar M, Crouse D et al. Care of the critically ill burn patient: An overview from the perspective of optimizing palliative care. *Ann Am Thorac Soc.* 2017. doi:10.1513/annalsats.201607-577ps.

Appendix IV: Scoping Review

- Reese J, Blackford A, Sussman J et al. Cancer patients' function, symptoms and supportive care needs: A latent class analysis across cultures. *Qual Life Res*. 2014;24(1):135-146. doi:10.1007/s11136-014-0629-4.
- Seow H, Snyder C, Mularski R et al. A framework for assessing quality indicators for cancer care at the end of life. *J Pain Symptom Manage*. 2009;38(6):903-912. doi:10.1016/j.jpainsymman.2009.04.024.
- Smith A, Schonberg M, Fisher J et al. Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. *J Pain Symptom Manage*. 2010;39(6):972-981. doi:10.1016/j.jpainsymman.2009.10.004.
- Thompson S, Oliver D. A new model for long-term care: Balancing palliative and restorative care delivery. *J Hous Elderly*. 2008;22(3):169-194. doi:10.1080/02763890802232014.
- Wagner L, Schink J, Bass M et al. Bringing PROMIS to practice: Brief and precise symptom screening in ambulatory cancer care. *Cancer*. 2014;121(6):927-934. doi:10.1002/cncr.29104.
- Wittenberg E, Goldsmith J, Ferrell B, Platt C. Enhancing communication related to symptom management through plain language. *J Pain Symptom Manage*. 2015;50(5):707-711. doi:10.1016/j.jpainsymman.2015.06.007.

Dyspnea

- Campbell ML, Templin T, Walch J. Patients who are near death are frequently unable to self-report dyspnea. *J Palliat Med*. 2009;12(10):881-884.
- Campbell ML. Assessing respiratory distress when the patient cannot report dyspnea. *Nurs Clin North Am*. 2010;45(3):363-373.
- Caprio AJ, Hanson LC, Munn JC, et al. Pain, dyspnea, and the quality of dying in long-term care. *J Am Geriatr Soc*. 2008;56(4):683-688.
- Kamal AH, Maguire JM, Wheeler JL, Currow DC, Abernethy AP. Dyspnea review for the palliative care professional: assessment, burdens, and etiologies. *J Palliat Med*. 2011;14(10):1167-1172.
- Kamal AH, Miriovsky BJ, Currow DC, Abernethy AP. Improving the management of dyspnea in the community using rapid learning approaches. *Chronic Resp Dis*. 2012;9(1):51-61.
- Lai WS, Chao CS, Yang WP, Chen CH. Efficacy of guided imagery with theta music for advanced cancer patients with dyspnea: a pilot study. *Bio Res Nurs*. 2010;12(2):188-197.
- Mahler DA. Understanding mechanisms and documenting plausibility of palliative interventions for dyspnea. *Curr Opin Support Palliat*. 2011;5(2):71-76.
- Mercadante S, Villari P, David F, Agozzino C. Noninvasive ventilation for the treatment of dyspnea as a bridge from intensive to end-of-life care. *J Pain Symptom Manage*. 2009;38(3):e5-7.
- Mularski RA, Campbell ML, Asch SM, et al. A review of quality of care evaluation for the palliation of dyspnea. *Am J Respir Crit Care Med* 2010;181(6):534-538.
- Naqvi F, Cervo F, Fields S. Evidence-based review of interventions to improve palliation of pain, dyspnea, depression. *Geriatrics*. 2009;64(8):8-10.
- Reddy SK, Parsons HA, Elsayem A, Palmer JL, Bruera E. Characteristics and correlates of dyspnea in patients with advanced cancer. *J Palliat Med*. 2009;12(1):29-36.
- Rocker G. Palliation of dyspnea. *Chronic Resp Dis*. 2012;9(1):49-50.

Sajkov D, Petrovsky N, Palange P. Management of dyspnea in advanced pulmonary arterial hypertension. *Cur Op Support Palliat Care*. 2010;4(2):76-84.

Nausea

Baxter AL, Watcha MF, Baxter WV, Leong T, Wyatt M. Development and validation of a pictorial nausea rating scale for children. *Pediatrics*. 2011;127(6):1542-1549.

Dolan EA. Malignant bowel obstruction: a review of current treatment strategies. *Am J Hosp Palliat Med*. 2011;28(8):576-582.

Hardy JR, O'Shea A, White C, Gilshenan K, Welch L, Douglas C. The efficacy of haloperidol in the management of nausea and vomiting in patients with cancer. *J Pain Symptom Manage*. 2010;40(1):111-116.

Jimenez A, Madero R, Alonso A, et al. Symptom clusters in advanced cancer. *J Pain Symptom Manage*. 2011;42(1):24-31.

Mannix K. Palliation of nausea and vomiting. *Br J Hosp Med*. 2009;70(4):192-196.

Miller E, Jacob E, Hockenberry M. Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. *Oncol Nurs Forum*. 2011;38(5):E382-E393.

Perkins P, Dorman S. Haloperidol for the treatment of nausea and vomiting in palliative care patients. *Cochrane Database Syst Rev*. 2009(2):006271.

Radwany SM, von Gruenigen VE. Palliative and end-of-life care for patients with ovarian cancer. *Clin Obstet Gynecol*. 2012;55(1):173-184.

Pain

Barroso E, Carvalho A, Paiva C, Murphy B, Paiva B. The Vanderbilt Head and Neck Symptom Survey Brazilian Portuguese version 2.0 (VHNSS 2.0): Psychometric properties for patients with head and neck cancer who have undergone radiotherapy. *BMC Res Notes*. 2015;8(1). doi:10.1186/s13104-015-1470-8.

Bell CL, Kuriya M, Fischberg D. Pain outcomes of inpatient pain and palliative care consultations: Differences by race and diagnosis. *J Palliat Med*. Oct 2011;14(10):1142-1148.

Black B, Herr K, Fine P, et al. The relationships among pain, nonpain symptoms, and quality of life measures in older adults with cancer receiving hospice care. *Pain Med*. 2011;12(6):880-889.

Bostick C. Review of palliative & end-of-life care: Clinical practice guidelines. *Act Adapt Aging*. 2011;35(3):261-263.

Campbell L, Andrews N, Scipio C, Flores B, Feliu M, Keefe F. Pain coping in Latino populations. *J Pain*. 2009;10(10):1012-1019. doi:10.1016/j.jpain.2009.03.004.

Chien C, Shih Y. Use of personalized decision analysis in decision making for palliative vs. surgical management of the oldest-old patients with localized skin cancer in a culturally sensitive environment: A case study of a 96-year-old male Taiwanese patient. *J Pain Symptom Manage*. 2013;45(4):792-797. doi:10.1016/j.jpainsymman.2012.03.004.

Committee on Advancing Pain Research. A call for cultural transformation of attitudes toward pain and its prevention and management. *J Pain Palliat Care Pharmacother* 2011;25(4):365-369. doi:10.3109/15360288.2011.621516.

- Conway M, White N, Jean CS, Zempsky WT, Steven K. Use of continuous intravenous ketamine for end-stage cancer pain in children. *J Pediatr Oncol Nurs*. 2009;26(2):100-106.
- Day M. Interdisciplinary hospice team processes and multidimensional pain: A Qualitative study. *J Soc Work End Life Palliat Care*. 2012;8(1):53-76.
- Delgado-Guay MO, Hui D, Parsons HA, et al. Spirituality, religiosity, and spiritual pain in advanced cancer patients. *J Pain Symptom Manage*. 2011;41(6):986-994.
- Dhingra L, Lam K, Cheung W et al. Variation in symptom distress in underserved Chinese American cancer patients. *Cancer*. 2015;121(18):3352-3359. doi:10.1002/cncr.29497.
- Dowding D, Lichtner V, Allcock N et al. Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *Int J Nurs Stud*. 2016;53:152-162. doi:10.1016/j.ijnurstu.2015.08.009.
- Duke G, Petersen S. Perspectives of Asians living in Texas on pain management in the last days of life. *Int J Palliat Nurs*. 2015;21(1):24-34. doi:10.12968/ijpn.2015.21.1.24.
- Edwards L, Edwards C. Psychosocial Treatments in Pain Management of Sickle Cell Disease. *J Nat Med Assoc*. 2010;102(11):1084-1094. doi:10.1016/s0027-9684(15)30737-9.
- Erstad BL, Puntillo K, Gilbert HC, Grap MJ, Li D, Medina J. Pain management principles in the critically ill. *Chest*. 2009;135(3):1075-1086.
- Fine P, Herr K, Titler M, et al. The cancer pain practice index: A measure of evidence-based practice adherence for cancer pain management in older adults in hospice care. *J Pain Symptom Manage*. 2010;39(5):791-802.
- Gordon R, Corcoran J, Bartley-Daniele P, Sklenar D, Sutton P, Cartwright F. A transdisciplinary team approach to pain management in inpatient health care settings. *Pain Manag Nurs*. 2014;15(1):426-435. doi:10.1016/j.pmn.2013.01.004.
- Hodge F, Itty T, Cadogan M, Martinez F. "Weaving Balance into Life": Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians. *J Cancer Surviv*. 2011;6(2):182-188. doi:10.1007/s11764-011-0209-3.
- Huang K, Owino C, Vreeman R et al. Assessment of the face validity of two pain scales in Kenya: A validation study using cognitive interviewing. *BMC Palliat Care*. 2012;11(1). doi:10.1186/1472-684x-11-5.
- Janvier A, Meadow W, Leuthner S et al. Whom are we comforting? An analysis of comfort medication delivered to dying neonates. *J Ped*. 2011;159(2):206-210. doi:10.1016/j.jpeds.2011.01.022.
- Khosla N, Washington K, Regunath H. Perspectives of health care providers on US south Asians' attitudes towards pain management at end of life. *Am J Hosp Palliat Care*. 2016;33(9):849-857. doi:10.1177/1049909115593063.
- Liberman J, O'Brien M, Hall W, Hill D. Ending inequities in access to effective pain relief? *Lancet*. 2010;376(9744):856-857.
- Lin R, Reid M, Liu L, Chused A, Evans A. The barriers to high-quality inpatient pain management. *Am J Hosp Palliat Care*. 2014;32(6):594-599. doi:10.1177/1049909114530491.
- Macauley R. The role of the principle of double effect in ethics education at US medical schools and its potential impact on pain management at the end of life. *J Med Ethics*. 2012;38(3):174-178.
- Miller E, Jacob E, Hockenberry M. Nausea, pain, fatigue, and multiple symptoms in hospitalized children with cancer. *Oncol Nurs Forum*. 2011;38(5):E382-E393.

- Modesto-Lowe V, Girard L, Chaplin M. Cancer pain in the opioid-addicted patient: Can we treat it right? *J Opioid Manag.* 2012;8(3):167-175.
- Mutto EM, Cavazzoli C, Ballbe JA, Tambone V, Centeno C, Villar MJ. Teaching dying patient care in three universities in Argentina, Spain, and Italy. *J Palliat Med.* 2009;12(7):603-607.
- Oakes L, Anghelescu D, Windsor K, Barnhill P. An institutional quality improvement initiative for pain management for pediatric cancer inpatients. *J Pain Symptom Manage.* 2008;35(6):656-669. doi:10.1016/j.jpainsymman.2007.07.008.
- Paice JA, Ferrell B. The management of cancer pain. *Cancer J Clin.* 2010;6(3):157-182.
- Parker Oliver D, Demiris G, Wittenberg-Lyles E, Porock D, Collier J, Arthur A. Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *Am J Hosp Palliat Care.* 2010;27(7):465-473.
- Parker Oliver D, Wittenberg-Lyles E, Washington KT, Sehwat S. Social work role in hospice pain management: A national survey. *J Soc Work End Life Palliat Care.* 2009;5(1-2):61-74.
- Pasero C, McCaffery M. *Pain Assessment and Pharmacological Management.* St. Louis, MO: Mosby Publishing; 2011.
- Peat S. Using cannabinoids in pain and palliative care. *Int J Palliat Nurs.* 2010;16(10):481-485.
- Prommer E. Ketamine for pain: an update of uses in palliative care. *J Palliat Med.* 2012;15(4):474-483.
- Sehn F, Chachamovich E, Vidor L et al. Cross-cultural adaptation and validation of the Brazilian Portuguese version of the pain catastrophizing scale. *Pain Med.* 2012;13(11):1425-1435. doi:10.1111/j.1526-4637.2012.01492.x.

Other

- Bishop MF, Stephens L, Goodrich M, Byock I. Medication kits for managing symptomatic emergencies in the home: a survey of common hospice practice. *J Palliat Med.* 2009;12(1):37-44.
- Bookbinder M, McHugh ME. Symptom management in palliative care and end of life care. *Nurs Clin North Am.* 2010;45(3):271-327.
- Clark K, Byfieldt N, Dawe M, Currow DC. Treating constipation in palliative care: The impact of other factors aside from opioids. *Am J Hosp Palliat Care.* 2012;29(2):122-125.
- Delgado-Guay M, Yennurajalingam S, Parsons H, Palmer JL, Bruera E. Association between self-reported sleep disturbance and other symptoms in patients with advanced cancer. *J Pain Symptom Manage.* 2011;41(5):819-827.
- Lynch MT, Dahlin C, Bakitas MK. Bowel obstruction and delirium: Managing difficult symptoms at end of life. *Clin J Oncol Nurs.* 2012;16(4):391-398.
- Strassels SA, Maxwell TL, Tyler S. Constipation in persons receiving hospice care. *J Pain Symptom Manage.* 2010;40 (6):810-820.
- Ullrich CK, Dussel V, Hilden JM, et al. Fatigue in children with cancer at the end of life. *J Pain Symptom Manage.* 2010;40(4):483-494.

Domain 3: Psychological and Psychiatric Aspects of Care

- Attilio T, Otis-Green S, Dahlin C. Applying the national quality forum preferred practices for palliative and hospice care: A social work perspective. *J Soc Work End Life Palliat Care*. 2008;4(1):3-16. doi:10.1080/15524250802071999.
- Breitbart W. The spiritual domain of palliative care: Who should be “spiritual care professionals”? *Palliat and Support Care*. 2009;7(02):139. doi:10.1017/s1478951509000182.
- Buxton D. Child and Adolescent Psychiatry and Palliative Care. *J Am Acad Child Adolesc Psychiatry*. 2015;54(10):791-792. doi:10.1016/j.jaac.2015.05.017.
- Guo Q, Jacelon C. An integrative review of dignity in end-of-life care. *Palliat Med*. 2014;28(7):931-940. doi:10.1177/0269216314528399.
- Lamba S, Berlin A, Goett R, Ponce CB, Holland B, Walther S, AAHPM Research Committee Writing Group. Assessing emotional suffering in palliative care: Use of a structured note template to improve documentation. *J Pain Symptom Manage*. 2016 Jul;52(1):1-7. PMID: 27241439.
- Meier D, Beresford L. Palliative care’s challenge: Facilitating transitions of care. *J Palliat Med*. 2008;11(3):416-421. doi:10.1089/jpm.2008.9956.
- Robert R, Zhukovsky D, Mauricio R, Gilmore K, Morrison S, Palos G. Bereaved parents’ perspectives on pediatric palliative care. Parents’ Perspectives on Pediatric Palliative Care. *J Soc Work End Life Palliat Care*. 2012;8(4):316-338. doi:10.1080/15524256.2012.732023.
- Schaphmire T, Head B, Faul A. Just give me hope: Lived experiences of Medicaid patients with advanced cancer. *J Soc Work End Life Palliat Care*. 2012;8(1):29-52. doi:10.1080/15524256.2012.650672.

Anxiety

- Anderson W, Alexander S, Rodriguez K et al. “What concerns me is...” Expression of emotion by advanced cancer patients during outpatient visits. *Support Care in Cancer*. 2007;16(7):803-811. doi:10.1007/s00520-007-0350-8.
- Austin P, Wiley S, McEvoy PM, Archer L. Depression and anxiety in palliative care inpatients compared with those receiving palliative care at home. *Palliat Support Care*. 2011;9(4):393-400.
- Choi YK. The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients. *J Music Ther*. 2010;47(1):53-69.
- Delgado-Guay M, Parsons HA, Li Z, Palmer JL, Bruera E. Symptom distress in advanced cancer patients with anxiety and depression in the palliative care setting. *Support Care in Cancer*. 2009;17(5):573-579.
- Fakhri S, Engelberg R, Downey L et al. Factors affecting patients’ preferences for and actual discussions about end-of-life care. *J Pain Symptom Manage*. 2016;52(3):386-394. doi:10.1016/j.jpainsymman.2016.03.012.
- Irwin SA, Iglewicz A. Oral ketamine for the rapid treatment of depression and anxiety in patients receiving hospice care. *J Palliat Med*. 2010;13(7):903-908.
- Johnson KS, Tulskey JA, Hays JC, et al. Which domains of spirituality are associated with anxiety and depression in patients with advanced illness? *J Gen Intern Med*. 2011;26(7):751-758.
- Mystakidou K, Tsilika E, Parpa E, et al. Illness-related hopelessness in advanced cancer: Influence of anxiety, depression, and preparatory grief. *Arch Psychiatr Nurs*. 2009;23(2):138-147.

Trachsel M, Irwin S, Biller-Andorno N, Hoff P, Riese F. Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry*. 2016;16(1). doi:10.1186/s12888-016-0970-y.

Assessment Communication

- Alexander S, Ladwig S, Norton S et al. Emotional distress and compassionate responses in palliative care decision-making consultations. *J Palliat Med*. 2014;17(5):579-584. doi:10.1089/jpm.2013.0551.
- Allen R, Hilgeman M, Ege M, Shuster J, Burgio L. Legacy activities as interventions approaching the end of life. *J Palliat Med*. 2008;11(7):1029-1038. doi:10.1089/jpm.2007.0294.
- Beach, PR, White BE. Applying the evidence to help caregivers torn in two. *Nursing*. 2017;45(6): 30-37.
- Casarett D, Pickard A, Bailey F et al. A nationwide VA palliative care quality measure: The family assessment of treatment at the end of life. *J Palliat Med*. 2008;11(1):68-75. doi:10.1089/jpm.2007.0104.
- Caserta M, Lund D, Utz R, Tabler J. "One Size Doesn't Fit All"—Partners in hospice care, an individualized approach to bereavement intervention. *OMEGA*. 2015;73(2):107-125. doi:10.1177/0030222815575895.
- Contro N, Sourkes BM. Opportunities for quality improvement in bereavement care at a children's hospital: assessment of interdisciplinary staff perspectives. *J Palliat Care*. 2012;28(1):28–35.
- Dallas R, Wilkins M, Wang J, Garcia A, Lyon M. Longitudinal pediatric palliative care: Quality of life & spiritual struggle (FACE): Design and methods. *Contemp Clin Trials*. 2012;33(5):1033-1043. doi:10.1016/j.cct.2012.05.009.
- Daly D, Matzel S. Building a transdisciplinary approach to palliative care in an acute care setting. *OMEGA*. 2013;67(1-2):43-51. doi:10.2190/om.67.1-2.e.
- Demiris G, Oliver D, Wittenberg-Lyles E. Assessing Caregivers for Team Interventions (ACT): A new paradigm for comprehensive hospice quality care. *Am J Hosp Palliat Care*. 2009;26(2):128-134. doi:10.1177/1049909108328697.
- Exline J, Prince-Paul M, Root B, Peereboom K, Worthington E. Forgiveness, depressive symptoms, and communication at the end of life: A study with family members of hospice patients. *J Palliat Med*. 2012;15(10):1113-1119. doi:10.1089/jpm.2012.0138.
- Fava G, Guidi J, Porcelli P et al. A cluster analysis-derived classification of psychological distress and illness behavior in the medically ill. *Psychological Medicine*. 2011;42(02):401-407. doi:10.1017/s0033291711001231.
- Garlo K, O'Leary J, Van Ness P, Fried T. Burden in caregivers of older adults with advanced illness. Caregivers of Older Adults with Advanced Illness. *J Am Geriatr Soc*. 2010;58(12):2315-2322. doi:10.1111/j.1532-5415.2010.03177.x.
- Howell K, Barrett-Becker E, Burnside A, Wamser-Nanney R, Layne C, Kaplow J. Children facing parental cancer versus parental death: The buffering effects of positive parenting and emotional expression. *J Child Fam Stud*. 2015;25(1):152-164. doi:10.1007/s10826-015-0198-3.
- Hyler L, Babcock C, Robinson L, Ackermann R. Transitions model: Melding of psychotherapy and palliative care using teams. *Clin Gerontol*. 2011;34(5):379-398. doi:10.1080/07317115.2011.595573.

Appendix IV: Scoping Review

- Kelemen A, Cagle J, Groninger H. Screening for intimacy concerns in a palliative care population: Findings from a pilot study. *J Palliat Med*. 2016;19(10):1102-1105. doi:10.1089/jpm.2016.0092.
- Kramer B, Boelk A. Correlates and predictors of conflict at the end of life among families enrolled in hospice. *J Pain Symptom Manage*. 2015;50(2):155-162. doi:10.1016/j.jpainsymman.2015.02.026.
- Kross E, Curtis J. Burden of psychological symptoms and illness in family of critically ill patients: What is the relevance for critical care clinicians?. *Crit Care Med*. 2008;36(6):1955-1956. doi:10.1097/ccm.0b013e31817616c0.
- Kühne F, Krattenmacher T, Bergelt C et al. "There is still so much ahead of us"—Family functioning in families of palliative cancer patients. *Fam Syst Health*. 2013;31(2):181-193. doi:10.1037/a0032274.
- Lincoln A, Arford T, Prener C, Garverich S, Koenen K. The need for trauma-sensitive language use in literacy and health literacy screening instruments. *J Health Commun*. 2013;18(sup1):15-19. doi:10.1080/10810730.2013.825676.
- Mausbach B, Harvey P, Goldman S, Jeste D, Patterson T. Development of a brief scale of everyday functioning in persons with serious mental illness. *Schizophr Bull*. 2006;33(6):1364-1372. doi:10.1093/schbul/sbm014.
- McCallum N, McGlone M. Death be not profane: Mortality salience and euphemism use. *West J Commun*. 2011;75(5):565-584. doi:10.1080/10570314.2011.608405.
- Meert K, Briller S, Myers Schim S, Thurston C, Kabel A. Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death Stud*. 2009;33(8):712-740. doi:10.1080/07481180903070434.
- Miovic M, Block S. Psychiatric disorders in advanced cancer. *Cancer*. 2007;110(8):1665-1676. doi:10.1002/cncr.22980.
- O'Mahony S, Gerhart J, Grosse J, Abrams I, Levy M. Posttraumatic stress symptoms in palliative care professionals seeking mindfulness training: Prevalence and vulnerability. *Palliat Med*. 2015;30(2):189-192. doi:10.1177/0269216315596459.
- Parker Oliver D, Washington K, Demiris G, Wittenberg-Lyles E, Novak H. Problem solving interventions: An opportunity for hospice social workers to better meet caregiver needs. *J Soc Work End Life Palliat Care*. 2012;8(1):3-9. doi:10.1080/15524256.2012.650669.
- Prince-Paul M. Relationships among communicative acts, social well-being, and spiritual well-being on the quality of life in patients with cancer enrolled in hospice. *J Palliat Med*. 2008;11(1):20-25. doi:10.1089/jpm.2007.0119.
- Rosenberg A, Postier A, Osenga K et al. Long-term psychosocial outcomes among bereaved siblings of children with cancer. *J Pain Symptom Manage*. 2015;49(1):55-65. doi:10.1016/j.jpainsymman.2014.05.006.
- Stein G. Providing palliative care to people with intellectual disabilities: Services, staff knowledge, and challenges. *J Palliat Med*. 2008;11(9):1241-1248. doi:10.1089/jpm.2008.0130.
- Stephens C, Sackett N, Pierce R et al. Transitional care challenges of rehospitalized veterans: Listening to patients and providers. *Popul Health Manag*. 2013;16(5):326-331. doi:10.1089/pop.2012.0104.
- Strada EA, Breitbart W. Addressing the psychological and psychiatric domain of palliative care. *Prim Psychiatry*. 2009;16(5):23-4.

- Tubbs-Cooley H, Santucci G, Kang T, Feinstein J, Hexem K, Feudtner C. Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care. *J Palliat Med*. 2011;14(5):631-637. doi:10.1089/jpm.2010.0409.
- Valente S, Saunders J. Psychiatric nurses' expertise, interest in end-of-life care, and requests for continuing education on end of life. *Am J Hosp Palliat Care*. 2009;27(1):24-30. doi:10.1177/1049909109341873.
- Velligan D, Fredrick M, Sierra C et al. Engagement-focused care during transitions from inpatient and emergency psychiatric facilities. *Patient Prefer Adherence*. 2017;(11):919-928. doi:10.2147/ppa.s132339.
- Weaver M, Heinze K, Bell C et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliat Med*. 2015;30(3):212-223. doi:10.1177/0269216315583446.
- Wilkins V, Quill T, King D. Assessing families in palliative care: A pilot study of the checklist of family relational abilities. *J Palliat Med*. 2009;12(6):517-519. doi:10.1089/jpm.2009.0021.

Delirium

- Balas M, Rice M, Chaperon C, Smith H, Disbot M, Fuchs B. Management of delirium in critically ill older adults. *Crit Care Nurse*. 2012;32(4).
- Bookbinder M, McHugh ME. Symptom management in palliative care and end of life care. *Nurs Clin North America*. 2010;45(3):271-327.
- Kiely D, Marcantonio E, Inouye S, et al. Persistent delirium predicts greater mortality. *J Am Geriatr Soc*. 2009;57(1):55-61.
- Kong E, Evans L, Guevara J. Non-pharmacological intervention for agitation in dementia: a systematic review and meta-analysis. *Aging Ment Health*. 2009;13(4):512-520.
- Lynch MT, Dahlin C, Bakitas MK. Bowel obstruction and delirium: Managing difficult symptoms at end of life. *Clin J Oncol Nurs*. 2012;16(4):391-398.
- Rao S, Ferris FD, Irwin SA. Ease of screening for depression and delirium in patients enrolled in inpatient hospice care. *J Palliat Med*. 2011;14(3):275-279.
- Scarpi E, Maltoni M, Miceli R, et al. Survival prediction for terminally ill cancer patients: Revision of the palliative prognostic score with incorporation of delirium. *Oncologist*. 2011;16(12):1793-1799.

Depression

- Ayalon L, Fialová D, Areán P, Onder G. Challenges associated with the recognition and treatment of depression in older recipients of home care services. *Int Psychogeriatr*. 2010;22(04):514-522. doi:10.1017/s1041610209991797.
- Bekelman DB, Rumsfeld JA, Havranek EP, et al. Symptom burden, depression, and spiritual well-being: A comparison of heart failure and advanced cancer patients. *J Gen Intern Med*. 2009;24(5):592-598.
- Cagle J, Osteen P, Sacco P, Jacobson Frey J. Psychosocial assessment by hospice social workers; A content review of instruments from a national sample. *J Pain Symptom Manage*. 2017;53(1):40-48. doi:10.1016/j.jpainsymman.2016.08.016.

- Gregurek R, Bras M, Dordevic V, Ratkovic AS, Brajkovic L. Psychological problems of patients with cancer. *Psychiatria Danubina*. 2010 Jun 30;22(2):227-30.
- Hailey C, Yopp J, Deal A et al. Psychological distress and communication with children about a parent's advanced cancer: A mixed-methods study. *J Clin Oncol*. 2016;34(26_suppl):236-236. doi:10.1200/jco.2016.34.26_suppl.236.
- Hopko DR, Bell JL, Armento ME, et al. The phenomenology and screening of clinical depression in cancer patients. *J Psychosoc Oncol*. 2008;26(1):31-51.
- Johnson KS, Tulskey JA, Hays JC, et al. Which domains of spirituality are associated with anxiety and depression in patients with advanced illness?. *J Gen Intern Med*. 2011;26(7):751-758.
- Jordan, A. H., & Litz, B. T. (2014). Prolonged grief disorder: Diagnostic, assessment, and treatment considerations. *Prof Psychol Res Pr*. 45(3), 180-187. <http://dx.doi.org/10.1037/a0036836>
- Kerr CW, Drake J, Milch RA, et al. Effects of methylphenidate on fatigue and depression: a randomized, double-blind, placebo-controlled trial. *J Pain Symptom Manage*. 2012;43(1):68-77.
- Lautrette A, Darmon M, Megarbane B et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med*. 2007;356(5):469-478. doi:10.1056/nejmoa063446.
- Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *Gen Hosp Psychiatry*. 2010 Aug 31;32(4):433-42.
- Maciejewski, PK, Maercker, A, Boelen, PA, & Prigerson, HG. "Prolonged grief disorder" and "persistent complex bereavement disorder," but not "complicated grief," are one and the same diagnostic entity: an analysis of data from the Yale Bereavement Study. *World Psychiatry*. 2016 15(3), 266–275. <http://doi.org/10.1002/wps.20348>
- Metzger P, Gray M. End-of-life communication and adjustment: Pre-loss communication as a predictor of bereavement-related outcomes. *Death Stud*. 2008;32(4):301-325. doi:10.1080/07481180801928923.
- Meyer F, Fletcher K, Prigerson H, Braun I, Maciejewski P. Advanced cancer as a risk for major depressive episodes. *Psychooncology*. 2014;24(9):1080-1087. doi:10.1002/pon.3722.
- Mystakidou K, Parpa E, Tsilika E, Galanos A, Vlahos L. Does quality of sleep mediate the effect of depression on hopelessness? *Int J Psychol Psychoanal*. 2009;44(4):282-289.
- Olden M, Rosenfeld B, Pessin H, Breitbart W. Measuring depression at end of life: Is the Hamilton depression rating scale a valid instrument? *Assessment*. 2009;16(1):43-54.
- Powazki R, Walsh D, Hauser K, Davis M. Communication in palliative medicine: A clinical review of family conferences. *J Palliat Med*. 2014;17(10):1167-1177. doi:10.1089/jpm.2013.0538.
- Rao S, Ferris FD, Irwin SA. Ease of screening for depression and delirium in patients enrolled in inpatient hospice care. *J Palliat Med*. 2011;14(3):275 - 279.
- Rayner L, Lee W, Price A, et al. The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: cross-sectional survey with four-week follow-up. *Palliat Med*. 2011;25(3):229-241.
- Schapiro T, Head B, Faul A. Just give me hope: Lived experiences of Medicaid patients with advanced cancer. *J Soc Work End Life Palliat Care*. 2012;8(1):29-52. doi:10.1080/15524256.2012.650672.
- Silver M. Depression and heart failure: A overview of what we know and don't know. *Cleve Clin J Med*. 2010;77(S3):S7-S11.

Grief

- Boelen P, Prigerson H. The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults. *Eur Arch Psychiatry Clin Neurosci*. 2007;257(8):444-452. doi:10.1007/s00406-007-0744-0.
- DiGiacomo M, Hatano Y, Phillips J, Lewis J, Abernethy A, Currow D. Caregiver characteristics and bereavement needs: Findings from a population study. *Palliat Med*. 2016;31(5):465-474. doi:10.1177/0269216316663855.
- Ghesquiere A, Aldridge M, Johnson-Hürzeler R, Kaplan D, Bruce M, Bradley E. Hospice services for complicated grief and depression: Results from a national survey. *J Am Geriatr Soc*. 2015;63(10):2173-2180. doi:10.1111/jgs.13656.
- Holland J, Currier J, Kirkendall A, Keene J, Luna N. Sadness, anxiety, and experiences with emotional support among veteran and nonveteran patients and their families at the end of life. *J Palliat Med*. 2014;17(6):708-711. doi:10.1089/jpm.2013.0485.
- Hottensen D. Bereavement: Caring for families and friends after a patient dies. *OMEGA*. 2013;67(1-2):121-126. doi:10.2190/om.67.1-2.n.
- Jenkins C, Edmundson A, Averett P, Yoon I. Older lesbians and bereavement: Experiencing the loss of a partner. *J Gerontol Soc Work*. 2014;57(2-4):273-287. doi:10.1080/01634372.2013.850583.
- Kim Y, Carver C, Spiegel D, Mitchell H, Cannady R. Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. *Psychooncology*. 2015;26(4):484-492. doi:10.1002/pon.4042.
- Metzger P, Gray M. End-of-life communication and adjustment: Pre-loss communication as a predictor of bereavement-related outcomes. *Death Stud*. 2008;32(4):301-325. doi:10.1080/07481180801928923.
- Morris S, Block S. Adding value to palliative care services: The development of an institutional bereavement program. *J Palliat Med*. 2015;18(11):915-922. doi:10.1089/jpm.2015.0080.

Mental Health

- Eggenberger E, Heimerl K, Bennett M. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *Int Psychogeriatr*. 2012;25(03):345-358. doi:10.1017/s1041610212001664.
- Irwin K, Henderson D, Knight H, Pirl W. Cancer care for individuals with schizophrenia. *Cancer*. 2013;120(3):323-334. doi:10.1002/cncr.28431.
- Kiely D, Prigerson H, Mitchell S. Health care proxy grief symptoms before the death of nursing home residents with advanced dementia. *Am J Geriatr Psychiatry*. 2008;16(8):664-673. doi:10.1097/jgp.0b013e3181784143.
- Reinhardt J, Chichin E, Posner L, Kassabian S. Vital conversations with family in the nursing home: Preparation for end-stage dementia care. *J Soc Work End Life Palliat Care*. 2014;10(2):112-126. doi:10.1080/15524256.2014.906371.

Other Psychological Symptoms

- Crunkilton D, Rubins V. Psychological distress in end-of-life care. *J Soc Work End Life Palliat Care*. 2009;5:75-93.

- Kirch R, Reaman G, Feudtner C et al. Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine Workshop highlights and next steps. *CA Cancer J Clin*. 2016;66(5):398-407. doi:10.3322/caac.21347.
- Le T, Najolia G, Minor K, Cohen A. The effect of limited cognitive resources on communication disturbances in serious mental illness. *Psychiatry Res*. 2017;248:98-104. doi:10.1016/j.psychres.2016.12.025.
- Sacco P, Cagle J, Moreland M, Camlin E. Screening and assessment of substance use in hospice care: Examining content from a national sample of psychosocial assessments. *J Palliat Med*. 2017;20(8):850-856. doi:10.1089/jpm.2016.0538.
- Schroepfer TA, Noh H, Kavanaugh M. The myriad strategies for seeking control in the dying process. *Gerontologist*. 2009;49(6):755-766.

Domain 4: Social Aspects of Care

- Adames H, Chavez-Dueñas N, Fuentes M, Salas S, Perez-Chavez J. Integration of Latino/a cultural values into palliative health care: A culture centered model. *Palliat Sup Care*. 2013;12(02):149-157. doi:10.1017/s147895151300028x.
- Adams K, Cimino J, Arnold R, Anderson W. Why should I talk about emotion? Communication patterns associated with physician discussion of patient expressions of negative emotion in hospital admission encounters. *Patient Educ Couns*. 2012;89(1):44-50. doi:10.1016/j.pec.2012.04.005.
- Allen R, Hilgeman M, Ege M, Shuster J, Burgio L. Legacy activities as interventions of approaching the end of life. *J Palliat Med*. 2008;11(7):1029-1038. doi:10.1089/jpm.2007.0294.
- Altilio T, Gardia G, Otis-Green S. Social work practice in palliative and end of life care. *J Soc Work End Life Palliat Care*. 2008;4(4):1-19.
- Arthur D. Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective. *J Soc Work End Life Palliat Care*. 2015;11(2):178-201. doi:10.1080/15524256.2015.1074141.
- Back A, Trinidad S, Hopley E, Edwards K. Reframing the goals of care conversation: "We're in a Different Place". *J Palliat Med*. 2014;17(9):1019-1024. doi:10.1089/jpm.2013.0651.
- Bern-Klug M. A framework for categorizing social interactions related to end-of-life care in nursing homes. *Gerontologist*. 2009;49(4):495-507.
- Brand S, Fasciano K, Mack J. Communication preferences of pediatric cancer patients: talking about prognosis and their future life. *Support Care Cancer*. 2016;25(3):769-774. doi:10.1007/s00520-016-3458-x.
- Brooten D, Youngblut J, Seagrave L et al. Parent's perceptions of health care providers actions around ICU death. *Am J Hosp Palliat Care*. 2012;30(1):40-49. doi:10.1177/1049909112444301.
- Cagle J, Bunting M. Patient reluctance to discuss pain: Understanding stoicism, stigma, and other contributing factors. *J Soc Work End Life Palliat Care*. 2017;13(1):27-43. doi:10.1080/15524256.2017.1282917.
- Cagle J, Kovacs P. Education: A complex and empowering social work intervention at the end of life. *Health Soc Work*. 2009;34(1):17-27. doi:10.1093/hsw/34.1.17.

- Cagle J, Osteen P, Sacco P, Jacobson Frey J. Psychosocial assessment by hospice social workers: A content review of instruments from a national sample. *J Pain Symptom Manage*. 2017;53(1):40-48. doi:10.1016/j.jpainsymman.2016.08.016.
- Cagle JG, Bolte S. Sexuality and life-threatening illness: Implications for social work and palliative care. *Health Soc Work*. 2009;34(3):223-233.
- Cagle JG. Education: A complex and empowering social work intervention at the end of life. *Health Soc Work*. 2009;34(1):17-27.
- Chan W, Epstein I. Researching "Good Death" in a Hong Kong palliative care program: A clinical data-mining study. *OMEGA*. 2012;64(3):203-222. doi:10.2190/om.64.3.b.
- Chandran D, Corbin J, Shillam C. An ecological understanding of caregiver experiences in palliative care. *J Soc Work End Life Palliat Care*. 2016;12(1-2):162-182. doi:10.1080/15524256.2016.1156602.
- Ciemins E, Brant J, Kersten D, Mullette E, Dickerson D. A qualitative analysis of patient and family perspectives of palliative care. *J Palliat Med*. 2015;18(3):282-285. doi:10.1089/jpm.2014.0155.
- Crump S, Schaffer M, Schulte E. Critical care nurses' perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care. *Dimens Crit Care Nurs*. 2010;29(6):297-306. doi:10.1097/dcc.0b013e3181f0c43c.
- Dev R, Coulson L, Del Fabbro E et al. A prospective study of family conferences: Effects of patient presence on emotional expression and end-of-life discussions. *J Pain Symptom Manage*. 2013;46(4):536-545. doi:10.1016/j.jpainsymman.2012.10.280.
- Dougherty C, Pyper G, Au D, Levy W, Sullivan M. Drifting in a shrinking future. *J Cardiovasc Nurs*. 2007;22(6):480-487. doi:10.1097/01.jcn.0000297384.36873.52.
- Gardner D. Cancer in a dyadic context: Older couples' negotiation of ambiguity and search for meaning at end of life. *J Soc Work End Life Palliat Care*. 2008;4(2):135-159. doi:10.1080/15524250802353959.
- Gordon T. Good grief: Exploring the dimensionality of grief experiences and social work support. *J Soc Work End Life Palliat Care*. 2013;9(1):27-42. doi:10.1080/15524256.2012.758607.
- Guo Q, Jacelon C. An integrative review of dignity in end-of-life care. *Palliat Med*. 2014;28(7):931-940. doi:10.1177/0269216314528399.
- Gutierrez K. Experiences and needs of families regarding prognostic communication in an intensive care unit. *Crit Care Nurs Q*. 2012;35(3):299-313. doi:10.1097/cnq.0b013e318255ee0d.
- Hansen L, Rosenkranz S, Mularski R, Leo M. Family perspectives on overall care in the intensive care unit. *Nurs Res*. 2016;65(6):446-454. doi:10.1097/nnr.0000000000000179.
- Haxton J, Boelk A. Serving families on the frontline: Challenges and creative solutions in rural hospice social work. *Soc Work Health Care*. 2010;49(6):526-550. doi:10.1080/00981381003648422.
- Haxton JE, Boelk AZ. Serving families on the frontline: challenges and creative solutions in rural hospice social work. *Soc Work Health Care*. 2010;49(6):526-560.
- Hebert R, Copeland V, Schulz R, Amato C, Arnold R. Preparing family caregivers for the death of a loved one: Implications for hospital social workers. *J Soc Work End Life Palliat Care*. 2008;4(4):269-285. doi:10.1080/15524250903081533.

- Hebert R, Schulz R, Copeland V, Arnold R. Preparing family caregivers for death and bereavement: Insights from caregivers of terminally ill patients. *J Pain Symptom Manage*. 2009;37(1):3-12. doi:10.1016/j.jpainsymman.2007.12.010.
- Hopeck P, Harrison T. Reframing, refocusing, referring, reconciling, and reflecting: Exploring conflict resolution strategies in end-of-life situations. *Health Commun*. 2016;32(2):240-246. doi:10.1080/10410236.2015.1099509.
- Kayser K, DeMarco R, Stokes C, DeSanto-Madeya S, Higgins P. Delivering palliative care to patients and caregivers in inner-city communities: Challenges and opportunities. *Palliat Support Care*. 2013;12(05):369-378. doi:10.1017/s1478951513000230.
- Kelemen A, Cagle J, Groninger H. Screening for intimacy concerns in palliative care population: Findings from a pilot study. *J Palliat Med*. 2016;19(10):1102-1105. doi:10.1089/jpm.2016.0092.
- Kintzle S, Bride BE. Intervention following a sudden death: The social work-medical examiner model. *Health Soc Work*. 2010;35(3):221-224.
- Kirkendall A, Waldrop D, Moone R. Caring for people with intellectual disabilities and life-limiting illness: Merging person-centered planning and patient-centered, family-focused care. *J Soc Work End Life Palliat Care*. 2012;8(2):135-150. doi:10.1080/15524256.2012.685440.
- Ko E, Hohman M, Lee J, Ngo A, Woodruff S. Feasibility and acceptability of a brief motivational stage-tailored intervention to advance care planning. *Am J Hosp Palliat Care*. 2016;33(9):834-842. doi:10.1177/1049909115593736.
- Kramer BT, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: The experiences of spouses and adults children of persons with lung cancer. *Gerontologist*. 2010;50 (2):215-225.
- Lankarani-Fard A, Knapp H, Lorenz K et al. Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: The go wish card game. *J Pain Symptom Manage*. 2010;39(4):637-643. doi:10.1016/j.jpainsymman.2009.08.011.
- Lingler J, Sherwood P, Crighton M, Song M, Happ M. Conceptual challenges in the study of caregiver-care recipient relationships. *Nurs Res*. 2008;57(5):367-372. doi:10.1097/01.nnr.0000313499.99851.0c.
- Lofgren S, Friedman R, Ghermay R et al. Integrating early palliative care for patients with HIV. *Am J Hosp Palliat Care*. 2014;32(8):829-834. doi:10.1177/1049909114550391.
- LoPresti M, Dement F, Gold H. End-of-life care for people with cancer from ethnic minority groups. *Am J Hosp Palliat Care*. 2014;33(3):291-305. doi:10.1177/1049909114565658.
- McCormick A, Curtis J, Stowell-Weiss P, Toms C, Engelberg R. Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *J Palliat Med*. 2010;13(3):297-304. doi:10.1089/jpm.2009.0204.
- McCormick A, Engelberg R, Curtis J. Social workers in palliative care: Assessing activities and barriers in the intensive care unit. *J Palliat Med*. 2007;10(4):929-937. doi:10.1089/jpm.2006.0235.
- McCormick AJ, Curtis JR, Stowell-Weiss P, Toms CE, R. Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *J Palliat Med*. 2010;13(3):297-304.
- Meert K, Briller S, Myers Schim S, Thurston C, Kabel A. Examining the needs of bereaved parents in the pediatric intensive care unit: A qualitative study. *Death Stud*. 2009;33(8):712-740. doi:10.1080/07481180903070434.

- Moore R, Hallenbeck J. Narrative empathy and how dealing with stories help: Creating a space for empathy in culturally diverse care settings. *J Pain Symptom Manage*. 2010;40(3):471-476. doi:10.1016/j.jpainsymman.2010.03.013.
- National Association of Social Workers. Certified Hospice and Palliative Social Work (CHP-SW) 2009. <http://naswdc.org/credentials/credentials/chpse.asp>. Accessed November 30, 2012.
- National Association of Social Workers. *Social Work Speaks, NASW Policy Statements, 2012-2014*. 9th ed. Washington, District of Columbia: NASW Press; 2012.
- National Association of Social Workers. Social Workers in Hospice and Palliative Care: Occupational Profile. 2010. <http://workforce.socialworkers.org/studies/profiles/Hospice.pdf>. Accessed November 30, 2012.
- Otis-Green S, Sidhu R, Del Ferraro C, Ferrell B. Integrating social work into palliative care for lung cancer patients and families: A multidimensional approach. *J Psychosoc Oncol*. 2014;32(4):431-446. doi:10.1080/07347332.2014.917140.
- Parker Oliver D, Washington K, Demiris G, Wittenberg-Lyles E, Novak H. Problem solving interventions: An opportunity for hospice social workers to better meet caregiver needs. *J Soc Work End Life Palliat Care*. 2012;8(1):3-9. doi:10.1080/15524256.2012.650669.
- Parrish M, Cárdenas Y, Epperhart R et al. Public hospital palliative social work: Addressing patient cultural diversity and psychosocial needs. *J Soc Work End Life Palliat Care*. 2012;8(3):214-228. doi:10.1080/15524256.2012.708113.
- Perry B, Pescosolido B. Social network activation: The role of health discussion partners in recovery from mental illness. *Social Science & Medicine*. 2015;125:116-128. doi:10.1016/j.socscimed.2013.12.033.
- Powazki R, Walsh D. The family conference in palliative medicine. *Am J Hosp Palliat Care*. 2013;31(6):678-684. doi:10.1177/1049909113499444.
- Prince-Paul M. Relationships among communicative acts, social well-being, and spiritual well-being on the quality of life at the end of life in patients with cancer enrolled in hospice. *J Palliat Med*. 2008;11(1):20-25. doi:10.1089/jpm.2007.0119.
- Reith M, Payne M. *Social Work in End of Life and Palliative Care*. Chicago, Illinois: Lyceum Books; 2009.
- Riggs J, Woodby L, Burgio K, Amos Bailey F, Williams B. "Don't Get Weak in Your Compassion": Bereaved next of kin's suggestions for improving end-of-life care in Veterans Affairs Medical Centers. *J Am Geriatr Soc*. 2014;62(4):642-648. doi:10.1111/jgs.12764.
- Rosenberg A, Postier A, Osenga K et al. Long-term psychosocial outcomes among bereaved siblings of children with cancer. *J Pain Symptom Manage*. 2015;49(1):55-65. doi:10.1016/j.jpainsymman.2014.05.006.
- Sanders S, Bullock K, Broussard C. Exploring professional boundaries in end-of-life care: Considerations for hospice social workers and other members of the team. *J Soc Work End Life Palliat Care*. 8(1):2012;1:10-28.
- Schroepfer T. Critical events in the dying process: The potential for physical and psychosocial suffering. *J Palliat Med*. 2007;10(1):136-147. doi:10.1089/jpm.2006.0157.
- Scott A, Caughlin J. Enacted goal attention in family conversations about end-of-life health decisions. *Commun Monogr*. 2014;81(3):261-284. doi:10.1080/03637751.2014.925568.

Appendix IV: Scoping Review

- Simons K, Park-Lee E. Social work students' comfort with end-of-life care. *J Soc Work End Life Palliat Care*. 2009;5(1-2):34-48.
- Social Work Policy Institute. Hospice social work: Linking policy, practice, and research. A report from the March 25, 2010 symposium. 2010. <http://www.socialworkpolicy.org/wp-content/uploads/2010/09/SWPIHospice-Report-FINAL.pdf>. Accessed November 30, 2012.
- Stanley P, Hurst M. Narrative palliative care: A method for building empathy. *J Soc Work End Life Palliat Care*. 2011;7(1):39-55.
- Stevenson M, Achille M, Lugasi T. Pediatric palliative care in Canada and the United States: A qualitative metasummary of the needs of patients and families. *J Palliat Med*. 2013;16(5):566-577. doi:10.1089/jpm.2011.0076.
- Su C, McMahan R, Williams B, Sharma R, Sudore R. Family matters: Effects of birth order, culture, and family dynamics on surrogate decision-making. *J Am Geriatr Soc*. 2014;62(1):175-182. doi:10.1111/jgs.12610.
- Waldrop DP. Evidence-based psychosocial treatment at end of life. *J Gerontol Soc Work*. 2008;50(S1):267-292.
- Weaver M, Heinze K, Bell C et al. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. *Palliat Med*. 2015;30(3):212-223. doi:10.1177/0269216315583446.
- Weidner NJ, Cameron M, Lee RC, McBride J, Mathias EJ, Byczkowski TL. End-of-life care for the dying child: What matters most to parents. *J Palliat Care*. 2011;27(4):279-287.
- Werner-Lin A, Biank N. Holding parents so they can hold their children: Grief work with surviving spouses to support parentally bereaved children. *OMEGA*. 2013;66(1):1-16. doi:10.2190/om.66.1.a.
- Williams B, Bailey F, Noh H, Woodby L, Wittich A, Burgio K. "I Was Ready to Take Him Home": Next-of-kin's accounts of loved one's death during hospice and palliative care discussions in Veterans Affairs Medical Centers. *J Soc Work End Life Palliat Care*. 2015;11(1):50-73. doi:10.1080/15524256.2015.1021070.
- Williams S, Williams C, Zimmerman S, Munn J, Dobbs D, Sloane P. Emotional and physical health of informal caregivers of residents at end of life: The role of social support. *J Gerontol B Psychol Sci Soc Sci*. 2008;63(3):S171-S183. doi:10.1093/geronb/63.3.s171.
- Wittenberg-Lyles E, Goldsmith J, Ragan S. The shift to early palliative care. *Clin J Oncol Nurs*. 2011;15(3):304-310. doi:10.1188/11.cjon.304-310.

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

- Alcorn SR, Balboni MJ, Prigerson HG, et al. "If God wanted me yesterday, I wouldn't be here today:" Religious and spiritual themes in patients' experiences of advanced cancer. *J Palliat Med*. 2010;13(5):581-588.
- Anandarajah G, Roseman J, Lee D, Dhandhanian N. A 10-year longitudinal study of effects of a multifaceted residency spiritual care curriculum: Clinical ability, professional formation, end of life, and culture. *J Pain Symptom Manage*. 2016;52(6):859-872.e1. doi:10.1016/j.jpainsymman.2016.06.006.

- Ando M, Morita T, Miyashita M, Sanjo M, Kira H, Shima Y. Effects of bereavement life review on spiritual well-being and depression. *J Pain Symptom Manage*. 2010;40(3):453-459.
- Astrow A, Sharma R, Huang Y, Xu Y, Sulmasy D. A Chinese version of the spiritual needs assessment for patients survey instrument. *J Palliat Med*. 2012;15(12):1297-1315. doi:10.1089/jpm.2012.0131.
- Bai M, Lazenby M. A systematic review of associations between spiritual well-being and quality of life at the scale and factor levels in studies among patients with cancer. *J Palliat Med*. 2015;18(3):286-298. doi:10.1089/jpm.2014.0189.
- Balboni M, Puchalski C, Peteet J. The relationship between medicine, spirituality and religion: Three models for integration. *J Relig Health*. 2014;53(5):1586-1598. doi:10.1007/s10943-014-9901-8.
- Balboni M, Sullivan A, Amobi A et al. Why Is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, physicians and the role of training. *J Clin Oncol*. 2013;31(4):461-467. doi:10.1200/jco.2012.44.6443.
- Balboni T, Balboni M, Paulk ME, et al. Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer*. 2011;117(23).
- Balboni T, Fitchett G, Handzo G et al. State of the science of spirituality and palliative care research part II: Screening, assessment, and interventions. *J Pain Symptom Manage*. 2017;54(3):441-453. doi:10.1016/j.jpainsymman.2017.07.029.
- Balboni T, Vanderwerker L, Block S et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol*. 2007;25(5):555-560. doi:10.1200/jco.2006.07.9046.
- Balboni T, Paulk M, Balboni M, et al. Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. *J Clin Oncol*. 2009;28(3):445-452.
- Bekelman D, Dy S, Becker D et al. Spiritual well-being and depression in patients with heart failure. *J Gen Intern Med*. 2007;22(4):470-477. doi:10.1007/s11606-006-0044-9.
- Bekelman DB, Rumsfeld JA, Havranek EP, et al. Symptom burden, depression, and spiritual well-being: A comparison of heart failure and advanced cancer patients. *J Gen Intern Med*. 2009;24(5):592-598.
- Bergman J, Fink A, Kwan L, Maliski S, Litwin MS. Spirituality and end-of-life care in disadvantaged men dying of prostate cancer. *World J Urol*. 2011;29(1):43-49.
- Bernstein K, D'Angelo L, Lyon M. An exploratory study of HIV+ adolescents' spirituality: Will you pray with me?. *J Relig Health*. 2012;52(4):1253-1266. doi:10.1007/s10943-012-9565-1.
- Bodek H. Facilitating the provision of quality spiritual care in palliative care. *OMEGA*. 2013;67(1-2):37-41. doi:10.2190/om.67.1-2.d.
- Borneman T, Bluman RO, Klein L, Thomas J, Ferrell B. Spiritual care for Jewish patients facing a life-threatening illness. *J Palliat Care*. 2013;29(1):58.
- Borneman T, Ferrell B, Otis-Green S, Baird P, Puchalski C. Evaluation of the FICA Spiritual Assessment Tool (501). *J Pain Symptom Manage*. 2010;39(2):406-407. doi:10.1016/j.jpainsymman.2009.11.149.
- Borneman T, Ferrell BR, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. *J Pain Symptom Manage*. 2012;40(2):163-173.

Appendix IV: Scoping Review

- Burke L, Neimeyer R, Young A, Bonin E, Davis N. Complicated spiritual grief II: A deductive inquiry following the loss of a loved one. *Death Stud.* 2013;38(4):268-281. doi:10.1080/07481187.2013.829373.
- Burke L, Neimeyer R. Spiritual distress in bereavement: Evolution of a research program. *Religions.* 2014;5(4):1087-1115. doi:10.3390/rel5041087.
- Callahan A. A relational model for spiritually-sensitive hospice care. *J Soc Work End Life Palliat Care.* 2013;9(2-3):158-179. doi:10.1080/15524256.2013.794051.
- Callahan AM. Spiritually-sensitive care in hospice social work. *J Soc Work End Life Palliat Care.* 2009;5(3-4):169-185.
- Camargos M, Paiva C, Barroso E, Carneseca E, Paiva B. Understanding the differences between oncology patients and oncology health professionals concerning spirituality/religiosity. *Medicine (Baltimore).* 2015;94(47):e2145. doi:10.1097/md.0000000000002145.
- Carrion I, Nedjat-Haiem F, Macip-Billbe M, Black R. "I Told Myself to Stay Positive" perceptions of coping among Latinos with a cancer diagnosis living in the United States. *Am J Hosp Palliat Care.* 2016;34(3):233-240. doi:10.1177/1049909115625955.
- Churchill L. Embracing a broad spirituality in end of life discussions and advance care planning. *J Relig Health* 2014;54(2):759-764. doi:10.1007/s10943-014-9988-y.
- Clayton J, Butow P, Arnold R, Tattersall M. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer.* 2005;103(9):1965-1975. doi:10.1002/cncr.21011.
- Cooper R, Ferguson A, Bodurtha J, Smith T. AMEN in challenging conversations: Bridging the gaps between faith, hope, and medicine. *J Oncol Pract.* 2014;10(4):e191-e195. doi:10.1200/jop.2014.001375.
- Delgado-Guay M, Rodriguez-Nunez A, De la Cruz V et al. Advanced cancer patients' reported wishes at the end of life: a randomized controlled trial. *Support Care Cancer.* 2016;24(10):4273-4281. doi:10.1007/s00520-016-3260-9.
- Delgado-Guay MO, Hui D, Parsons HA, et al. Spirituality, religiosity, and spiritual pain in advanced cancer patients. *J Pain Symptom Manage.* 2011;41(6):986-994.
- Doka KJ. Religion and spirituality: Assessment and intervention. *J Soc Work End Life Palliat Care.* 2011;7(1):99-109.
- Ellington L, Reblin M, Ferrell B et al. The religion of "I Don't Know". *OMEGA.* 2015;72(1):3-19. doi:10.1177/0030222815574689.
- Elliott B, Gessert C, Larson P, Russ T. Religious beliefs and practices in end-stage renal disease: Implications for clinicians. *J Pain Symptom Manage.* 2012;44(3):400-409. doi:10.1016/j.jpainsymman.2011.09.019.
- Emanuel L, Handzo G, Grant G et al. Workings of the human spirit in palliative care situations: A consensus model from the Chaplaincy Research Consortium. *BMC Palliative Care.* 2015;14(1). doi:10.1186/s12904-015-0005-3.
- Epstein-Peterson Z, Sullivan A, Enzinger A et al. Examining forms of spiritual care provided in the advanced cancer setting. *Am J Hosp Palliat Care.* 2014;32(7):750-757. doi:10.1177/1049909114540318.

- Falb M, Pargament K. Buddhist coping predicts psychological outcomes among end-of-life caregivers. *Psycholog Relig Spiritual*. 2013;5(4):252-262. doi:10.1037/a0032653.
- Fang M, Sixsmith J, Sinclair S, Horst G. A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review. *BMC Geriatr*. 2016;16(1). doi:10.1186/s12877-016-0282-6.
- Fanslow-Brunjes C. Beyond pain - The search for hope in the patient's journey. *Asian Pac J Cancer Prev*. 2010; 11 MECC Supplement, 63-66.
- 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. doi:10.1089/jpm.2016.0138.
- Fitchett G, Lyndes KA, Cadge W, Berlinger N, Flanagan E, Misasi J. The role of professional chaplains on pediatric palliative care teams: Perspectives from physicians and chaplains. *J Palliat Med*. 2011;14 (6):704-707.
- George L, Park C. Does spirituality confer meaning in life among heart failure patients and cancer survivors?. *Psycholog Relig Spiritual*. 2017;9(1):131-136. doi:10.1037/rel0000103.
- Gomez-Castillo B, Hirsch R, Groninger H et al. Increasing the number of outpatients receiving spiritual assessment: A pain and palliative care service quality improvement project. *J Pain Symptom Manage*. 2015;50(5):724-729. doi:10.1016/j.jpainsymman.2015.05.012.
- Harris G, Allen R, Dunn L, Parmelee P. "Trouble Won't Last Always": Religious coping and meaning in the stress process. *Qual Health Res*. 2013;23(6):773-781. doi:10.1177/1049732313482590.
- HealthCare Chaplaincy Network. Spiritual Care: What it means, why it matters in health care. 2016; HealthCare Chaplaincy Network.
- Hebert R, Dang Q, Schulz R. Religious beliefs and practice are associated with better mental health in family caregivers of patients with dementia: Findings from the REACH study. *Am J Geriatr Psychiatry*. 2007;15(4):292-300. doi:10.1097/01.jpg.0000247160.11769.ab.
- Hexem KR, Mollen CJ, Carroll K, Lanctot DA, Feudtner C. How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *J Palliat Med*. 2011;14(1):39-44.
- Hui D, de la Cruz M, Thorney S, Parsons HA, Delgado-Guay M, Bruera E. The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. *Am J Hosp Palliat Care*. 2011;28(4):264-270.
- Johnson KS, Tulskey JA, Hays JC, et al. Which domains of spirituality are associated with anxiety and depression in patients with advanced illness? *J Gen Intern Med*. 2011;26(7):751-758.
- Kamper R, Van Cleve L, Savedra M. Children with advanced cancer: Responses to a spiritual quality of life interview. *J Spec Pediatr Nurs*. 2010;15(4):301-306.
- Karches K, Chung G, Arora V, Meltzer D, Curlin F. Religiosity, spirituality, and end-of-life planning: A single-site survey of medical inpatients. *J Pain Symptom Manage*. 2012;44(6):843-851. doi:10.1016/j.jpainsymman.2011.12.277.
- Kiesewetter I, Schulz C, Bausewein C, Fountain R, Schmitz A. Patients' perception of types of errors in palliative care – Results from a qualitative interview study. *BMC Palliat Care*. 2016;15(1). doi:10.1186/s12904-016-0141-4.
- Kim J, Puchalski CM. Development and validation of a scale assessing spiritual needs for Korean patients with cancer. *J Palliat Care*. 2008 Dec 1;24(4):240.

Appendix IV: Scoping Review

- King S, Fitchett G, Murphy P, Pargament K, Harrison D, Loggers E. Determining best methods to screen for religious/spiritual distress. *Support Care Cancer*. 2016;25(2):471-479. doi:10.1007/s00520-016-3425-6.
- Knapp C, Madden V, Wang H, Curtis C, Sloyer P, Shenkman E. Spirituality of parents in palliative care. *J Palliat Med*. 2011;14(4):437-443.
- Kolva E, Rosenfeld B, Pessin H, Breitbart W, Brescia R. Anxiety in terminally ill cancer patients. *J Pain Symptom Manage*. 2011;42(5):691-701. doi:10.1016/j.jpainsymman.2011.01.013.
- LeBaron V, Smith P, Quiñones R et al. How community clergy provide spiritual care: Toward a conceptual framework for clergy end-of-life education. *J Pain Symptom Manage*. 2016;51(4):673-681. doi:10.1016/j.jpainsymman.2015.11.016.
- Lin H. Searching for meaning. *Cancer Nurs*. 2008;31(3):250-258. doi:10.1097/01.ncc.0000305726.72969.07.
- Little NK. Clinical pastoral education as professional training: some entrance, curriculum and assessment implications. *J Pastoral Care Counsel*. 2010;64(3):5.1-8.
- Massey K, Barnes M, Villines D et al. What do I do? Developing a taxonomy of chaplaincy activities and interventions for spiritual care in intensive care unit palliative care. *BMC Palliat Care*. 2015;14(1). doi:10.1186/s12904-015-0008-0.
- McEvoy M, Schlair S, Sidlo Z, Burton W, Milan F. Assessing third-year medical students' ability to address a patient's spiritual distress using an OSCE case. *Acad Med*. 2014;89(1):66-70. doi:10.1097/acm.0000000000000061.
- Medical Student Section. Addressing Patient Spirituality in Medicine, American Medical Association Resolution 2016, Resolution 004.
- Milstein J, Raingruber B. Choreographing the end of life in a neonate. *Am J Hosp Palliat Care*. 2007;24(5):343-349. doi:10.1177/1049909107305645.
- Murray RP. Spiritual care beliefs and practices of special care and oncology RNs at patients' end of life. *J Hosp Palliat Nurs*. 2010;12(1):51-58.
- Murray S, Kendall M, Boyd K, Grant L, Highet G, Sheikh A. Archetypal trajectories of social, psychological, and spiritual wellbeing and distress in family care givers of patients with lung cancer: Secondary analysis of serial qualitative interviews. *BMJ*. 2010;340(jun09 4):c2581-c2581. doi:10.1136/bmj.c2581.
- Otis-Green S, Ferrell B, Borneman T, Puchalski C, Uman G, Garcia A. Integrating spiritual care within palliative care: An overview of nine demonstration projects. *J Palliat Med*. 2012;15(2):154-162. doi:10.1089/jpm.2011.0211.
- Otis-Green S. Integrating spirituality into care at the end of life: Providing person-centered quality care. *Death Stud*. 2015;39(3):185-187. doi:10.1080/07481187.2014.899425.
- Petersen C, Callahan M, McCarthy D, Hughes R, White-Traut R, Bansal N. An online educational program improves pediatric oncology nurses' knowledge, attitudes, and spiritual care competence. *J Ped Oncol Nurs*. 2017;34(2):130-139. doi:10.1177/1043454216646542.
- Piotrowski L. Advocating and educating for spiritual screening assessment and referrals to chaplains. *OMEGA*. 2013;67(1-2):185-192. doi:10.2190/om.67.1-2.v.

- Puchalski C, Ferrell B, Virani R et al. Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *J Palliat Med*. 2009;12(10):885-904. doi:10.1089/jpm.2009.0142.
- Puchalski C, Vitillo R, Hull S, Reller N. Improving the spiritual dimension of whole person care: Reaching national and international consensus. *J Palliat Med*. 2014;17(6):642-656. doi:10.1089/jpm.2014.9427.
- Puchalski C. Spirituality and the care of patients at the end-of-life: An essential component of care. *OMEGA*. 2008;56(1):33-46. doi:10.2190/om.56.1.d.
- Puchalski C. Spirituality in the cancer trajectory. *Ann Oncol*. 2012;23(suppl 3):49-55. doi:10.1093/annonc/mds088.
- Reblin M, Otis-Green S, Ellington L, Clayton M. Strategies to support spirituality in health care communication. *J of Hol Nurs*. 2014;32(4):269-277. doi:10.1177/0898010114531856.
- Robinson M, Thiel M, Shirkey K, Zurakowski D, Meyer E. Efficacy of training interprofessional spiritual care generalists. *J Palliat Med*. 2016;19(8):814-821. doi:10.1089/jpm.2015.0373.
- Sinclair S, Beamer K, Hack T et al. Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliat Med*. 2016;31(5):437-447. doi:10.1177/0269216316663499.
- Sinclair S, McConnell S, Raffin Bouchal S et al. Patient and healthcare perspectives on the importance and efficacy of addressing spiritual issues within an interdisciplinary bone marrow transplant clinic: A qualitative study. *BMJ Open*. 2015;5(11):e009392. doi:10.1136/bmjopen-2015-009392.
- Smith-Stoner M. End-of-Life Preferences for Atheists. *J Palliat Med*. 2007;10(4):923-928. doi:10.1089/jpm.2006.0197.
- Smyre C, Yoon J, Rasinski K, Curlin F. Limits and responsibilities of physicians addressing spiritual suffering in terminally ill patients. *J Pain Symptom Manage*. 2015;49(3):562-569. doi:10.1016/j.jpainsymman.2014.06.016.
- Steinhauser K, Fitchett G, Handzo G et al. State of the science of spirituality and palliative care research part I: Definitions, measurement, and outcomes. *J Pain Symptom Manage*. 2017;54(3):428-440. doi:10.1016/j.jpainsymman.2017.07.028.
- Stephenson P, Berry D. Describing spirituality at the end of life. *West J Nurs Res*. 2014;37(9):1229-1247. doi:10.1177/0193945914535509.
- Sun V, Kim J, Irish T et al. Palliative care and spiritual well-being in lung cancer patients and family caregivers. *Psychooncology*. 2015;25(12):1448-1455. doi:10.1002/pon.3987.
- Talley J, Magie R. The integration of the "Spirituality in Medicine" curriculum into the osteopathic communication at Kansas City University of Medicine and Biosciences. *Acad Med*. 2014;89(1):43-47. doi:10.1097/acm.0000000000000078.
- The PEW Charitable Trusts. How Faith Communities Facilitate Conversations around End-of-Life Concerns. 2017; <http://www.pewtrusts.org/en/projects/improving-end-of-life-care>
- Vanderweele, T. Initiative on Health, Religion, and Spirituality. Retrieved from <https://www.hsph.harvard.edu/tyler-vanderweele/religion-and-public-health-seminar/>
- Vehling S, Kamphausen A, Oechsle K, Hroch S, Bokemeyer C, Mehnert A. The preference to discuss expected survival is associated with loss of meaning and purpose in terminally ill cancer patients. *J Palliat Med*. 2015;18(11):970-976. doi:10.1089/jpm.2015.0112.

Appendix IV: Scoping Review

- Vilalta A, Valls J, Porta J, Viñas J. Evaluation of spiritual needs of patients with advanced cancer in a palliative care unit. *J Palliat Med*. 2014;17(5):592-600. doi:10.1089/jpm.2013.0569.
- Vivat B. Measures of spiritual issues for palliative care patients: a literature review. *Palliat Med*. 2008;22(7):859-868. doi:10.1177/0269216308095990.
- Wachholtz A, Pearce M, Koenig H. Exploring the relationship between spirituality, coping, and pain. *J Behav Med*. 2007;30(4):311-318. doi:10.1007/s10865-007-9114-7.
- Wall R, Engelberg R, Gries C, Glavan B, Curtis J. Spiritual care of families in the intensive care unit. *Crit Care Med*. 2007;35(4):1084-1090. doi:10.1097/01.ccm.0000259382.36414.06.
- Winkelman W, Lauderdale K, Balboni M et al. The relationship of spiritual concerns to the quality of life of advanced cancer patients: Preliminary findings. *J Palliat Med*. 2011;14(9):1022-1028. doi:10.1089/jpm.2010.0536.
- Wittenberg E, Ferrell B, Goldsmith J, Buller H. Provider difficulties with spiritual and forgiveness communication at the end of life. *Am J Hosp Palliat Care*. 2016;33(9):843-848. doi:10.1177/1049909115591811.
- Yaghoobzadeh A, Soleimani M, Allen K, Chan Y, Herth K. Relationship between spiritual well-being and hope in patients with cardiovascular disease. *J Relig Health*. 2017. doi:10.1007/s10943-017-0467-0.
- Young W, Nadarajah S, Skeath P, Berger A. Spirituality in the context of life-threatening illness and life-transforming change. *Palliat Support Care*. 2014;13(03):653-660. doi:10.1017/s1478951514000340.
- Zollfrank A, Trevino K, Cadge W et al. Teaching health care providers to provide spiritual care: A pilot study. *J Palliat Med*. 2015;18(5):408-414. doi:10.1089/jpm.2014.0306.

Domain 6: Cultural Aspects of Care

- 2016 National Healthcare Quality and Disparities Report. Rockville, MD: Agency for Healthcare Research and Quality; July 2017. *AHRQ Pub*.
- Adames H, Chavez-Dueñas N, Fuentes M, Salas S, Perez-Chavez J. Integration of Latino/a cultural values into palliative health care: A culture centered model. *Palliat Support Care*. 2013;12(02):149-157. doi:10.1017/s147895151300028x.
- American Association of Colleges of Nursing. *Culture Competencies for Graduate Nursing Students*. Washington, District of Columbia: American Association of Colleges of Nursing; 2010.
- Anderson N, Andrews M, Bent K et al. Chapter 5: Culturally based health and illness beliefs and practices across the lifespan. Based Health and Illness Beliefs and Practices Across the Life Span. *J Transcul Nurs*. 2010;21(4_suppl):152S-235S. doi:10.1177/1043659610381094.
- Andrews M, Boyle J, eds. *Transcultural Concepts of Nursing Care*. 6th edition ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2011.
- Anngela-Cole L, Ka'Opua L, Busch M. Issues confronting social workers in the provision of palliative care services in the Pacific Basin (Hawai'i and the U.S. Affiliated Pacific Island Nations and Territories). *J Soc Work End Life Palliat Care*. 2010;6(3-4):150-163.
- Arenella C. Hospice and palliative care for African Americans: Overcoming disparities. *J Palliat Med*. 2016;19(2):126-126. doi:10.1089/jpm.2015.0310.

- Arriaza P, Martin S, Csikai E. An assessment of hospice bereavement programs for Hispanics. *J Soc Work End Life Palliat Care*. 2011;7(2-3):121-138. doi:10.1080/15524256.2011.593151.
- Arthur D. Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective. *J Soc Work End Life Palliat Care*. 2015;11(2):178-201. doi:10.1080/15524256.2015.1074141.
- Barclay J, Blackhall L, Tulsky J. Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med*. 2007;10(4):958-977. doi:10.1089/jpm.2007.9929.
- Barnato A, Anthony D, Skinner J, Gallagher P, Fisher E. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med*. 2009;24(6):695-701. doi:10.1007/s11606-009-0952-6.
- Berkman C, Ko E. Preferences for disclosure of information about serious illness among older Korean American immigrants in New York City. *J Palliat Med*. 2009;12(4):351-357. doi:10.1089/jpm.2008.0236.
- Berlacher K, Arnold R, Reitschuler-Cross E, Teuteberg J, Teuteberg W. The impact of communication skills training on cardiology fellows' and attending physicians' perceived comfort with difficult conversations. *J Palliat Med*. 2017;20(7):767-769. doi:10.1089/jpm.2016.0509.
- Berry-Cabán C, Crespo H. Cultural competency as a skill for health care providers. *Hisp Health Care Int*. 2008;6(3):115-121. doi:10.1891/1540-4153.6.3.115.
- Bhat A, Wehbe-Alamah H, McFarland M, Filter M, Keiser M. Advancing cultural assessments in palliative care using web-based education. *J Hosp Palliat Nurs*. 2015;17(4):348-355. doi:10.1097/njh.0000000000000175.
- Black H, Santanello H, Rubinstein R. A pragmatic belief system in family meaning-making after death. *Death Stud*. 2014;38(8):522-530. doi:10.1080/07481187.2013.879754.
- Boucher N, Guadalupe E, Lara L, Alejandro M. Health care and end-of-life decisions: Community engagement with adults in east Harlem. *J Community Health*. 2014;39(6):1032-1039. doi:10.1007/s10900-014-9929-4.
- Boucher N. Direct engagement with communities and interprofessional learning to factor culture into end-of-life health care delivery. *Am J Public Health*. 2016;106(6):996-1001. doi:10.2105/ajph.2016.303073.
- Boucher N. Faith, family, filiality, and fate. *J Applied Gerontol*. 2016;36(3):351-372. doi:10.1177/0733464815627958.
- Boucher N. Supporting Muslim patients during advanced illness. *Perm J*. 2017. doi:10.7812/tpj/16-190.
- Braun U, Beyth R, Ford M, McCullough L. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *J Gen Intern Med*. 2008;23(3):267-274. doi:10.1007/s11606-007-0487-7.
- Bravo V. Coping with dying and deaths at home: how undocumented migrants in the United States experience the process of transnational grieving. *Mortality*. 2016;22(1):33-44. doi:10.1080/13576275.2016.1192590.
- Bryan Y. Communicating with Spanish-speaking patients. *JAMA*. 2009;301(22):2327. doi:10.1001/jama.2009.766.
- Bullock K. The Influence of Culture on End-of-Life Decision Making. *J Soc Work End Life Palliat Care*. 2011;7(1):83-98. doi:10.1080/15524256.2011.548048.

- Cagle J, LaMantia M, Williams S, Pek J, Edwards L. Predictors of preference for hospice care among diverse older adults. *Am J Hosp Palliat Care*. 2015;33(6):574-584. doi:10.1177/1049909115593936.
- Campbell L, Andrews N, Scipio C, Flores B, Feliu M, Keefe F. Pain coping in Latino populations. *J Pain*. 2009;10(10):1012-1019. doi:10.1016/j.jpain.2009.03.004.
- Carr D. Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable?. *OMEGA*. 2011;63(1):1-20. doi:10.2190/om.63.1.a.
- Carrion I, Cagle J, Van Dussen D, Culler K, Hong S. Knowledge about hospice care and beliefs about pain management. *Am J Hosp Palliat Care*. 2014;32(6):647-653. doi:10.1177/1049909114536023.
- Carrion I, Nedjat-Haiem F, Macip-Billbe M, Black R. "I Told Myself to Stay Positive" perceptions of coping among Latinos with a cancer diagnosis living in the United States. *Am J Hosp Palliat Care*. 2016;34(3):233-240. doi:10.1177/1049909115625955.
- Carrion I, Nedjat-Haiem F, Marquez D. Examining cultural factors that influence treatment decisions: A pilot study of Latino men with cancer. *J Cancer Educ*. 2013;28(4):729-737. doi:10.1007/s13187-013-0522-9.
- Carrion I, Nedjat-Haiem F. Caregiving for older Latinos at end of life. *Am J Hosp Palliat Care*. 2012;30(2):183-191. doi:10.1177/1049909112448227.
- Carrion I, Park N, Lee B. Hospice use among African Americans, Asians, Hispanics, and Whites. *Am J Hosp Palliat Care*. 2011;29(2):116-121. doi:10.1177/1049909111410559.
- Carteret, M. "Cross-cultural Values of Latino Families." *Dimensions of Culture*. 2008. Web. 21 Oct. 2010.
- Cartwright C, Hughes M, Lienert T. End-of-life care for gay, lesbian, bisexual and transgender people. *Cult Health Sex*. 2012;14(5):537-548.
- Chan C, Ho A, Leung P et al. The blessings and the curses of filial piety on dignity at the end of life: Lived experience of Hong Kong Chinese adult children caregivers. *J Ethn Cult Divers Soc Work*. 2012;21(4):277-296. doi:10.1080/15313204.2012.729177.
- Chettih M. Turning the lens inward: Cultural competence and providers' values in health care decision making. *Gerontologist*. 2012;52(6):739-747. doi:10.1093/geront/gns008.
- Coats H, Crist J, Berger A, Sternberg E, Rosenfeld A. African American elders' serious illness experiences. *Qual Health Res*. 2016;27(5):634-648. doi:10.1177/1049732315620153.
- Colclough Y, Young H. Decision making at end of life among Japanese American families. *J Fam Nurs*. 2007;13(2):201-225. doi:10.1177/1074840707300761.
- Colclough Y. Native American death taboo: Implications for health care providers. *Am J Hosp Palliat Care*. 2016;34(6):584-591. doi:10.1177/1049909116638839.
- Colón M. Acculturation and attitudes of Latinos toward hospice. *J Soc Work End Life Palliat Care*. 2012;8(3):229-248.
- Committee on Advancing Pain Research. A call for cultural transformation of attitudes toward pain and its prevention and management. *J Pain Palliat Care Pharmacother*. 2011;25(4):365-369. doi:10.3109/15360288.2011.621516.
- Coolen, P.R. Cultural relevance in end-of-life care. *Ethnomed*. 2012. Retrieved from <https://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care>

- Cruz-Oliver D, Sanchez-Reilly S. Barriers to quality end-of-life care for Latinos. *J Hosp Palliat Nurs*. 2016;18(6):505-511. doi:10.1097/njh.0000000000000277.
- Cruz-Oliver D, Talamantes M, Sanchez-Reilly S. What evidence is available on end-of-life (EOL) care and Latino elders? A literature review. *Am J Hosp Palliat Care*. 2013;31(1):87-97. doi:10.1177/1049909113480841.
- Davies B, Contro N, Larson J, Widger K. Culturally-sensitive information-sharing in pediatric palliative care. *PEDIATRICS*. 2010;125(4):e859-e865. doi:10.1542/peds.2009-0722.
- Davies B, Larson J, Contro N, Cabrera A. Perceptions of discrimination among Mexican American families of seriously ill children. *J Palliat Med*. 2011;14(1):71-76. doi:10.1089/jpm.2010.0315.
- Davies B. Conducting a qualitative culture study of pediatric palliative care. *Qual Health Res*. 2009;19(1):5-16.
- Decourtney C.A., Branch P.K. & Morgan K.M. Gathering information to develop palliative care programs for Alaska's Aboriginal peoples. *J Palliat Care*. 2010; 26, 22–31.
- del Río N. The influence of Latino ethnocultural factors on decision making at the end of life: Withholding and withdrawing artificial nutrition and hydration. *J Soc Work End Life Palliat Care*. 2010;6(3-4):125-149. doi:10.1080/15524256.2010.529009.
- DeSanto-Madeya S, Nilsson M, Loggers E et al. Associations between United States acculturation and the end-of-life experience of caregivers of patients with advanced cancer. *J Palliat Med*. 2009;12(12):1143-1149. doi:10.1089/jpm.2009.0063.
- Dillon P, Basu A. African Americans and hospice care: A culture-centered exploration of enrollment disparities. *Health Commun*. 2016;31(11):1385-1394. doi:10.1080/10410236.2015.1072886.
- Doolen J, York N. Cultural differences with end-of-life care in the critical care unit. *Dimens Crit Care Nurs*. 2007;26(5):194-198. doi:10.1097/01.dcc.0000286822.04238.df.
- Doorenbos A, Lindhorst T, Schim S et al. Development of a web-based educational intervention to improve cross-cultural communication among hospice providers. *J Soc Work End Life Palliat Care*. 2010;6(3-4):236-255. doi:10.1080/15524256.2010.529022.
- Drisdom S. Barriers to using palliative care. *Clin J Oncol Nurs*. 2013;17(4):376-380. doi:10.1188/13.cjon.376-380.
- Duke G, Petersen S. Perspectives of Asians living in Texas on pain management in the last days of life. *Int J Palliat Nurs*. 2015;21(1):24-34. doi:10.12968/ijpn.2015.21.1.24.
- Elliott A, Alexander S, Mescher C, Mohan D, Barnato A. Differences in physicians' verbal and nonverbal communication with Black and White patients at the end of life. *J Pain Symptom Manage*. 2016;51(1):1-8. doi:10.1016/j.jpainsymman.2015.07.008.
- Erickson SE, Vasilevskis EE, Kuzniewicz MW, et al. The effect of race and ethnicity on outcomes among patients in the intensive care unit: A comprehensive study involving socioeconomic status and resuscitation preferences. *Crit Care Med*. 2011;39(3):429-435.
- Evan B, Ume E. Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where are we and where do we need to go. *Nurs Outlook*. 2012;60(6):370-375.
- Evans B, Coon D. The "Reckoning Point" as a marker for formal palliative and end-of-life care in Mexican American families. *J Fam Nurs*. 2016;22(4):606-630. doi:10.1177/1074840716677994.
- Feldstein C, Grudzen M, Johnson A, LeBaron S. Integrating spirituality and culture with end-of-life care in medical education. *Clin Gerontol*. 2008;31(4):71-82. doi:10.1080/07317110801947185.

- Fischer S, Sauaia A, Min S, Kutner J. Advance directive discussions: Lost in translation or lost opportunities?. *J Palliat Med*. 2012;15(1):86-92. doi:10.1089/jpm.2011.0328.
- Fournier AL. Creating a sacred space in the intensive care unit at the end of life. *Dimens Crit Care Nurs*. 2017; 36(2):110-115. doi:10.1097/DCC.0000000000000231.
- Fowler K. "The Wholeness of Things": Infusing diversity and social justice into death education. *OMEGA*. 2008;57(1):53-91. doi:10.2190/om.57.1.d.
- Freudtner, C., Walter, J.K., & Faerber, J.A. Good-parent beliefs of parents of seriously ill children. *JAMA Pediatric*. 2015;169(1), 39-47.
- Frost D, Cook D, Heyland D, Fowler R. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review. *Crit Care Med*. 2011;39(5):1174-1189. doi:10.1097/ccm.0b013e31820eac2f.
- Gabbay E, McCarthy M, Fins J. The care of the ultra-orthodox Jewish patient. *J Relig Health*. 2017;56(2):545-560. doi:10.1007/s10943-017-0356-6.
- Gao X, Sun F, Ko E, Kwak J, Shen H. Knowledge of advance directive and perceptions of end-of-life care in Chinese-American elders: The role of acculturation. *Palliat Support Care*. 2015;13(06):1677-1684. doi:10.1017/s147895151500067x.
- Gaudio F, Hichenberg S, Eisenberg M, Kerr E, Zaider T, Kissane D. Latino values in the context of palliative care. *Am J Hosp Palliat Care*. 2012;30(3):271-278. doi:10.1177/1049909112448926.
- Gray W, Szulczewski L, Regan S, Williams J, Pai A. Cultural influences in pediatric cancer. *J Pediatr Oncol Nurs*. 2014;31(5):252-271. doi:10.1177/1043454214529022.
- Hampton M., Baydala A., Bourassa C., et al. Completing the circle: Elders speak about end-of-life care with Aboriginal families in Canada. *J Palliat Care*. 2010; 26, 6–14.
- Harle M, Dela R, Veloso G, Rock J, Faulkner J, Cohen M. The experiences of Filipino American patients with cancer. *Oncol Nurs Forum*. 2007;34(6):1170-1175. doi:10.1188/07.onf.1170-1175.
- Haxton J, Boelk A. Serving families on the frontline: Challenges and creative solutions in rural hospice social work. *Soc Work Health Care*. 2010;49(6):526-550. doi:10.1080/00981381003648422.
- Heyman J, Gutheil I. Older Latinos' attitudes toward and comfort with end-of-life planning. *Health Soc Work*. 2010;35(1):17-26. doi:10.1093/hsw/35.1.17.
- Hilliard T, Washington T, Hines C, McGill T. Wishes left unspoken: Engaging underserved populations in end-of-life advance care planning. *J Health Care Poor Underserved*. 2013;24(3):979-986. doi:10.1353/hpu.2013.0130.
- Hodge F, Itty T, Cadogan M, Martinez F. "Weaving Balance into Life": Development and cultural adaptation of a cancer symptom management toolkit for Southwest American Indians. *J Cancer Surviv*. 2011;6(2):182-188. doi:10.1007/s11764-011-0209-3.
- Holmstrom E. Strengthening end-of-life care for African-American patients and families through education and community outreach. *OMEGA*. 2013;67(1-2):115-119. doi:10.2190/om.67.1-2.m.
- Hutchinson S, Hersch G, Davidson H, Chu A, Mastel-Smith B. Voices of elders. *J Transcult Nurs*. 2011;22(4):397-404. doi:10.1177/1043659611414138.
- Hutson S. Climbing back up the mountain. *Am J Hosp Palliat Care*. 2016;33(10):972-976. doi:10.1177/1049909115600857.
- Jang Y, Chiriboga D, Allen J, Kwak J, Haley W. Willingness of older Korean-American adults to use hospice. *J Am Geriatr Soc*. 2010;58(2):352-356. doi:10.1111/j.1532-5415.2009.02684.x.

- Jaramillo S, Hui D. End-of-life care for undocumented immigrants with advanced cancer: Documenting the undocumented. *J Pain Symptom Manage*. 2016;51(4):784-788. doi:10.1016/j.jpainsymman.2015.11.009.
- Johnson J, Hayden T, True J et al. The impact of faith beliefs on perceptions of end-of-life care and decision making among African American church members. *J Palliat Med*. 2016;19(2):143-148. doi:10.1089/jpm.2015.0238.
- Johnson KS, Kuchibhalta M, Tulskey JA. Racial differences in location before hospice enrollment and association with length of stay. *J Am Geriatr Soc*. 2011;59(4):732-737.
- Johnstone M, Kanitsaki O. Ethics and advanced care planning in a culturally diverse society. *J Transcultur Nurs*. 2009;20(4):405-416. doi:10.1177/1043659609340803.
- Jordan T, Aubrey H, Stevenson A. Health literacy. *Groupwork*. 2013;23(3):45-62. doi:10.1921/6701230304.
- Kagawa-Singer M. Impact of culture on health outcomes. *J Pediatr Hematol*. 2011;33(2):S90-95.
- Kataoka-Yahiro M, McFarlane S, Kojane J, Li D. Culturally competent palliative and hospice care training for ethnically diverse staff in long-term care facilities. *Am J Hosp Palliat Care*. 2016;34(4):335-346. doi:10.1177/1049909116638347.
- Kehl K, Gartner C. Can you hear me now? The experience of a deaf family member surrounding the death of loved ones. *Palliat Med*. 2009;24(1):88-93. doi:10.1177/0269216309348180.
- Khosla N, Washington K, Regunath H. Perspectives of health care providers on US south Asians' attitudes toward pain management at end of life. *Am J Hosp Palliat Care*. 2016;33(9):849-857. doi:10.1177/1049909115593063.
- Kim E. "A Word can become a Seed": A lesson learned about cultural humility. *J Cancer Educ*. 2015;31(4):813-815. doi:10.1007/s13187-015-0878-0.
- Ko E, Berkman C. Advance directives among Korean American older adults: Knowledge, attitudes, and behavior. *J Geron Soc Work*. 2012;55(6):484-502. doi:10.1080/01634372.2012.667523.
- Ko E, Cho S, Perez R, Yeo Y, Palomino H. Good and bad death: Exploring the perspectives of older Mexican Americans. *J Geron Soc Work*. 2013;56(1):6-25. doi:10.1080/01634372.2012.715619.
- Ko E, Lee J. End-of-life communication: Ethnic differences between Korean American and non-Hispanic white older adults. *J Aging Health*. 2009;21(7):967-984. doi:10.1177/0898264309344179.
- Ko E, Nelson-Becker H, Park Y, Shin M. End-of-life decision making in older Korean adults: Concerns, preferences, and expectations. *Educ Gerontol*. 2013;39(2):71-81. doi:10.1080/03601277.2012.682947.
- Ko E, Nelson-Becker H, Shin M, Park Y. Preferences and expectations for delivering bad news among Korean older adults. *J Soc Serv Res*. 2014;40(4):402-414. doi:10.1080/01488376.2014.894356.
- Ko E, Roh S, Higgins D. Do older Korean immigrants engage in end-of-life communication? *Educ Gerontol*. 2013;39(8):613-622. doi:10.1080/03601277.2012.706471.
- Kreling B, Selsky C, Perret-Gentil M, Huerta E, Mandelblatt J. 'The worst thing about hospice is that they talk about death': contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliat Med*. 2010;24(4):427-434. doi:10.1177/0269216310366605.
- Kuschner W. Racial disparities in end-of-life care. *Arch Intern Med*. 2011;171(10):941. doi:10.1001/archinternmed.2011.195.

- Kwak J, Ko E, Kramer B. Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: Perspectives of care managers on challenges and recommendations. *Health Soc Care Community*. 2013;22(2):169-177. doi:10.1111/hsc.12073.
- Kwak J, Salmon J. Attitudes and preferences of Korean-American older adults and caregivers on end-of-life care. *J Am Geriatr Soc*. 2007;55(11):1867-1872. doi:10.1111/j.1532-5415.2007.01394.x.
- Lackan NA, Eschbach K, Stimpson JP, Freeman JL, Goodwin JS. Ethnic differences in in-hospital place of death among older adults in California: effects of individual and contextual characteristics and medical resource supply. *Medical Care*. 2009;47(2):138-145.
- Lawton A, White J, Fromme E. End-of-life and advanced care planning considerations for lesbian, gay, bisexual, and transgender patients #275. *J Palliat Med*. 2014;17(1):106-108. doi:10.1089/jpm.2013.9457.
- Leong M, Olnick S, Akmal T, Copenhaver A, Razzak R. How Islam influences end-of-life care: Education for palliative care clinicians. *J Pain Symptom Manage*. 2016;52(6):771-774.e3. doi:10.1016/j.jpainsymman.2016.05.034.
- Lin H. Searching for meaning. *Cancer Nurs*. 2008;31(3):250-258. doi:10.1097/01.ncc.0000305726.72969.07.
- Lopez, Hofer, Bumgarner & Taylor. Developing culturally responsive approaches to serving diverse populations: A resource guide for community-based organizations. National Research Center on Hispanic Children & Families. 2017.
- LoPresti M, Dement F, Gold H. End-of-life care for people with cancer from ethnic minority groups. *Am J Hosp Palliat Care*. 2014;33(3):291-305. doi:10.1177/1049909114565658.
- Lu A, Mohan D, Alexander S, Mescher C, Barnato A. The language of end-of-life decision making: A simulation study. *J Palliat Med*. 2015;18(9):740-746. doi:10.1089/jpm.2015.0089.
- Mack JW, Paulk ME, Vinswanath K, Prigerson HG. Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med*. 2010;170(17):1533-1540.
- Martin S. The right not to know: Exploring the attitudes of older Iranian immigrants about medical disclosure of terminal illness. *Indian J Geron*, 2012; 26(1): 94-118.
- Mazanec P, Daly B, Townsend A. Hospice utilization and end-of-life care decision making of African Americans. *Am J Hosp Palliat Care*. 2010;27(8):560-566. doi:10.1177/1049909110372087.
- McCormick AJ. Self-determination, the right to die, and culture: a literature review. *Soc Work*. 2011;56(2):119-128.
- Meltzer E, Gallagher J, Suppes A, Fins J. Lip-reading and the ventilated patient. *Crit Care Med*. 2012;40(5):1529-1531. doi:10.1097/ccm.0b013e318241e56c.
- Meuche G. Embracing the oneness of all things: A personal reflection on the implications of Shamanism for social work practice in end-of-life and palliative care. *J Soc Work End Life Palliat Care*. 2015;11(1):3-5. doi:10.1080/15524256.2015.1021068.
- Mitchell B, Mitchell L. Review of the literature on cultural competence and end-of-life treatment decisions: The role of the hospitalist. *J Nat Med Assoc*. 2009;101(9):920-926. doi:10.1016/s0027-9684(15)31040-3.
- Mixer S, Lindley L, Wallace H, Fornehed M, Wool C. The relationship between the nursing environment and delivering culturally sensitive perinatal hospice care. *Int J Palliat Nurs*. 2015;21(9):423-429. doi:10.12968/ijpn.2015.21.9.423.

- Mjelde-Mossey L, Chan C. Survey on death and dying in Hong Kong. *Soc Work Health Care*. 2007;45(1):49-65. doi:10.1300/j010v45n01_04.
- Mondia S, Hichenberg S, Kerr E, Eisenberg M, Kissane D. The impact of Asian American value systems on palliative care. *Am J Hosp Palliat Care*. 2011;29(6):443-448. doi:10.1177/1049909111426281.
- Moore R, Hallenbeck J. Narrative empathy and how dealing with stories helps: Creating space for empathy in culturally diverse settings. *J Pain Symptom Manage*. 2010;40(3):471-476. doi:10.1016/j.jpainsymman.2010.03.013.
- Moore R. Appreciating cultural dimensions and connections in hospice care. *J Soc Work End Life Palliat Care*. 2015;11(1):6-10. doi:10.1080/15524256.2015.1021069.
- Moss K, Williams I. End-of-life preferences in Afro-Caribbean older adults: A systematic literature review. *OMEGA*. 2014;69(3):271-282. doi:10.2190/om.69.3.c.
- National Association of Social Workers. Standards and Indicators for Cultural Competence in Social Work Practice. 2015. <https://www.socialworkers.org/LinkClick.aspx?fileticket=7dVckZAYUmk%3D&portalid=0>
- National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines c), Distress Management; Chaplaincy Services (DIS 21), Version 3 2012. Fort Washington, Pennsylvania 2012.
- Nedjat-Haiem F, Lorenz K, Ell K, Hamilton A, Palinkas L. Experiences with advanced cancer among Latinas in a public health care system. *J Pain Symptom Manage*. 2012;43(6):1013-1024. doi:10.1016/j.jpainsymman.2011.06.018.
- Newhouse L. Working with Russian-Jewish immigrants in end-of-life care settings. *J Soc Work End Life Palliat Care*. 2013;9(4):331-342. doi:10.1080/15524256.2013.846884.
- Nguyen G, Shungu N, Niederdeppe J et al. Cancer-related information seeking and scanning behavior of older Vietnamese immigrants. *J Health Commun*. 2010;15(7):754-768. doi:10.1080/10810730.2010.514034.
- Noh H. Values important to terminally ill African American older adults in receiving hospice care. *J Soc Work End Life Palliat Care*. 2014;10(4):338-355. doi:10.1080/15524256.2014.975317.
- Nolan B, Mathos K, Fusco L, Post E. Behavioral health providers for persons who are deaf, deafblind, or hard-of-hearing: A national survey of the structural and process domains of care. *Soc Work Public Health*. 2015;30(5):462-472. doi:10.1080/19371918.2015.1051261.
- O'Mara S, Zborovskaya Y. End-of-life care in the Hispanic community. *J Hosp Palliat Nurs*. 2016;18(1):53-59. doi:10.1097/njh.0000000000000210.
- Paal P, Bükki J. "If I had stayed back home, I would not be alive any more..." – Exploring end-of-life preferences in patients with migration background. *PLoS ONE*. 2017;12(4):e0175314. doi:10.1371/journal.pone.0175314.
- Pabon S, Wisotzkey S. ¿Hablas Inglés? Language barriers in healthcare. *Nurs Manage*. 2013;44(8):19-21. doi:10.1097/01.numa.0000432229.14948.54.
- Parrish M, Cárdenas Y, Epperhart R et al. Public hospital palliative social work: Addressing patient cultural diversity and psychosocial needs. *J Soc Work End Life Palliat Care*. 2012;8(3):214-228. doi:10.1080/15524256.2012.708113.

- Payne R. Racially associated disparities in hospice and palliative care access: Acknowledging the facts while addressing the opportunities to improve. *J Palliat Med*. 2016;19(2):131-133. doi:10.1089/jpm.2015.0475.
- Pekmezaris R, Walia R, Nouryan C et al. The impact of an end-of-life communication skills intervention on physicians-in-training. *Gerontol Geriatr Educ*. 2011;32(2):152-163.
- Periyakoil V, Neri E, Kraemer H. No Easy Talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PLoS ONE*. 2015;10(4):e0122321. doi:10.1371/journal.pone.0122321.
- Perkins H, Cortez J, Hazuda H. Cultural beliefs about a patient's right time to die: An exploratory study. *J Gen Intern Med*. 2009;24(11):1240-1247. doi:10.1007/s11606-009-1115-5.
- Pruchno R, Cartwright F, Wilson-Genderson M. The effects of race on patient preferences and spouse substituted judgments. *Int J Aging Hum Dev*. 2009;69(1):31-54. doi:10.2190/ag.69.1.c.
- Quill, T. E., & Abernethy, A. P. Generalist plus specialist palliative care – creating a more sustainable model. *N Engl J Med*. 2013; 368, 1173-1175.
- Quinones-Gonzalez S. Bridging the communication gap in hospice and palliative care for Hispanics and Latinos. *OMEGA*. 2013;67(1-2):193-200. doi:10.2190/om.67.1-2.w.
- Reese D, Beckwith S. Organizational barriers to cultural competence in hospice. *Am J Hosp Palliat Care*. 2014;32(7):685-694. doi:10.1177/1049909113520614.
- Reese D, Buila S, Cox S, Davis J, Olsen M, Jurkowski E. University–Community–Hospice partnership to address organizational barriers to cultural competence. *Am J Hosp Palliat Care*. 2016;34(1):64-78. doi:10.1177/1049909115607295.
- Reese D, Smith M, Butler C, Shrestha S, Erwin D. African American client satisfaction with hospice. *Am J Hosp Palliat Care*. 2013;31(5):495-502. doi:10.1177/1049909113494462.
- Reese D. University-community-hospice partnership to address organizational barriers to cultural competence. *Am J Hosp Palliat Care*. 2011;28(1).
- Rhodes R, Batchelor K, Lee S, Halm E. Barriers to end-of-life care for African Americans from the providers' perspective. *Am J Hosp Palliat Care*. 2013;32(2):137-143. doi:10.1177/1049909113507127.
- Rhodes R, Elwood B, Lee S, Tiro J, Halm E, Skinner C. The desires of their hearts: The multidisciplinary perspectives of African Americans on end-of-life care in the African American community. *Am J Hosp Palliat Care*. 2016;34(6):510-517. doi:10.1177/1049909116631776.
- Rising M. Truth telling as an element of culturally competent care at end of life. *J Trans Cultur Nurs*. 2016;28(1):48-55. doi:10.1177/1043659615606203.
- Rosenblatt P. Racism and black-white relationships in end-of-life care in the United States: A speculative analysis. *Illn Crises Loss*. 2009;17(2):113-124. doi:10.2190/il.17.2.c.
- Saccomano S, Abbatiello G. Cultural considerations at the end of life. *Nurse Pract*. 2014;39(2):24-31. doi:10.1097/01.npr.0000441908.16901.2e.
- Salinas J, Sheffield K. English language use, health and mortality in older Mexican Americans. *J Immigr Minor Health*. 2009;13(2):232-238. doi:10.1007/s10903-009-9273-4.
- Salman K, Zoucha R. Considering faith within culture when caring for the terminally ill Muslim patient and family. *J Hosp Palliat Nurs*. 2010;12(3):158-163.

- Schenker Y, Fernandez A, Kerr K, O’Riordan D, Pantilat S. Interpretation for discussions about end-of-life issues: Results from a national survey of health care interpreters. *J Palliat Med*. 2012;15(9):1019-1026. doi:10.1089/jpm.2012.0032.
- Schenker Y, Smith AK, Arnold RM, Fernandez A. “Her husband doesn’t speak much English”: Conducting a family meeting with an interpreter. *J Palliat Med*. 2012;15(4):494-498.
- Sharma R, Dy S. Cross-cultural communication and use of the family meeting in palliative care. *Am J Hosp Palliat Care*. 2010;28(6):437-444. doi:10.1177/1049909110394158.
- Sharma R, Khosla N, Tulskey J, Carrese J. Traditional expectations versus US realities: First- and second-generation Asian Indian perspectives on end-of-life care. *J Gen Intern Med*. 2011;27(3):311-317. doi:10.1007/s11606-011-1890-7.
- Silva M, Genoff M, Zaballa A et al. Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *J Pain Symptom Manage*. 2016;51(3):569-580. doi:10.1016/j.jpainsymman.2015.10.011.
- Smith A, Sudore R, Pérez-Stable E. Palliative care for Latino patients and their families. *JAMA*. 2009;301(10):1047. doi:10.1001/jama.2009.308.
- Song J, Bartels D, Ratner E, Alderton L, Hudson B, Ahluwalia J. Dying on the streets: Homeless persons’ concerns and desires about end of life care. *J Gen Intern Med*. 2007;22(4):435-441. doi:10.1007/s11606-006-0046-7.
- Soriano M, Lagman R. When the patient says no. *Am J Hosp Palliat Care*. 2011;29(5):401-404. doi:10.1177/1049909111421163.
- Sweet L, Adamis D, Meagher D et al. Ethical challenges and solutions regarding delirium studies in palliative care. *J Pain Symptom Manage*. 2014;48(2):259-271. doi:10.1016/j.jpainsymman.2013.07.017.
- Szmulowicz E, el-Jawahri A, Chiappetta L, Kamdar M, Block S. Improving residents’ end-of-life communication skills with a short retreat: A randomized controlled trial. *J Palliat Med*. 2010;13(4):439-452. doi:10.1089/jpm.2009.0262.
- Taxis J, Keller T, Cruz V. Mexican Americans and hospice care. *J Hosp Palliative Nurs*. 2008;10(3):133-141. doi:10.1097/01.njh.0000306739.10636.5f.
- Thienprayoon R, Marks E, Funes M, Martinez-Puente L, Winick N, Lee S. Perceptions of the pediatric hospice experience among English- and Spanish- speaking families. *J Palliat Med*. 2016;19(1):30-41. doi:10.1089/jpm.2015.0137.
- Waldrop DP, Kirkendall AM. Rural-urban differences in end-of-life care: Implications for practice. *Soc Work Health Care*. 2010;49(3):263-289. doi:10.1080/00981380903364742
- Wang J, Kearney J. The experience of Chinese American parents of children with life-limiting illness: A comprehensive review. *Int J Palliat Nurs*. 2013;19(7):347-354. doi:10.12968/ijpn.2013.19.7.347.
- Washington K, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: A systematic review. *Health & Social Work*. 2008;33(4):267-274. doi:10.1093/hsw/33.4.267.
- Wicher C, Meeker M. What influences African American end-of-life preferences? *J Health Care Poor Underserved*. 2012;23(1):28-58. doi:10.1353/hpu.2012.0027.

Appendix IV: Scoping Review

- Williams D, Fisicaro T, Veloski J, Berg D. Development and evaluation of a program to strengthen first year residents' proficiency in leading end-of-life discussions. *Am J Hosp Palliat Care*. 2010;28(5):328-334. doi:10.1177/1049909110391646.
- Williams S, Hanson L, Boyd C et al. Communication, decision making, and cancer: What African Americans want physicians to know. *J Palliat Med*. 2008;11(9):1221-1226. doi:10.1089/jpm.2008.0057.
- Wright A, Stieglitz H, Kupersztch Y et al. United States acculturation and cancer patients' end-of-life care. *PLoS ONE*. 2013;8(3):e58663. doi:10.1371/journal.pone.0058663.
- Yennurajalingam S, Noguera A, Parsons H et al. A multicenter survey of Hispanic caregiver preferences for patient decision control in the United States and Latin America. *Palliat Med*. 2013;27(7):692-698. doi:10.1177/0269216313486953.
- Yonashiro-Cho J, Cote S, Enguidanos S. Knowledge about and perceptions of advance care planning and communication of Chinese-American older adults. *J Am Geriatr Soc*. 2016;64(9):1884-1889. doi:10.1111/jgs.14261.
- Yu Xu. Death and dying in the Chinese culture: Implications for health care practice. *Home Health Care Manag Pract*. 2007;19(5):412-414. doi:10.1177/1084822307301306.
- Zager B, Yancy M. A call to improve practice concerning cultural sensitivity in advance directives: A review of the literature. *Worldviews Evid Based Nurs*. 2011;8(4):202-211. doi:10.1111/j.1741-6787.2011.00222.x.
- Zahuranec DB, Brown DL, Lisabeth LD, et al. Ethnic differences in do-not-resuscitate orders after intracerebral hemorrhage. *Crit Care Med*. 2009;37(10):2807-2811.
- Zhang A, Zyzanski S, Siminoff L. Ethnic differences in the caregiver's attitudes and preferences about the treatment and care of advanced lung cancer patients. *Psychooncology*. 2011;21(11):1250-1253. doi:10.1002/pon.2031.

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

- Adams G, Green A, Towe S, Huett A. Bereaved caregivers as educators in pediatric palliative care: Their experiences and impact. *J Palliat Med*. 2013;16(6):609-615. doi:10.1089/jpm.2012.0475.
- Arora N, Street R, Epstein R, Butow P. Facilitating patient-centered cancer communication: A road map. *Patient Educ Couns*. 2009;77(3):319-321. doi:10.1016/j.pec.2009.11.003.
- Arruda E, Paun O. Dementia caregiver grief and bereavement: An integrative review. *West J Nurs Res*. 2016;39(6):825-851. doi:10.1177/0193945916658881.
- Balducci L. Death and dying: What the patient wants. *Ann Oncol*. 2012;23(suppl 3):56-61. doi:10.1093/annonc/mds089.
- Barclay J, Blackhall L, Tulskey J. Communication strategies and cultural issues in the delivery of bad news. *J Palliat Med*. 2007;10(4):958-977. doi:10.1089/jpm.2007.9929.
- Bergman E, Haley W. Depressive symptoms, social network, and bereavement service utilization and preferences among spouses of former hospice patients. *J Palliat Med*. 2009;12(2):170-176. doi:10.1089/jpm.2008.0237.
- Bhat A, Wehbe-Alamah H, McFarland M, Filter M, Keiser M. Advancing cultural assessments in palliative care using web-based education. *J Hosp Palliat Nurs*. 2015;17(4):348-355. doi:10.1097/njh.0000000000000175.

- Boelen P, Prigerson H. The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults. *Eur Arch Psychiatry Clin Neurosci*. 2007;257(8):444-452. doi:10.1007/s00406-007-0744-0.
- Boyratz G, Horne S, Sayger† T. Finding positive meaning after loss: The mediating role of reflection for bereaved individuals. *J Loss Trauma*. 2010;15(3):242-258. doi:10.1080/15325020903381683.
- Brennan CW, Prince-Paul M, Wiencek CA. Providing a “good death” for oncology patients during the final hours of life in the intensive care unit. *AACN Advanced Critical Care*. 2011;22(4):379-396.
- Bullock K. The influence of culture on end-of-life decision making. *J Soc Work End Life Palliat Care*. 2011;7(1):83-98. doi:10.1080/15524256.2011.548048.
- Cagle J, Bunting M. Patient reluctance to discuss pain: Understanding stoicism, stigma, and other contributing factors. *J Soc Work End Life Palliat Care*. 2017;13(1):27-43. doi:10.1080/15524256.2017.1282917.
- Campbell ML, Templin T, Walch J. Patients who are near death are frequently unable to self-report dyspnea. *J Palliat Med*. 2009;12(10):881-884.
- Carrion I, Cagle J, Van Dussen D, Culler K, Hong S. Knowledge about hospice care and beliefs about pain management. *Am J Hosp Palliat Care*. 2014;32(6):647-653. doi:10.1177/1049909114536023.
- Cassel JB, Hager MA, Clark RR, et al. Concentrating hospital-wide deaths in a palliative care unit: The effect on place of death and system-wide mortality. *J Palliat Med*. 2010;13(4):371-374.
- Cherlin E, Barry C, Prigerson H et al. Bereavement services for family caregivers: How often used, why, and why not. *J Palliat Med*. 2007;10(1):148-158. doi:10.1089/jpm.2006.0108.
- Cox G, Stevenson RG. *Final acts: the end of life: hospice and palliative care*. Amityville: Baywood Publishing, 2013.
- Coyne P, Lyckholm L. Artificial nutrition for cognitively impaired individuals: Strategies to promote appropriate care. *J Hosp Palliat Nurs*. 2012;12(4):263-267.
- Cruz-Oliver D, Sanchez-Reilly S. Barriers to quality end-of-life care for Latinos. *J Hosp Palliat Nurs*. 2016;18(6):505-511. doi:10.1097/njh.0000000000000277.
- Cruz-Oliver D, Talamantes M, Sanchez-Reilly S. What evidence is available on end-of-life (EOL) care and Latino elders? A literature review. *Am J Hosp Palliat Care*. 2013;31(1):87-97. doi:10.1177/1049909113480841.
- Dickinson G. Diversity in Death: Body disposition and memorialization. *Illn Crises Loss*. 2012;20(2):141-158. doi:10.2190/il.20.2.d.
- Dillon P, Basu A. African Americans and hospice care: A culture-centered exploration of enrollment disparities. *Health Comm*. 2016;31(11):1385-1394. doi:10.1080/10410236.2015.1072886.
- Fawole O, Dy S, Wilson R et al. A systematic review of communication quality improvement interventions for patients with advanced and serious illness. *J Gen Intern Med*. 2012;28(4):570-577. doi:10.1007/s11606-012-2204-4.
- Ferrell B, Wittenberg E, Battista V, Walker G. Exploring the spiritual needs of families with seriously ill children. *Int J Palliat Nurs*. 2016;22(8):388-394. doi:10.12968/ijpn.2016.22.8.388.
- Foster T, Gilmer M, Davies B et al. Bereaved parents’ and siblings’ reports of legacies created by children with cancer. *Parents’ and Siblings’ Reports of Legacies Created by Children with Cancer*. *J Pediatr Oncol Nurs*. 2009;26(6):369-376. doi:10.1177/1043454209340322.

- Gordon N, O’Riordan D, Dracup K, De Marco T, Pantilat S. Let us talk about it: Heart failure patients’ preferences toward discussions about prognosis, advance care planning, and spiritual support. *J Palliat Med*. 2017;20(1):79-83. doi:10.1089/jpm.2016.0097.
- Gramling R, Norton S, Ladwig S et al. Latent classes of prognosis conversations in palliative care: A mixed-methods study. *J Palliat Med*. 2013;16(6):653-660. doi:10.1089/jpm.2012.0381.
- Hebert R, Schulz R, Copeland V, Arnold R. What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved one? An ethnographic study of caregivers of patients at end of life. *J Palliat Med*. 2008;11(3):476-483. doi:10.1089/jpm.2007.0165.
- Hickman S, Keevern E, Hammes B. Use of the physician orders for life-sustaining treatment program in clinical settings: A systematic review of the literature. *J Am Geriatr Soc*. 2015;63(2):341-350. doi:10.1111/jgs.13248.
- Kim Y, Carver C, Schulz R, Lucette A, Cannady R. Finding benefit in bereavement among family cancer caregivers. *J Palliat Med*. 2013;16(9):1040-1047. doi:10.1089/jpm.2013.0049.
- Kreling B, Selsky C, Perret-Gentil M, Huerta E, Mandelblatt J. ‘The worst thing about hospice is that they talk about death’: Contrasting hospice decisions and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliat Med*. 2010;24(4):427-434. doi:10.1177/0269216310366605.
- Kwak J, Salmon J. Attitudes and preferences of Korean-American older adults and caregivers on end-of-life care. *J Am Geriatr Soc*. 2007;55(11):1867-1872. doi:10.1111/j.1532-5415.2007.01394.x.
- LeGrand SB, Walsh D. Comfort measures: Practical care of the dying cancer patient. *Am J Palliat Care*. 2010;27(7):488-493.
- Liew T. Applicability of the pre-death grief concept to dementia family caregivers in Asia. *Int J Geriatr Psychiatry*. 2015;31(7):749-754. doi:10.1002/gps.4387.
- Lusardi P, Jodka P, Stambovsky M, et al. The going home initiative: Getting critical care patients home with hospice. *Crit Care Nurs*. 2011;31(5):46-57.
- Lynes C, Phillips J, Keane C, Sloan D, Berger A. An evaluation of a bereavement program in a US research hospital. *Am J Hosp Palliat Care*. 2014;33(2):150-153. doi:10.1177/1049909114557538.
- Mack J, Joffe S. Communicating About prognosis: Ethical responsibilities of pediatricians and parents. *PEDIATRICS*. 2014;133(Supplement):S24-S30. doi:10.1542/peds.2013-3608e.
- Manusov V, Keeley M. When family talk is difficult: Making sense of communication at the end of life. *J Fam Commun*. 2015;15(4):387-409. doi:10.1080/15267431.2015.1076424.
- McNutt B, Yakushko O. Disenfranchised grief among lesbian and gay bereaved individuals. *J LGBT Issues Couns*. 2013;7(1):87-116. doi:10.1080/15538605.2013.758345.
- Mendieta M, Buckingham R. A review of palliative and hospice care in the context of Islam: Dying with faith and family. *J Palliat Med*. 2017;20(11):1284-1290. doi:10.1089/jpm.2017.0340.
- Mercadante S, Intravaia G, Villari P, Ferrera P, David F, Casuccio A. Controlled sedation for refractory symptoms in dying patients. *J Pain Symptom Manage*. 2009;37(5):771-779.
- Milberg A, Olsson E, Jakobsson M, Olsson M, Friedrichsen M. Family members’ perceived needs for bereavement follow-up. *J Pain Symptom Manage*. 2008;35(1):58-69. doi:10.1016/j.jpainsymman.2007.02.039.

- Miller JH, Stiles A. Family presence during resuscitation and invasive procedures: The nurse experience. *Qual Health Res.* 2009;19(10):1431-1442.
- Morris S, Block S. Adding value to palliative care services: The development of an institutional bereavement program. *J Palliat Med.* 2015;18(11):915-922. doi:10.1089/jpm.2015.0080.
- Moss AH, Lunney JR, Auber M, et al. Prognostic significance of the “surprise” question in cancer patients. *J Palliat Med.* 2012;13(7):837-840.
- Mullen MA, Gow RM. Understanding ethical issues, ICD, and DNR orders: an obstacle to imminent death? *Heart Rhythm.* 2010;7(6):858-860.
- Nakao K. Knowledge, preferences, and arrangement of end-of-life care and decision-making among Japanese American older adults. University of California, Los Angeles; 2009.
- O’Mahony S, McHenry J, Snow D, Cassin C, Schumacher D, Selwyn P. A review of barriers to utilization of the Medicare hospice benefits in urban populations and strategies for enhanced access. *J Urban Health.* 2008;85(2):281-290. doi:10.1007/s11524-008-9258-y.
- Pantilat S. Communicating with seriously ill patients. *JAMA.* 2009;301(12):1279. doi:10.1001/jama.2009.396.
- Parker S, Clayton J, Hancock K et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: Patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage.* 2007;34(1):81-93. doi:10.1016/j.jpainsymman.2006.09.035.
- Parkes CM, Laungani P, Young, B. Death and bereavement across cultures (3rd ed). London: Routledge, 2015.
- Perkins H, Cortez J, Hazuda H. Cultural beliefs about a patient’s right time to die: An exploratory study. *J Gen Intern Med.* 2009;24(11):1240-1247. doi:10.1007/s11606-009-1115-5.
- Perkins HS, Cortez JD, Hazuda HP. Patients’ diverse beliefs about what happens at the time of death. *J Hosp Med.* 2012;7(2):110-116.
- Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA.* 2009;301(11):1140-1147.
- Quinones-Gonzalez S. Bridging the communication gap in hospice and palliative care for Hispanics and Latinos. *OMEGA.* 2013;67(1-2):193-200. doi:10.2190/om.67.1-2.w.
- Reese D, Smith M, Butler C, Shrestha S, Erwin D. African American client satisfaction with hospice. *Am J Hosp Palliat Care.* 2013;31(5):495-502. doi:10.1177/1049909113494462.
- Richardson R, Ferguson P, Maxymiv S. Applying a positive youth development perspective to observation of bereavement camps for children and adolescents. *J Soc Work End Life Palliat Care.* 2017;13(2-3):173-192. doi:10.1080/15524256.2017.1346544.
- Rodriguez-Arias D, Smith MJ, Lazar NM. Donation after circulatory death: Burying the dead donor rule. *Am J Bio Ethics.* 2011;11(8):36-43.
- Salman K, Zoucha R. Considering faith within culture when caring for the terminally ill Muslim patient and family. *J Hosp Palliat Nurs.* 2010;12(3):156-163. doi:10.1097/njh.0b013e3181d76d26.
- Sanders J. Finding the right words at the right time – High-value advance care planning. *N Engl J Med.* 2015;372(7):598-599. doi:10.1056/nejmp1411717.
- Scott SA. Life-support interventions at the end of life: Unintended consequences. *Am J Nurs.* 2010;110(1):32-39.

- Sharma R, Dy S. Cross-cultural communication and use of the family meeting in palliative care. *Am J Hosp Palliat Care*. 2010;28(6):437-444. doi:10.1177/1049909110394158.
- Sisk B, Bluebond-Langner M, Wiener L, Mack J, Wolfe J. Prognostic disclosures to children: A historical perspective. *PEDIATRICS*. 2016;138(3):e20161278-e20161278. doi:10.1542/peds.2016-1278.
- Snaman J, Kaye E, Levine D et al. Empowering bereaved parents through the development of a comprehensive bereavement program. *J Pain Symptom Manage*. 2017;53(4):767-775. doi:10.1016/j.jpainsymman.2016.10.359.
- Snaman J, Kaye E, Torres C, Gibson D, Baker J. Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys. *Cancer*. 2016;122(17):2757-2765. doi:10.1002/cncr.30087.
- Steinberg S. Cultural and religious aspects of palliative care. *Int J Crit Illn Inj Sci*. 2011;1(2):154. doi:10.4103/2229-5151.84804.
- Stroebe M, Schut H, Boerner K. Cautioning health-care professionals. *OMEGA*. 2017;74(4):455-473. doi:10.1177/0030222817691870.
- Tan J, Docherty S, Barfield R, Brandon D. Addressing parental bereavement support needs at the end of life for infants with complex chronic conditions. *J Palliat Med*. 2012;15(5):579-584. doi:10.1089/jpm.2011.0357.
- Teno J, Casarett D, Spence C, Connor S. It is "Too Late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage*. 2012;43(4):732-738. doi:10.1016/j.jpainsymman.2011.05.012.
- Thompson A, Miller K, Barrera M et al. A qualitative study of advice from bereaved parents and siblings. *J Soc Work End Life Palliat Care*. 2011;7(2-3):153-172. doi:10.1080/15524256.2011.593153.
- Thrane S. Hindu end of life. *J Hosp Palliat Nurs*. 2010;12(6):337-342. doi:10.1097/njh.0b013e3181f2ff11.
- Trice E, Prigerson H. Communication in end-stage cancer: Review of the literature and future research. *J Health Commun*. 2009;14(sup1):95-108. doi:10.1080/10810730902806786.
- Walczak A, Henselmans I, Tattersall M et al. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psychooncology*. 2014;24(3):287-293. doi:10.1002/pon.3635.
- Waldrop D, Kirkendall A. Rural-urban differences in end-of-life care: Implications for practice. *Soc Work Health Care*. 2010;49(3):263-289. doi:10.1080/00981380903364742.
- Waldrop DP, Rinfrette ES. Making the transition to hospice: Exploring hospice professionals' perspectives. *Death Stud*. 2009;33(6):557-580.
- Washington K, Bickel-Swenson D, Stephens N. Barriers to hospice use among African Americans: A systematic review. *Health Soc Work*. 2008;33(4):267-274. doi:10.1093/hsw/33.4.267.
- Wintermeyer-Pingel S, Murphy D, Hammelef K. Improving a grief and loss program: Caring for patients, family, and staff. *OMEGA*. 2013;67(1-2):233-239. doi:10.2190/om.67.1-2.z3.
- Wittenberg-Lyles E, Goldsmith J, Ragan S, Sanchez-Reilly S. *Dying with Comfort: Family Illness Narratives and Early Palliative Care*. Cresskill, New Jersey: Hampton Press; 2010.
- Yennurajalingam S, Noguera A, Parsons H et al. A multicenter survey of Hispanic caregiver preferences for patient decision control in the United States and Latin America. *Palliat Med*. 2013;27(7):692-698. doi:10.1177/0269216313486953.

Zager B, Yancy M. A call to improve practice concerning cultural sensitivity in advance directives: A review of the literature. *Worldviews Evid Based Nurs*. 2011;8(4):202-211. doi:10.1111/j.1741-6787.2011.00222.x.

Bereavement

Acierno R, Rheingold A, Amstadter A, et al. Behavioral activation and therapeutic exposure for bereavement in older adults. *Am J Hosp Palliat Care*. 2012;29(1):13-25.

Allen M. A child dies in the emergency department: Development of a program to support bereaved families and staff. *Clin Nurse Spec*. 2009;23(3):96.

Ando M, Morita T, Miyashita M, Sanjo M, Kira H, Shima Y. Effects of bereavement life review on spiritual well-being and depression. *J Pain Symptom Manage*. 2010;40(3):453-459.

Armentrout DC. Living with grief following the removal of infant life support: Parents' perspectives. *Crit Care Nurs Clin North Am*. 2009;21(2):253-265.

Baker JN, Harper J, Kane JR, et al. Implementation and evaluation of automated patient death notification policy at a tertiary pediatric oncology referral center. *J Pain Symptom Manage*. 2011;42(5):652-626.

Compton S, Levy P, Griffin M, Waselewsky D, Mango L, Zalenski R. Family-witnessed resuscitation: Bereavement outcomes in an urban environment. *J Palliat Med*. 2011;14(6):715-721.

Herbert MK. Bereavement therapy. *J Soc Work End Life Palliat Care*. 2011;7(2-3):114.

Jind L, Elklit A, Christiansen D. Cognitive schemata and processing among parents bereaved by infant death. *J Clin Psychol Med Settings*. 2010;17(4):366-377.

Johnson JG, First MB, Block S, et al. Stigmatization and receptivity to mental health services among recently bereaved adults. *Death Stud*. 2009;33(8):691-711.

Jones BW. Hospice disease types which indicate a greater need for bereavement counseling. *Am J Hosp Palliat Care*. 2010;27(3):187-190.

Kapari M, Addington-Hall J, Hotopf M. Risk factors for common mental disorder in caregiving and bereavement. *J Pain Symptom Manage*. 2010;40(6):844-856.

Kavanaugh K, Andreoni VA, Wilkie DJ, et al. Developing a blended course on dying, loss, and grief. *Nurse Educ*. 2009;34(3):126-131.

Keene EA, Hutton N, Hall B, Rushton C. Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient. *Ped Nurs*. 2012;36(4):185-189.

Lichtenthal WG, Currier JM, Neimeyer RA, Keesee NJ. Sense and significance: A mixed methods examination of meaning making after the loss of one's child. *J Clin Psych*. 2010;66(7):791-812.

Lichtenthal WG, Nilsson M, Kissane DW, et al. Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatr Serv*. 2011;62(10):1225-1229.

Lund D, Caserta M, Utz R, De Vries B. Experiences and early coping of bereaved spouses/partners in an intervention based on the dual process model. *OMEGA*. 2010;61(4):291-313.

Martin M. Transcultural perspective of perinatal loss and bereavement: An overview. *PA Nurse*. 2009;64(3):4-6.

Mauritz M, van Meijel B. Loss and grief in patients with schizophrenia: On living in another world. *Arch Psychiatr Nurs*. 2009;23(3):251-260.

Appendix IV: Scoping Review

- Meert KL, Briller SH, Schim SM, Thurston C, Kabel A. Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. *Death Stud.* 2009;33(8):712-740.
- Meert KL, Schim SM, Briller SH. Parental bereavement needs in the pediatric intensive care unit: Review of available measures. *J Palliat Med.* 2011;14(8):951-964.
- Melhem NM, Porta G, Shamseddeen W, Walker Payne M, Brent DA. Grief in children and adolescents bereaved by sudden parental death. *Arch Gen Psychiatry.* 2011;68(9):911-919.
- Mystakidou K, Tsilika E, Parpa E, et al. Illness-related hopelessness in advanced cancer: Influence of anxiety, depression, and preparatory grief. *Arch Psychiatr Nurs.* 2009;23(2):138-147.
- Newson RS, Boelen PA, Hek K, Hofman A, Tiemeier H. The prevalence and characteristics of complicated grief in older adults. *J Affect Disord.* 2011;132(1-2):231-238.
- Parkes CM, Prigerson H, eds. *Bereavement: Studies of Grief in Adult Life* 4th ed. New York, NY: Routledge Taylor and Francis Group; 2009.
- Ronen R, Packman W, Field NP, Davies B, Kramer R, Long JK. The relationship between grief adjustment and continuing bonds for parents who have lost a child. *OMEGA.* 2009;60(1):1-31.
- Rubin SS, Nadav OB, Malkinson R, Koren D, Goffer-Shnarch M, Michaeli E. The two-track model of bereavement questionnaire (TTBQ): Development and validation of a relational measure. *Death Stud.* 2009;33(4):305-333.
- Tubbs-Cooley HL, Santucci G, Kang TI, Feinstein JA, Hexen KR, Feudtner C. Pediatric nurses' individual and group assessments of palliative, end-of-life and bereavement care. *J Palliat Med.* 2011;14(5):631-637.
- Wilson J. The assimilation of Problematic Experiences Sequence: An approach to evidence-based practice in bereavement counseling. *J Soc Work End Life Palliat Care.* 2011;7(4):350-362.
- Worden W. *Grief Counseling & Grief Therapy: A Handbook for the Mental Health Practitioner.* 4th ed. New York, NY Springer Press; 2009.

Domain 8: Ethical and Legal Aspects of Care

Advance Care Planning

- Alfonso H. The importance of living wills and advance directives. *J Geron Nurs.* 2009;35(10):42-45.
- Appel J. When any answer is a good answer: A mandated-choice model for advance directives. *Camb Q Healthc Ethics.* 2010;19(3):417-421.
- Arthur D. Social work practice with LGBT elders at end of life: Developing practice evaluation and clinical skills through a cultural perspective. *J Soc Work End Life Palliat Care.* 2015;11(2):178-201. doi:10.1080/15524256.2015.1074141.
- Billings JA. Advance care planning safeguards. *J Gen Intern Med.* 2012. doi:10.1007/s11606-012-2191-5.
- Blinderman CD, Krakauer EL, Solomon MZ. Time to revise the approach to determining cardiopulmonary resuscitation status. *JAMA.* 2012;307(9):917-918.

- Bomba P, Morrissey M, Leven D. Key role of social work in effective communication and conflict resolution process: Medical orders for life-sustaining treatment (MOLST) program in New York and shared medical decision making at the end of life. *J Soc Work End Life Palliat Care*. 2011;7(1):56-82. doi:10.1080/15524256.2011.548047.
- Brinkman-Stoppelenburg A, Rietjens J, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliat Med*. 2014;28(8):1000-1025. doi:10.1177/0269216314526272.
- Byock IR, Corbeil YJ, Goodrich ME. Beyond polarization, public preferences suggest policy opportunities to address aging, dying, and family caregiving. *Am J Hosp Palliat Care*. 2009;26(3):200-208.
- Clements JM. Patient perceptions on the use of advance directives and life prolonging technology. *Am J Hosp Palliat Care*. 2009;26(4):270-276.
- de Caprariis P, Rucker B, Lyon C. Discussing advance care planning and directives in the general population. *S Med J*. 2017;110(9):563-568. doi:10.14423/smj.0000000000000697.
- del Río N. The influence of Latino ethnocultural factors on decision making at the end of life: Withholding and withdrawing artificial nutrition and hydration. *J Soc Work End Life Palliat Care*. 2010;6(3-4):125-149. doi:10.1080/15524256.2010.529009.
- Dunn A, Littrivis E. Aligning patient preferences and patient care at the end of life. *J Gen Intern Med*. 2011;26(7):681-682.
- Durall A, Zurakowski D, Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. *PEDIATRICS*. 2012;129(4):e975-e982. doi:10.1542/peds.2011-2695.
- Fromme EK, Zive D, Schmidt TA, Olszewski E, Tolle SW. POLST Registry do-not-resuscitate orders and other patient treatment preferences. *JAMA*. 2012;307(1):34-35.
- Frost D, Cook D, Heyland D, Fowler R. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review. *Crit Care Med*. 2011;39(5):1174-1189. doi:10.1097/ccm.0b013e31820eac2.
- Golden AG, Tewary S, Qadri S, Zaw K, Ruiz JG, Roos BA. The positive attitudes and perceptions of care managers about advance directives. *Am J Hosp Palliat Care*. 2011;28(2):98-101.
- Hammes BJ, Rooney BL, Gundrum JD, Hickman SE, Hager N. The POLST program: A retrospective review of the demographics of use and outcomes in one community where advance directives are prevalent. *J Palliat Med*. 2012;15(1):77-85.
- Hickman S, Keevern E, Hammes B. Use of the physician orders for life-sustaining treatment program in the clinical settings: A systematic review of the literature. *J Am Geriatr Soc*. 2015;63(2):341-350. doi:10.1111/jgs.13248.
- Hirschman KB, Corcoran AM, Straton JB, Kapo JM. Advance care planning and hospice enrollment: Who really makes the decision to enroll? *J Palliat Med*. 2010;13(5):519-523.
- Ho A, Jameson K, Pavlish C. An exploratory study of interprofessional collaboration in end-of-life decision-making beyond palliative care settings. *J Interprof Care*. 2016;30(6):795-803. doi:10.1080/13561820.2016.1203765.
- Jethwa K, Onalaja O. Advance care planning and palliative medicine in advanced dementia: A literature review. *BJPsych Bulletin*. 2015;39(02):74-78. doi:10.1192/pb.bp.114.046896.

- Jones P. Thoughtfulness and grace: End-of-life decision making for children with severe development disabilities. *Am J Bioeth.* 2016;16(2):72-73. doi:10.1080/15265161.2015.1132046.
- Kim H, Ersek M, Bradway C, Hickman S. Physician orders for life-sustaining treatment for nursing home residents with dementia. *J Am Assoc Nurse Pract.* 2015;27(11):606-614. doi:10.1002/2327-6924.12258.
- Kon AA. The shared decision-making continuum. *JAMA.* 2010;304(8):903-904.
- Kroch EA, Johnson M, Martin J, Duan M. Making hospital mortality measurement more meaningful: Incorporating advance directives and palliative care designations. *Am J Med Qual.* 2010;25(1):24-33.
- Levi BH, Green MJ. Too soon to give up: Re-examining the value of advance directives. *Am J Bioeth.* 2010;10(4):3-22.
- Lubell J. End-of-life care. Advance directives have value, but some in industry cite drawbacks, too. *Mod Healthc.* 2010;40(35):30-31.
- Mahon MM. Advanced care decision making: Asking the right people the right questions. *J Psychosoc Nurs Ment Health Serv.* 2010;48(7):13-19.
- Mitchell JK. POLST complement advance directives to better honor patients' preferences for end-of-life care. *ONS Connect.* 2011;26(1):19.
- Nicholas LH, Langa KM, Iwashyna TJ, Weir DR. Regional variation in the association between advance directives and end-of-life Medicare expenditures. *JAMA.* 2011;306(13):1447-1453.
- Olick RS. Defining features of advance directives in law and clinical practice. *Chest.* 2012;141(1):232-238.
- Ozanne EM, Partridge A, Moy B, Ellis KJ, Sepucha KR. Doctor-patient communication about advance directives in metastatic breast cancer. *J Palliat Med.* 2009;12(6):547-553.
- Prochaska M, Sulmasy D. Recommendations to surrogates at the end of life: A critical narrative review of the empirical literature and a normative analysis. *J Pain Symptom Manage.* 2015;50(5):693-700. doi:10.1016/j.jpainsymman.2015.05.004.
- Resnick HE, Hickman S, Foster GL. Documentation of advance directives among home health and hospice patients: United States, 2007. *Am J Hosp Palliat Care.* 2012;29(1):26-35.
- Resnick HE, Hickman SE, Foster GL. Advance directives in home health and hospice agencies: United States, 2007. *Am J Hosp Palliat Care.* 2011;28(7):467-474.
- Rhodes R, Elwood B, Lee S, Tiro J, Halm E, Skinner C. The desires of their hearts: The multidisciplinary perspectives of African Americans on end-of-life care in the African American community. *Am J Hosp Palliat Care.* 2016;34(6):510-517. doi:10.1177/1049909116631776.
- Sam S, Pekmezaris R, Nouryan CN, et al. Survey of emergency medical services professionals' experience with advance directives and medical orders for life-sustaining treatment. *J Am Geriatr Soc.* 2011;59(12):2383-2384.
- Sauler M, Siegel MD. The past, present, and future of advance directives as a guide to end-of-life decision making. *Chest.* 2012;141(1):9-10.
- Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med.* 2010;362(13):1211-1218.

- Song J, Ratner ER, Wall MM, et al. Effect of an End-of-Life Planning Intervention on the completion of advance directives in homeless persons: A randomized trial. *Ann Intern Med*. 2010;153(2):76-84.
- Song J, Ratner ER, Wall MM, et al. Summaries for patients. End-of-life planning intervention and the completion of advance directives in homeless persons. *Ann Intern Med*. 2010;153(2):38-38.
- Su C, McMahan R, Williams B, Sharma R, Sudore R. Family matters: Effects of birth order, culture, and family dynamics on surrogate decision-making. *J Am Geriatr Soc*. 2014;62(1):175-182. doi:10.1111/jgs.12610.
- Wiener L, Ballard E, Brennan T, Battles H, Martinez P, Pao M. How I wish to be remembered: The use of advance care planning document in adolescent and young adult populations. *J Palliat Med*. 2008;11(10):1309-1313. doi:10.1089/jpm.2008.0126.

Care Coordination

- Back A, Steihauser K, Kamal A, Jackson V. Building resilience for palliative care clinicians: An approach to burnout prevention based on individual skills and workplace factors. *J Pain Symptom Manage*. 2016;52(2):284-291. doi:10.1016/j.jpainsymman.2016.02.002.
- Bull J, Whitten E, Morris J et al. Demonstration of a sustainable community-based model of care across the palliative care continuum. *J Pain Symptom Manage*. 2012;44(6):797-809. doi:10.1016/j.jpainsymman.2011.12.278.
- Carlson M, Lim B, Meier D. Strategies and innovative models for delivering palliative care in nursing homes. *JAMA*. 2011;12(2):91-98. doi:10.1016/j.jamda.2010.07.016.
- Elliott M, Haviland A, Cleary P et al. Care experiences for managed care Medicare enrollees near end of life. *J Am Geriatr Soc*. 2013;61(3):407-412. doi:10.1111/jgs.12121.
- Fournier AL. Creating a sacred space in the intensive care unit at the end of life. *Dimens Crit Care Nurs*. 2017;36(2):110-5. doi:10.1097/DCC.0000000000000231.
- Grudzen C, Stone S, Morrison R. The palliative care model for emergency department patients with advanced illness. *J Palliat Med*. 2011;14(8):945-950. doi:10.1089/jpm.2011.0011.
- Guo Q, Jacelon C. An integrative review of dignity in end-of-life care. *Palliat Med*. 2014;28(7):931-940. doi:10.1177/0269216314528399.
- Haley E, Meisel D, Gitelman Y, Dingfield L, Casarett D, O'Connor N. Electronic goals of care alerts: An innovative strategy to promote primary palliative care. *J Pain Symptom Manage*. 2017;53(5):932-937. doi:10.1016/j.jpainsymman.2016.12.329.
- Leong M, Olrick S, Akmal T, Copenhaver A, Razzak R. How Islam influences end-of-life care: Education for palliative care clinicians. *J Pain Symptom Manage*. 2016;52(6):771-774.e3. doi:10.1016/j.jpainsymman.2016.05.034.
- Otis-Green S, Ferrell B, Borneman T, Puchalski C, Uman G, Garcia A. Integrating spiritual care within palliative care: An overview of nine demonstration projects. *J Palliat Med*. 2012;15(2):154-162. doi:10.1089/jpm.2011.0211.
- Silva M, Genoff M, Zaballa A, Stabler S, Gany F, Diamond L. Interpreting in palliative care: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *J Clin Oncol*. 2014;32(31_suppl):123-123. doi:10.1200/jco.2014.32.31_suppl.123.

Appendix IV: Scoping Review

- Tamburro R, Shaffer M, Hahnen N, Felker P, Ceneviva G. Care goals and decisions for children referred to a pediatric palliative care program. *J Palliat Med*. 2011;14(5):607-613. doi:10.1089/jpm.2010.0450.
- Virdun C, Lockett T, Lorenz K, Davidson P, Phillips J. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliat Med*. 2016;31(7):587-601. doi:10.1177/0269216316673547.

Communication

- Downey L, Au D, Curtis J, Engelberg R. Life-sustaining treatment preferences: Matches and mismatches between patients' preferences and clinicians' perceptions. *J Pain Symptom Manage*. 2013;46(1):9-19. doi:10.1016/j.jpainsymman.2012.07.002.
- Hinds P, Oakes L, Hicks J et al. Parent-clinician communication intervention during end-of-life decision making for children with incurable cancer. *J Palliat Med*. 2012;15(8):916-922. doi:10.1089/jpm.2012.0006.
- Jones J, Nowels C, Kutner J, Matlock D. Shared decision making and the use of a patient decision aid in advanced serious illness: provider and patient perspectives. *Health Expect*. 2014;18(6):3236-3247. doi:10.1111/hex.12313.
- Rising M. Truth telling as an element of culturally competent care at end of life. *J Transcult Nurs*. 2016;28(1):48-55. doi:10.1177/1043659615606203.
- White D, Ernecoff N, Buddadhumaruk P et al. Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients. *JAMA*. 2016;315(19):2086. doi:10.1001/jama.2016.5351.

Ethics

- Adams DM. The role of the clinical ethics consultant in "unsettled" cases. *J Clin Ethics*. 2011;22(4):328-334.
- American Nurses Association. Position Statement - The Nurse's Role in Ethics and Human Rights: Protecting and Promoting Individual Worth, Dignity, and Human Rights in Practice Settings. Washington, DC: American Nurses Association; 2010.
- Brody H, Hermer LD, Scott LD, Grumbles LL, Kutac JE, McCammon SD. Artificial nutrition and hydration: the evolution of ethics, evidence, and policy. *J Gen Intern Med*. 2011;26(9):1053-1058.
- Bush S, Leonard M, Agar M et al. End-of-life delirium: Issues regarding recognition, optimal management, and the role of sedation in the dying phase. *J Pain Symptom Manage*. 2014;48(2):215-230. doi:10.1016/j.jpainsymman.2014.05.009.
- Carter BS, Wocial LD. Ethics and palliative care: Which consultant and when? *Am J Hosp Palliat Care*. 2012;29(2):146-150.
- Cohen MJ, Torres-Vigil I, Burbach B, de la Rosa A, Bruera E. The meaning of parental hydration to family caregivers and patients receiving hospice care. *J Pain Symptom Manage*. 2012;43(5):855-863.
- Coyle N. Palliative Care, hospice care, and bioethics. *J Hosp Palliat Nurs*. 2014;16(1):6-12. doi:10.1097/njh.0000000000000032.

- Grant S, Modi P, Singer E. Futility and the care of surgical patients: Ethical dilemmas. *World J Surg*. 2014;38(7):1631-1637. doi:10.1007/s00268-014-2592-1.
- Jones BJ. Ethics and artificial nutrition towards the end of life. *Clinical Med*. 2010;10(6):607-610.
- Jonsen A, Siegler M, Winslade W. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* 7th edition ed. New York, NY: McGraw-Hill; 2010.
- Kaufert J, Wiebe R, Schwartz K, Labine L, Lutfiyya ZM, Pearse C. End-of-life ethics and disability: differing perspectives on case-based teaching. *Med Health Care Philos*. 2010;13(2):115-126.
- Kirby J. Accessing the ethics of complex health care practices: Would a “domains of ethics analysis” approach help? *HEC Forum*. 2010;22(2):133-143.
- Koch T. Care, compassion, or cost: Redefining the basis of treatment in ethics and law. *J Law Med Ethics*. 2011;39(2):130-139.
- Liao S, Ito S. Brain death: Ethical challenges to palliative care concepts of family care. *J Pain Symptom Manage*. 2010;40(2):309-313.
- Macauley R. The role of the principle of double effect in ethics education at US medical schools and its potential impact on pain management at the end of life. *J Med Ethics*. 2012;38(3):174-178.
- Marco CA, Lu DW, Stettner E, Sokolove PE, Ufberg JW, Noeller TP. Ethics curriculum for emergency medicine graduate medical education. *J Emerg Med*. 2011;40(5):550-556.
- Monturo C. The artificial nutrition debate: Still an issue after all these years. *Nutr Clin Pract*. 2009;24(2):206-213.
- Rady M, Verheijde J. Ethical considerations in end-of-life deactivation of durable mechanical circulatory support devices. *J Palliat Med*. 2013;16(12):1498-1502. doi:10.1089/jpm.2013.0343.
- Ramsey DJ, Schmidt ML, Anderson-Shaw L. Online ethics discussion forum facilitates medical center clinical ethics case reviews. *JONAS Healthc Law Ethics Regul*. 2010;12(1):15-20.
- Schenker Y, Meisel A. Informed consent in clinical care: practical considerations in the effort to achieve ethical goals. *JAMA*. 2011; 305: 1130–1131.
- Snyder L. American College of Physicians Ethics Manual: Sixth edition. *Ann Intern Med*. 2012;156(1, 2):73-104.
- Swetz KM, Thorsteindottir B, Feely MA, Parsi K. Balancing evidence-based medicine, justice in health care, and the technological imperative: A unique role for the palliative medicine clinician. *J Palliat Med*. 2012;15(4):390-391.

Legal

- Alfandre D. Response to: “Do-not-resuscitate orders in suicidal patients: clinical, ethical, and legal Dilemmas.” *Psychosom*. 2011;52(5):498.
- Baumrucker SJ, Sheldon JE, Stolick M, et al. End-of-life care when the state is the guardian. *Am J Hosp Palliat Med*. 2010;27(4):289-294.
- Baumrucker SJ, Stolick M, Morris GM, et al. A cognitively impaired patient without a surrogate: Who makes the decision? *Am J Hosp Palliat Care*. 2011;28(8):583-587.
- Grant M, Elk R, Ferrell B, Morrison RS, von Gunten CF. Current status of palliative care--clinical implementation, education, and research. *CA Cancer J Clin*. 2009;59(5):327-335.

Appendix IV: Scoping Review

- Kramer DB, Kesselheim AS, Salberg L, Brock DW, Maisel WH. Ethical and legal views regarding deactivation of cardiac implantable electrical devices in patients with hypertrophic cardiomyopathy. *Am J Cardiol*. 2011;107(7):1071-1075.e1075.
- Mallia P. Clinical intervention in aging: Ethicolegal issues in assessing risk and benefit. *Clin Interv Aging*. 2010;5:373-380.
- Pope TM. Legal briefing: Conscience clauses and conscientious refusal. *J Clin Ethics*. 2010;21(2):163-176.
- Pope TM. Legal briefing: Informed consent. *J Clin Ethics*. 2010;21(1):72-82.
- Rady MY, Verheijde JL, McGregor JL. Scientific, legal, and ethical challenges of end-of-life organ procurement in emergency medicine. *Resuscitation*. 2010;81(9):1069-1078.

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	Argentum
Academy of Neonatal Nursing	Ariadne Labs
Accountable Care Learning Collaborative	Association for Clinical Pastoral Education
Accreditation Commission for Health Care	Association of Professional Chaplains
Aging Life Care Association	Association of Rehabilitation Nurses
American Academy of Home Care Medicine	Blue Shield of California
American Academy of Hospice and Palliative Medicine	California State University Institute for Palliative Care
American Academy of Nursing	Cambia Health Foundation
American Academy of Pediatrics	Cambia Health Solutions
American Association of Colleges of Nursing	Catholic Health Association of the United States
American Association of Critical Care Nurses	Center for Practical Bioethics
American Association of Neuroscience Nurses	Center to Advance Palliative Care
American Association of Nurse Practitioners	Coalition for Compassionate Care of California
American Board of Internal Medicine	Coalition to Transform Advanced Care
American Cancer Society	College of Pastoral Supervision and Psychotherapy
American Case Management Association	Community Health Accreditation Partner
American College of Surgeons	Discern Health
American Health Care Association	ElevatingHOME & Visiting Nurse Associations of America
American Heart Association/American Stroke Association	Emergency Nurses Association
American Holistic Nurses Association	End of Life Nursing Education Consortium
American Medical Group Association	Excellus BlueCross BlueShield
American Nephrology Nurses Association	Family Caregiver Alliance
American Nurses Association	Gerontological Advanced Practice Nurses Association
American Psychiatric Nurses Association	

Appendix V: Endorsing and Supporting Organizations

HealthCare Chaplaincy Network	National Partnership for Women and Families
Horizon Healthcare Services, Inc.	National Patient Advocate Foundation
Hospice and Palliative Nurses Association	National Pediatric Hospice and Palliative Care Collaborative
Infusion Nurses Society	National POLST Paradigm
Institute for Healthcare Improvement	Neshama: Association of Jewish Chaplains
International Transplant Nurses Society	Northwell Health
LeadingAge	Nurses Organization of Veterans Affairs
Long-Term Quality Alliance	Oncology Nurses Society
National Alliance for Caregiving	Physician Assistants in Hospice and Palliative Medicine
National Association of Catholic Chaplains	Respecting Choices
National Association of Clinical Nurse Specialists	Sigma Theta Tau International Nursing Honor Society
National Association of Home Care and Hospice	Social Work Hospice & Palliative Care Network
National Association of Pediatric Nurse Practitioners	Society of Palliative Care Pharmacists
National Association of Social Workers	Society for Social Work Leadership in Health Care
National Consumer Voice for Quality Long-Term Care	Supportive Care Coalition
National Hospice and Palliative Care Organization	The Conversation Project
National PACE Association	The National Association of Directors of Nursing Administration in Long Term Care
National Palliative Care Research Center	

Supporting Organizations*

Alzheimer's Association	LEAD Coalition
American Association of Colleges of Pharmacy	National Association of Accountable Care Organizations
American Geriatrics Society	National League for Nursing
American Society of Hematology	The Joint Commission
Anthem, Inc.	

**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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American Academy of Home Care Medicine
www.aahcm.org

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

American Health Care Association
www.ahcancal.org

American Medical Group Association
www.amga.org

Association of Professional Chaplains
www.professionalchaplains.org

Center to Advance Palliative Care
www.capc.org

HealthCare Chaplaincy Network
www.healthcarechaplaincy.org

Hospice and Palliative Nurses Association
www.hpna.org

Long-Term Quality Alliance
www.ltqa.org

National Association for Home Care and Hospice
www.nahc.org

National Hospice and Palliative Care Organization
www.nhpco.org

National Palliative Care Research Center
www.npcrc.org

National Pediatric Hospice and Palliative Care Collaborative

National Quality Forum
www.qualityforum.org

Physician Assistants in Hospice and Palliative Medicine
www.pahpm.org

Social Work Hospice & Palliative Care Network
www.swhpn.org

National Consensus Project for Quality Palliative Care

www.nationalcoalitionhpc.org/ncp

