

Pediatric-Hospice and Palliative Medicine Competencies

Version 2.0

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INTRODUCTION

Pediatric Hospice and Palliative Care (P-HPC) is focused on identifying, preventing, and treating the stress and symptoms associated with serious and life-threatening conditions in children¹, their families², and the teams who care for them. Initiated at the time of diagnosis, provided in conjunction with treatments of curative intent, and continued throughout the illness, palliative care includes any intervention that focuses on relieving suffering, slowing the progression of disease, and improving quality of life.

While the specific domains and structures of high-quality palliative care have been comprehensively described in *Clinical Practice Guidelines for Quality Palliative Care*³ and in the *NHPCO Standards of Practice for Pediatric Palliative Care and Hospice*,⁴ providing effective symptom management, facilitating decision making in difficult circumstances, and coordinating care are essential elements for improving patients' and families' suffering.⁵⁻⁹

The Hospice and Palliative Medicine Competencies (version 2.3)¹⁰ describes a competent subspecialist in hospice and palliative medicine (HPM) caring for patients across the age spectrum. In this spectrum of patients with serious and life-threatening conditions, the pediatric population is a minority with specific needs that are similar and different than the rest of the population. The specific competencies appropriate for a pediatric HPM subspecialist, practicing in a pediatric environment, are addressed in this document.

In conjunction with a trained interdisciplinary team, a competent subspecialist in pediatric HPM is equipped to ensure the following:

- Pain and symptom control, psychosocial distress, spiritual issues, and practical needs are addressed with the patient and family throughout the continuum of care and balanced with curative, restorative, life prolonging, and palliative interventions to realize patient- and family-derived goals of care.
- The patient and family obtain the information they need to understand their condition and treatment options. Their values and goals are elicited over time, with sensitivity to relevant cultural issues; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient's condition.
- Care is provided within the context of the evolving physical, emotional, and cognitive development of the patient.
- Care is provided within the context of a trusting and respectful relationship with the patient and family.
- Coordination of care across settings is ensured through regular and high-quality communication among providers, especially at times of transition or changing needs, and through effective continuity of care.
- Both patient and family are prepared for the dying process and for death (when it is anticipated), insofar as they desire to be prepared. Opportunities for meaning making are supported, and bereavement care is available for the patient and family for as long as necessary.

As the field continues to mature, these competencies should serve as a cornerstone for designing the HPM Milestones that will better define the outcome measures for learners and will help establish more effective measures and evaluation methods. In pediatrics, they should be refined for application in training other pediatric subspecialists (critical care, oncology, etc), as well as for learners at other stages of

development (medical students, residents, etc.). They should inform the development of standards of practice- and performance-improvement initiatives for HPM subspecialists and interdisciplinary teams as well as outcome measures for palliative care patients.¹¹

As the field continues to evolve, pediatric HPC's potential role in the comanagement of patients at all stages of disease and in the presence of restorative, curative, and life-prolonging goals will become more important to recognize. These competencies will have to also evolve to mirror these changes in clinical practice and utilization.

1. PATIENT AND FAMILY CARE

The fellow should demonstrate compassionate, appropriate, and effective care based on the existing evidence base in pediatrics and pediatric and adult hospice and palliative medicine and aimed at maximizing the well-being and quality of life for patients with chronic, complex, and/or life-threatening conditions and their families. The fellow should provide care in collaboration with other subspecialists and in concert with an interdisciplinary team.

- 1.1. Gathers comprehensive and accurate information from all pertinent sources, including patients, family members, guardians, other healthcare providers, interdisciplinary team members, and medical records

- 1.1.1. Obtains a comprehensive medical history and physical examination, including:

- Patient and family understanding of illness and prognosis
- Goals of care/advance care planning/proxy decision-making
- Detailed symptom history (including use of validated scales)
- Psychosocial and coping history (including loss history)
- Spiritual history
- Functional assessment
- Quality-of-life assessment
- Neuropsychiatric evaluation of the patient (including stressors and areas of major concern)
- Pharmacologic history, including substance dependency or abuse in the patient or family
- Detailed neurological examination, including mental status examination
- Comprehensive social history outlining the support system for the child and family
- Developmental level and cognitive ability of the child
- Family functioning, including siblings' understanding of the condition, behavior challenges, and supports

- Assessment of the child's role in decision making
- 1.1.2. Performs appropriate diagnostic workup, reviews primary source information and evaluation, and correctly interprets diagnostic tests/procedures
- 1.1.3. Uses information technology, accesses online evidence-based medicine resources, and uses electronic repositories of information and medical records
- 1.2. Synthesizes and applies information in the clinical setting
 - 1.2.1. Develops a prioritized differential diagnosis and problem list
 - 1.2.2. Develops interdisciplinary recommendations for palliative interventions that are aimed at reducing suffering and consistent with patient and family values and goals of care
 - 1.2.3. Routinely obtains additional clinical information from all members of the interdisciplinary team, including other involved clinicians
 - 1.2.4. Assesses and communicates the prognosis to the patient and family
- 1.3. Assesses and manages patients with consideration of their developmental stage and cognitive ability
- 1.4. Assesses and manages patients, incorporating chronic, acute-on-chronic, and emergency care with the full spectrum of pediatric life-threatening conditions and the resultant common sequelae associated with these conditions
- 1.5. Assesses and manages physical symptoms, psychological/behavioral issues, social stressors, and spiritual aspects of the patient's and family's suffering
 - 1.5.1. Assesses and manages symptoms
 - 1.5.2. Uses pharmacologic and nonpharmacologic symptom interventions
 - 1.5.3. Assesses and manages symptoms associated with neuropsychiatric disorders
 - 1.5.4. Assesses and manages physical symptoms and psychosocial and spiritual distress in the patient and family
 - 1.5.5. Understands and addresses the interplay between physical symptoms and psychosocial and spiritual distress
 - 1.5.6. Understands and addresses the interplay between developmental stage and cognitive ability with physical, psychosocial, and spiritual suffering
 - 1.5.7. Reassesses symptoms frequently and makes therapeutic adjustments as needed
- 1.6. Coordinates, orchestrates, and facilitates key events in patient care, such as family meetings, consultation around goals of care, advance care planning, conflict resolution, forgoing or discontinuing life-sustaining therapies, discharge/transfer meetings, and sedation to unconsciousness, involving other team members as appropriate

- 1.7. Provides care to patients and families that reflects unique characteristics of different settings along the palliative care spectrum to ensure smooth transitions across settings of care
 - 1.7.1. Performs appropriate palliative care assessment and management for the home visit, long-term care facility visit, inpatient hospice unit visit, outpatient clinic visit, and hospital patient visit
 - 1.7.2. Delivers timely and accurate information about all settings of the palliative care continuum to patients and families to facilitate choices and ensure smooth transitions across settings of care
 - 1.7.3. Develops awareness of and addresses barriers to patient and family access to palliative care in multiple settings
 - 1.7.4. Works effectively with interdisciplinary team members to assist patients and families in formulating appropriate discharge and transition-of-care plans
 - 1.7.5. Demonstrates an interdisciplinary approach to the development of a birthing plan that optimizes family goals and minimizes suffering for a family managing a fetus diagnosed with a life-threatening condition
- 1.8. Bases care on the patient's past history and patient and family preferences and goals of care, prognostic information, evidence, clinical experience, and judgment
 - 1.8.1. Demonstrates a patient- and family-centered approach to care
 - 1.8.2. Makes recommendations to consulting physicians as appropriate
- 1.9. Demonstrates the ability to respond appropriately to suffering by addressing sources of medical and psychosocial/spiritual distress, bearing with the patient's and family's suffering and distress, and remaining a presence, as desired by the patient and family
 - 1.9.1. Recognizes and seeks to support the psychosocial and emotional needs of siblings by utilizing appropriate members of the interdisciplinary team (eg, child life, social workers, spiritual care providers, etc.)
- 1.10. Demonstrates care that shows respectful attention to age/developmental stage, gender, sexual orientation, culture, religion/spirituality, disability, and family interactions
- 1.11. Seeks to balance a patient's level of function and quality of life with concerns for longevity for patients and families
 - 1.11.1. Evaluates functional status over time
 - 1.11.2. Evaluates quality of life over time
 - 1.11.3. Provides expertise in maximizing patients' level of function and quality of life
 - 1.11.4. Seeks to preserve opportunities for individual and family life in the context of life-threatening conditions
 - 1.11.5. Recognizes the potential value of meaning making, creating a sense of legacy, and completing personal goals to patients and their family members

- 1.11.6. Synthesizes information and explains to the patient and family the potential uses and limitations of technology in balancing quality of life and quantity of life (eg, tracheostomy tube)
- 1.12. Provides patient, family, caregiver, and staff education
 - 1.12.1. Educates families and caregivers in maintaining and improving level of function to maximize quality of life
 - 1.12.2. Explains palliative care services, recommendations, and latest developments to patients, families, and caregivers
 - 1.12.3. Educates patients, families, and caregivers about disease trajectory and the role of palliative care over time in the care plan
 - 1.12.4. Provides education to various community resources involved in the care of the child and the family (eg, schools, community hospices)
- 1.13. Recognizes signs and symptoms of impending death and appropriately cares for imminently dying patients, including care for family members and involved staff
 - 1.13.1. Prepares family, other healthcare professionals, and caregivers for the patient's death
 - 1.13.2. Provides appropriate assessment and symptom management for the imminently dying patient
- 1.14. Provides treatment to the bereaved
 - 1.14.1. Provides support to family members at the time of death and immediately after
 - 1.14.2. Involves interdisciplinary team members in treating the bereaved
 - 1.14.3. Refers family members to bereavement programs
- 1.15. Coordinates care and refers patients and family members to other healthcare professionals to assess, treat, and manage patient and family care issues outside the scope of the palliative care practice and collaborates effectively with them
 - 1.15.1. Recognizes the need for collaboration with clinicians providing disease-modifying and/or symptom-modifying treatment
 - 1.15.2. Collaborates with and makes referrals to practitioners in adult hospice and palliative care (A-HPC) with expertise or clinical practice relevant to the care of pediatric patients with life-threatening conditions (eg, hospice agencies, transitions of care)
 - 1.15.3. Accesses specialized A-HPC resources appropriately
 - 1.15.4. Collaborates effectively with mental health clinicians to meet the needs of patients and family members with major mental health issues

2. MEDICAL KNOWLEDGE

The fellow should demonstrate knowledge about established and evolving biomedical, clinical, population, and social-behavioral sciences relevant to the care of patients with life-threatening conditions and to their families, and relate this knowledge to the hospice and palliative care practice.

- 2.1. Describes the scope and practice of pediatric hospice and palliative care (P-HPC), including:
 - Unique features of suffering for patients, families, and care providers in the care of children with life-threatening conditions
 - Unique features in caring for pediatric patients in regard to physiology, vulnerabilities, development, and decision-making
 - Understanding the cultural biases that affect care of children with life-threatening conditions and their effects on decision-making, grief and bereavement, transitions in care, and the risks and benefits of family-centered care
 - Current standards and best practices of pediatric hospice and palliative medicine (P-HPM)
 - Role of palliative care in comanagement of patients with life-threatening conditions in all stages of disease and in balancing and integrating modalities that are restorative, curative, life prolonging, or palliative and consistent with the patient's and family's goals
 - History of P-HPC, including the evolution of P-HPC
 - Settings where hospice and palliative care are provided
 - Elements of patient assessment and management across different hospice and palliative care settings, including home; hospital; inpatient hospice unit; outpatient clinic; and subacute, rehabilitation, and long-term care facilities
 - The Medicare/Medicaid hospice benefit, including essential elements of the program, eligibility, and key regulations for all levels of hospice care; specific understanding of how these benefits apply to children; and other variables affecting benefits, such as waivers, charity care programs, and local, regional, and federal regulations
 - Barriers faced by patients and families in accessing hospice and palliative care services
- 2.2. Recognizes and describes the role of physical and cognitive development in P-HPM
 - 2.2.1. Describes normal physical and cognitive development of a child, including key developmental milestones, concept of illness and disease, perception and unique sources of suffering and coping, and concept of spirituality and death
 - 2.2.2. Recognizes abnormal physical and cognitive development of a child and its effect on patient function and care
 - 2.2.3. Recognizes that children often assign a meaning to and work to address these perceptions

- 2.2.4. Recognizes the unique sources of coping and distress for a child at each developmental stage and works to maintain the sources of coping and minimize the sources of distress (eg, minimizes separation from family for a toddler, maintains body image for an adolescent)
- 2.3. Recognizes the role of the interdisciplinary team in hospice and palliative care
 - 2.3.1. Describes the role of the palliative care physician in the interdisciplinary team
 - 2.3.2. Identifies the various members of the interdisciplinary team and their roles and responsibilities
 - 2.3.3. Recognizes how and when to collaborate with other allied health professionals, such as dietitians, child-life specialists, expressive therapists, spiritual care providers, physical therapists, respiratory therapists, occupational therapists, speech therapists, and case managers
 - 2.3.4. Describes concepts of team process and recognizes psychosocial and organizational elements that promote or hinder successful interdisciplinary team function
- 2.4. Describes how to assess and communicate prognosis
 - 2.4.1. Identifies which elements of the patient's history and physical examination are critical to formulating prognosis for a given patient
 - 2.4.2. Describes common chronic illnesses with prognostic factors, expected natural course and predictable associated symptoms, trajectories, common treatments, and complications
 - 2.4.3. Describes strategies to communicate and facilitate coping with prognostic information to patients, families, and healthcare providers, including situations where the prognosis and outcome are unclear
- 2.5. Recognizes and describes the presentation and management of pediatric life-threatening conditions, including their epidemiology, evaluation, prognosis, treatment, patterns of disease progression and advanced or metastatic disease, emergencies, complications, associated symptoms, and symptomatic treatments
 - 2.5.1. Identifies common diagnostic and treatment methods in the initial evaluation and ongoing management of pediatric life-threatening conditions
 - 2.5.2. Identifies common elements in prognostication for pediatric life-threatening conditions at various stages, including the natural history of untreated conditions
 - 2.5.3. Identifies signs of advanced disease in pediatric life-threatening conditions
- 2.6. Describes the types of suffering associated with pediatric life-threatening conditions in the patient and family
- 2.7. Explains principles of assessing and treating common symptoms
 - 2.7.1. Describes the concept of "total pain," including the role of the interdisciplinary team in assessing and treating it

- 2.7.2. Explains the relevant basic science, pathophysiology, associated symptoms and signs, and diagnostic options useful in differentiating etiologies of symptoms
- 2.7.3. Describes a thorough, developmentally appropriate assessment of symptoms and functional status, including the use of appropriate diagnostic methods and symptom measurement tools
- 2.7.4. Names common patient, family, healthcare professional, and healthcare system barriers to the effective treatment of symptoms and describes common methods for overcoming these barriers
- 2.7.5. Describes effective collaboration with home-care resources (eg, hospice) in treating symptoms
- 2.8. Describes the pharmacologic treatment of symptoms
 - 2.8.1. Lists the common agents used to treat pain, dyspnea, nausea, vomiting, diarrhea, constipation, anxiety, depression, fatigue, pruritus, confusion, delirium, agitation, spasticity, seizures, and other common problems in palliative care practice
 - 2.8.2. Describes the indications, clinical pharmacology, alternate routes, monitoring of treatment outcomes, appropriate titration, and common side effects for medications commonly used in symptom management (eg, opioid and nonopioid analgesics, adjuvant analgesics, and other pharmacologic approaches)
 - 2.8.3. Describes appropriate prescribing, including off-label indications and uses of pharmacologic interventions
 - 2.8.4. Describes appropriate prescribing in different clinical care settings, such as the home, hospital, intensive care unit, long-term care facility, and inpatient hospice
 - 2.8.5. Describes the challenges unique to the use of opioids in symptom management, including
 - Equianalgesic conversions
 - Concepts of addiction, pseudoaddiction, dependence and tolerance, and their significance in symptom management, as well as approaches to management in patients with current or prior substance abuse
 - Legal and regulatory issues surrounding opioid prescribing
 - Common barriers to effective use of opioids (eg, individual, cultural, conceptual misunderstanding; side effects) and common strategies in overcoming these barriers (eg, family education, clear goals of therapy)
 - 2.8.6. Describes the importance of pain control and sedation during procedures in the care of pediatric patients
 - 2.8.7. Describes effective collaboration with home-care resources (eg, hospice) in treating symptoms
- 2.9. Describes the use of procedural, interventional, and nonpharmacologic approaches to the management of symptoms

- 2.9.1. Identifies indications, risks, and appropriate referral for interventional pain management procedures, including surgical procedures, commonly used for symptom management
- 2.9.2. Identifies indications, risks, management of common side effects, and appropriate referral for radiation therapy
- 2.9.3. Identifies indications, risks, and appropriate referral for commonly used complementary and alternative therapies
- 2.9.4. Explains the role of allied health professions in symptom management
- 2.10. Describes the etiology, pathophysiology, diagnosis, and management of common neuropsychiatric disorders encountered in palliative care practice, such as depression, anxiety, delirium, seizures, and brain injury
 - 2.10.1. Recognizes how to evaluate and treat common neuropsychiatric disorders
 - 2.10.2. Describes how to refer appropriately to neurological and mental health professionals
 - 2.10.3. Describes the indications, contraindications, pharmacology, appropriate prescribing practice, and side effects of common psychiatric medications
 - 2.10.4. Recognizes the diagnostic criteria and management issues of brain death, persistent vegetative state, and minimally conscious state
- 2.11. Recognizes common psychological stressors and disorders experienced by patients and families facing life-threatening conditions, and describes appropriate clinical assessment and management
 - 2.11.1. Recognizes psychological distress in patients, families, and care providers
 - 2.11.2. Describes concepts of coping styles, psychological defenses, and developmental stages relevant to the evaluation and management of psychological distress
 - 2.11.3. Describes how to provide basic, supportive counseling, and coaches families and care providers to maintain important developmentally appropriate supports and to strengthen coping skills
 - 2.11.4. Recognizes the needs of minor children when an adult parent or close relative is seriously ill or dying, and provides appropriate basic counseling or referral
 - 2.11.5. Recognizes the needs of parents and siblings of children who are seriously ill or dying and provides appropriate basic counseling or referral
 - 2.11.6. Explains appropriate utilization of consultation with specialists in psychosocial assessment and management
 - 2.11.7. Explains appropriate strategies to support and educate parents and care providers in recognizing psychological distress in children and appropriate ways to support them, including communication, truth telling, supporting coping, and recognizing when to ask for help

- 2.11.8. Describes typical coping mechanisms and important supports specific to each developmental stage
- 2.12. Recognizes common social problems experienced by patients and families facing life-threatening conditions and describes appropriate clinical assessment and management
 - 2.12.1. Is able to assess, counsel, support, and make referrals to alleviate the burden of caregiving
 - 2.12.2. Is able to assess, provide support, and make referrals around fiscal issues, insurance coverage, and legal concerns
 - 2.12.3. Is able to assess the patient's key relationships, including family structure, and determine legal decision makers and important participants in decision making for the patient
 - 2.12.4. Understands and describes effective strategies to interact with and advocate for children in child protective services
- 2.13. Recognizes common experiences of distress around spiritual, religious, and existential issues for patients and families facing life-threatening conditions, and describes elements of appropriate clinical assessment and management
 - 2.13.1. Describes the role of hope, despair, and meaning making in the context of life-threatening conditions
 - 2.13.2. Describes the role of development in the patient's understanding of spirituality and death
 - 2.13.3. Describes how to perform a basic spiritual/existential/religious evaluation
 - 2.13.4. Describes how to provide basic spiritual counseling
 - 2.13.5. Identifies the indications for referral to spiritual care providers or other spiritual counselors and resources
 - 2.13.6. Knows the developmental processes, tasks, and variations of meaning making for patients at the end of life and their families
 - 2.13.7. Describes processes for facilitating growth and development in the context of advanced illness
 - 2.13.8. Describes a child's developmental understanding of spirituality and death across the age spectrum
 - 2.13.9. Describes to families the child's developmental understanding of spirituality and coaches them on how to best provide support to the child
- 2.14. Is able to recognize, evaluate, and support diverse cultural values and customs with regard to information sharing, decision making, expression and treatment of physical and emotional distress, and preferences for sites of care and death
- 2.15. Recognizes major contributions from nonmedical disciplines such as sociology, anthropology, and health psychology in understanding and managing the patient's and family's experience of serious and life-threatening conditions

- 2.16. Recognizes the components of appropriate management for the syndrome of imminent death
 - 2.16.1. Identifies common symptoms, signs, complications, and variations in the normal dying process and their management
 - 2.16.2. Describes strategies to communicate with the patient and family about the dying process and provide support
- 2.17. Recognizes the elements of appropriate care of the patient and family at the time of death and immediately thereafter
 - 2.17.1. Describes appropriate and sensitive pronouncement of death
 - 2.17.2. Identifies the standard procedural components and psychosocial elements of postdeath care
 - 2.17.3. Recognizes the potential importance and existence of postdeath rituals and how to facilitate them
 - 2.17.4. Recognizes benefits and challenges posed by a death in different care settings (eg, hospital, home) and describes resources and strategies to address them
- 2.18. Describes the basic science, epidemiology, clinical features, natural course, and management options for normal and pathologic grief
 - 2.18.1. Demonstrates knowledge of typical grief patterns and elements of bereavement follow-up, including assessment, treatment, and referral options for bereaved family members
 - 2.18.2. Recognizes the risk factors, diagnostic features, epidemiology, and management of depression and prolonged grief disorder
 - 2.18.3. Recognizes, differentiates, and describes strategies to address grief and bereavement, including the unique features associated with the loss of a child, the role of anticipatory grief in medical decision making, and factors that facilitate and benefit the grieving process prior to and following the death of a child
 - 2.18.4. Appreciates risk of suicide in the bereaved and carries out an initial assessment for suicide risk
 - 2.18.5. Recognizes compassion fatigue and care provider grief and describes the role of and effective strategies for addressing them in patient care
- 2.19. Describes the challenges of utilizing effective strategies for collaborating with A-HPC practitioners and resources in the care of pediatric patients
 - 2.19.1. Recognizes situations in which partnering with A-HPC practitioners and resources is necessary for a P-HPC team in the care of a pediatric patient (eg, home hospice when no pediatric home hospice is available)
 - 2.19.2. Describes the benefits and challenges of utilizing A-HPC practitioners (eg, hospice nurses, adult hospice and palliative medicine [A-HPM] subspecialists) in the care of pediatric patients

- 2.19.3. Assesses the learning needs of and describes effective coaching strategies for A-HPC practitioners in the care of pediatric patients
- 2.19.4. Explains and describes strategies to address the challenges of transitioning care from P-HPC to A-HPC
- 2.20. Describes ethical and legal issues in palliative and end-of-life care and their clinical management
 - 2.20.1. Discusses ethical principles and frameworks for addressing clinical issues
 - 2.20.2. Describes federal, state, and local laws and practices that impact palliative care practice
 - 2.20.3. Consults a clinical ethicist when necessary
 - 2.20.4. Describes professional and institutional ethical policies relevant to palliative care practice

3. PRACTICE-BASED LEARNING AND IMPROVEMENT

The fellow should be able to investigate, evaluate, and continuously improve personal practices in caring for patients and families and appraise and assimilate scientific evidence relevant to palliative care.

- 3.1. Maintains a safe and competent practice, including self-evaluation and continuous learning
 - 3.1.1. Demonstrates an ability to reflect on personal learning strengths, deficiencies, and limits and develop a plan for improvement
 - 3.1.2. Demonstrates knowledge of and commitment to continuing professional development and lifelong learning
 - 3.1.3. Demonstrates knowledge of the roles and responsibilities of the trainee/mentor
 - 3.1.4. Demonstrates the ability to reflect on his or her personal learning style and use different opportunities for learning
 - 3.1.5. Demonstrates the ability to actively seek and use feedback
 - 3.1.6. Demonstrates the ability to develop an effective learning relationship with members of the faculty and other professionals
- 3.2. Accesses, analyzes, and applies the evidence base to clinical practice in palliative care
 - 3.2.1. Demonstrates knowledge of and recognizes limitations of evidence-based medicine in palliative care
 - 3.2.2. Actively seeks to apply the best available evidence to patient care to facilitate safe, up-to-date clinical practice and encourages others to do so
- 3.3. Develops competencies as an educator

- 3.3.1. Recognizes the importance of assessing learning needs in initiating a teaching encounter
- 3.3.2. Reflects on the benefits and drawbacks of alternative approaches to teaching and the role of different teaching techniques to address skills, knowledge, and attitudes
- 3.3.3. Shows respect toward learners and teachers, including children and families
- 3.3.4. Describes the importance of defining measurable learning goals and objectives as a basis for developing educational sessions
- 3.3.5. Demonstrates the ability to supervise clinical trainees (eg, medical students, residents, other healthcare professionals) and effectively give constructive feedback
- 3.4. Demonstrates knowledge of the process, benefits, challenges, and opportunities for scholarly activity and research in palliative care
 - 3.4.1. Recognizes and values the importance of addressing ethical issues in palliative care research
 - 3.4.2. Supports and participates in scholarly activity and research as appropriate to the setting
 - 3.4.3. Recognizes and values the use of data to demonstrate clinical, utilization, and financial outcomes of palliative care
- 3.5. Describes common approaches to quality and safety assurance
 - 3.5.1. Demonstrates an ability to evaluate, design, and implement quality and safety improvement and assurance measures
 - 3.5.2. Demonstrates knowledge of palliative care's clinical, financial, and quality-of-care outcome measures
 - 3.5.3. Demonstrates an awareness of and adherence to patient safety standards

4. INTERPERSONAL AND COMMUNICATION SKILLS

The fellow should be able to demonstrate interpersonal and communication skills that result in effective relationship building, information exchange, emotional support, shared decision making, and collaboration with patients, patients' families, and professional associates.

- 4.1. Initiates informed, relationship-centered dialogues about care
 - 4.1.1. Assesses patient and family wishes regarding the amount of information they wish to receive and the extent to which they want and are able to participate in clinical decision-making
 - 4.1.2. Assesses the developmental level and cognitive understanding of the patient and appropriately includes the patient in medical discussions and decision making

- 4.1.3. Determines, in collaboration with the patient and family, the appropriate participants in discussions concerning the patient's care
- 4.1.4. Demonstrates the ability to identify and include key stakeholders (eg, guardian ad litem, foster families, child protective services/court system, home nursing agencies) in caring and making medical decisions for patients with palliative care needs
- 4.1.5. Assesses patients' and family members' decision-making capacity
- 4.1.6. Assesses patients' and family members' strengths and limitations of understanding and communication
- 4.1.7. Recognizes differences between relationship-centered dialogues in adult and pediatric hospice and palliative care based on physiology, vulnerabilities, developmental stages, and the patient's role in decision making
- 4.2. Demonstrates empathy
 - 4.2.1. Uses empathic and facilitating verbal behaviors, such as naming, affirmation, normalization, reflection, silence, listening, self-disclosure, and humor in an effective, age-appropriate, and culturally appropriate manner
 - 4.2.2. Employs empathic and facilitating nonverbal behaviors such as touch, eye contact, open posture, and eye-level approach in an effective, age-appropriate, and culturally appropriate manner
 - 4.2.3. Allows for appropriate emotional expression from patients, families, care teams, and oneself
- 4.3. Demonstrates the ability to effectively recognize and respond to one's own emotions and those of others
 - 4.3.1. Expresses awareness of one's own emotional state before, during, and after patient and family encounters
 - 4.3.2. Reflects on one's own emotions after a patient and family encounter or related event
 - 4.3.3. Processes one's own emotions in a clinical setting in order to focus on the needs of the patient and family
 - 4.3.4. Responds to requests to participate in spiritual or religious activities and rituals, in a matter that preserves respect for both the patient and family, as well as one's own integrity and personal and professional boundaries
 - 4.3.5. Identifies and corrects one's own communication miscues
 - 4.3.6. Responds effectively to intense emotions of patients, families, and colleagues
- 4.4. Demonstrates the ability to educate patients and families about the medical, social, and psychological issues associated with pediatric life-threatening conditions

- 4.4.1. Demonstrates self-awareness and an ability to recognize differences between the clinician's own and the patient's and family's values, attitudes, assumptions, hopes, and fears related to illness, dying, and grief
- 4.4.2. Recognizes the importance of serving as an educator for the patient, family, and other surrogate decision makers
- 4.4.3. Identifies gaps in knowledge for patients and their families
- 4.4.4. Communicates new knowledge to patients and families, adjusting language and complexity of concepts based on the families' level of sophistication, understanding, and values, as well as on the developmental stage and cognitive ability of the patient
- 4.4.5. Educates patients and families about normal developmental processes, achievement of a satisfactory sense of legacy, and the possibilities for growth and healing at the end of life, including eliciting the child's wishes and desires
- 4.4.6. Educates patients and families regarding the balance of life plans and resources at the end-of-life and is able to work toward a solution and balance when multiple desires cannot be met
- 4.4.7. Recognizes ambivalence about care options and treatments and exhibits appropriate strategies to address it
- 4.4.8. Identifies patients and families who may benefit from a language translation service or interpreter
- 4.4.9. Educates patients and families with special needs about available and appropriate resources
- 4.4.10. Educates parents and legal surrogates in preparation for their role as medical decision makers
- 4.5. Assesses and uses age-, gender-, and culturally appropriate concepts and language when communicating with patients and families
 - 4.5.1. Routinely assesses patients and families to identify individuals who might benefit from age-, gender-, and culturally appropriate interventions or support
 - 4.5.2. Shows sensitivity to developmental stages and processes in approaching patients and families
 - 4.5.3. Appreciates the need to adjust communication strategies to honor different cultural beliefs
 - 4.5.4. Avoids euphemisms in explaining medical issues
 - 4.5.5. Identifies and reflects language appropriate to the patient's age, development, personality, and cognitive understanding
- 4.6. Demonstrates the above skills in the following paradigmatic situations with patients or families and documents a comprehensive, informative, sensitive note in the medical record:

- Sharing information (eg, giving bad news)
- Discussing the balance of interventions including curative, restorative, life-prolonging, and palliative-focused interventions in an attempt to realize goals of care
- Discussing the sharing of information with family members who want to protect the patient from distressing information
- Addressing care that is potentially harmful, nonbeneficial, or inconsistent with the goals of care with the patient, family, and care team
- Addressing the patient's and family's emotional distress about talking about death, dying, and end-of-life issues
- Introducing the option of palliative care consultation
- Discussing and establishing goals of care with patients and their families
- Discussing advance care planning and resuscitation status, including the use of tools such as MY Wishes and Five Wishes
- Discussing appropriate care settings for patients and their families
- Discussing the needs of a dying patient with parents
- Discussing the needs of siblings of a dying patient
- Discussing the needs of parents and family of a dying patient
- Discussing the needs of minor children of dying adults
- Discussing forgoing or discontinuing any life-sustaining therapy that is no longer beneficial
- Discussing continuation of life-sustaining or prolonging therapy with a focus on palliation and quality of life
- Discussing enrollment into hospice
- Dealing with requests for physician aid in dying
- Discussing palliative sedation
- Discussing the continuation or withdrawal of medically provided nutrition and hydration
- Discussing severe spiritual or existential suffering
- Referring to age-appropriate tasks of life review and meaning making, including relationships, sexuality, and social and spiritual aspects of life
- Saying good-bye to patients and families
- Pronouncing death in the presence of a patient's family

- Writing condolence notes and making bereavement calls and visits
- 4.7. Organizes and leads or cofacilitates a family meeting
 - 4.7.1. Identifies when a family meeting is needed
 - 4.7.2. Identifies appropriate goals for a family meeting
 - 4.7.3. Demonstrates a stepwise approach to leading a family meeting
 - 4.7.4. Demonstrates techniques for mediating intrafamily, family/healthcare team, and intra-healthcare team conflict
 - 4.7.5. Documents the course and outcome of a family meeting in the medical record
 - 4.8. Collaborates effectively with others as member or leader of an interdisciplinary team (IDT)
 - 4.8.1. Facilitates efficient team meetings
 - 4.8.2. Accepts and solicits insights from interdisciplinary team members regarding patient and family needs in developing a comprehensive plan of care
 - 4.8.3. Manages and recognizes the need for conflict resolution in IDT meetings
 - 4.8.4. Provides constructive feedback to IDT members
 - 4.8.5. Accepts and effectively incorporates feedback from IDT members
 - 4.9. Collaborates and develops effective relationships with referring physicians, consultant physicians, and other healthcare providers
 - 4.9.1. Provides a concise verbal history and physical exam presentation for a new palliative care patient
 - 4.9.2. Summarizes the active palliative care issues and treatment recommendations for a known patient in signing out to or updating a colleague
 - 4.9.3. Uses referring and consultant clinicians and allied health professionals in evaluating and determining the prognosis and treatment plans for patients with life-threatening conditions, as well as for specific complications and symptoms
 - 4.9.4. Communicates with referring and consultant clinicians about the care plan and recommendations for the patient and family
 - 4.9.5. Communicates with healthcare providers when there is disagreement about plans or goals of care
 - 4.9.6. Works toward consensus building about treatment plans and goals of care
 - 4.9.7. Supports and empowers colleagues to lead and participate in family meetings
 - 4.9.8. Elicits concerns from and provides emotional support and education to staff involved in difficult decisions and care scenarios

- 4.10. Maintains comprehensive, timely, and legible medical records
 - 4.10.1. Documents comprehensive notes in the medical record in a timeframe with individual program and institutional requirements and regulatory agencies
 - 4.10.2. Adapts documentation to different medical record formats available or required in different settings
 - 4.10.3. Addresses the major domains of palliative care as appropriate, in the initial history and physical exam
 - 4.10.4. Consistently includes all relevant domains of palliative care in progress notes and follow-up documentation
 - 4.10.5. Documents death pronouncement in the medical record and completes the death certificate in a correct and timely manner
 - 4.10.6. Appropriately documents bereavement follow up and plan in the medical record following a patient's death

5. PROFESSIONALISM

The fellow should be able to demonstrate a commitment to carrying out professional responsibilities, awareness of his or her role in reducing suffering and enhancing quality of life, adherence to ethical principles, sensitivity to a diverse patient population, and appropriate self-reflection.

- 5.1. Achieves balance among the needs of patients, families, and team members while balancing one's own needs for self-care
 - 5.1.1. Recognizes the signs of fatigue, compassion fatigue, burnout, and personal distress in self and colleagues
 - 5.1.2. Describes effective strategies for self-care, including balance; emotional support; and dealing with fatigue, compassion fatigue, burnout, and personal loss and distress
 - 5.1.3. Contributes to team wellness
 - 5.1.4. Explains how to set appropriate boundaries with colleagues, patients, and families
- 5.2. Recognizes one's own role and the role of the system in disclosure and prevention of medical error
 - 5.2.1. Assesses personal behavior and accepts responsibility for errors when appropriate
 - 5.2.2. Discloses medical errors in accordance with institutional policies and professional ethics
- 5.3. Demonstrates accountability to patients, society, and the profession and a commitment to excellence

- 5.3.1. Recognizes one's own professional responsibility to reduce suffering and enhance quality of life
- 5.3.2. Communicates the mission of palliative care to hospital administrators, clinicians, and the community
- 5.4. Describes the professional role and responsibility of a palliative care physician and hospice medical director in terms of quality of care, compliance, and communication with other professionals
- 5.5. Fulfills professional commitments
 - 5.5.1. Responds in a timely manner to requests from patients and families for medical information
 - 5.5.2. Responds to requests for help from colleagues
 - 5.5.3. Asks for help from colleagues
 - 5.5.4. Demonstrates accountability for personal actions and plans
 - 5.5.5. Fulfills professional responsibilities and works effectively as a team member
 - 5.5.6. Addresses concerns about quality of care and impaired performance among colleagues
 - 5.5.7. Treats coworkers with respect, dignity, and compassion
- 5.6. Demonstrates knowledge of ethics and law that should guide the care of patients, including special considerations around these issues across the age spectrum, including:
 - Informed consent and assent
 - Medical futility
 - Physician-assisted suicide
 - Indications for referring to an ethics consultant
 - Foregoing or discontinuing life-sustaining treatment
 - Confidentiality
 - Truth telling
 - Disclosure
 - Decision making
 - Surrogacy and the limits of surrogate decision making
 - Decision-making capacity
 - Conflicts of interest

- Use of medical hydration and nutrition
 - Euthanasia
 - Research ethics
 - Nurse/physician collaboration
 - Principle of double effect
 - Organ donation
- 5.7. Demonstrates respect and compassion toward all patients and their families as well as toward other clinicians
- 5.7.1. Demonstrates willingness and ability to identify one's own assumptions, individual and cultural values, hopes and fears related to life-threatening conditions and injuries, age, disability, dying, death, and grief
- 5.7.2. Displays sensitivity to issues surrounding age, ethnicity, sexual orientation, culture, spirituality and religion, and disability
- 5.8. Demonstrates the capacity to reflect on personal attitudes, values, strengths, vulnerabilities, and experiences to optimize personal wellness and capacity to meet the needs of patients and families
- 5.8.1. Recognizes the potential impact of being both a caregiver (including a parent) and a professional

6. SYSTEMS-BASED PRACTICE

The fellow should be able to demonstrate an awareness of and responsiveness to the larger context and system of health care, including hospice and other community-based services for patients and families, and the ability to effectively call on system resources to provide high-quality care.

- 6.1. Demonstrates care that is cost-effective and represents best practices
- 6.1.1. Recognizes relative costs of medications and other therapeutics and interventions
- 6.1.2. Implements best evidence-based practices for common palliative medicine scenarios across settings
- 6.1.3. Explains the rationale for the use of medication formularies
- 6.1.4. Identifies similarities and differences among reimbursements for palliative medicine, hospice, hospital, home health, and long-term care
- 6.1.5. Describes basic concepts and patterns of physician billing, coding, and reimbursement across settings
- 6.1.6. Describes the common pathways to achieving resources that balance hospice and palliative interventions with disease-directed interventions

- 6.1.7. Recognizes the need to balance home nursing and hospice services for children with special healthcare needs
- 6.2. Evaluates and implements systems improvements based on clinical practice or patient and family satisfaction data, in personal practice, in team practice, and within institutional settings
 - 6.2.1. Reviews pertinent clinical or patient and family satisfaction data about personal, team, or institutional practice patterns
- 6.3. Integrates knowledge of the healthcare system in developing plans of care
 - 6.3.1. Describes policies and procedures of pertinent healthcare systems
 - 6.3.2. Describes the philosophy, admissions criteria, range of services, and structure of hospice care, including up-to-date federal and state provisions for care, such as concurrent care
 - 6.3.3. Recognizes resources and barriers relevant to the care of specialized populations in hospice and palliative medicine and has basic knowledge of how to mobilize appropriate support for these populations
 - 6.3.4. Recognizes that not all hospice and palliative care organizations and providers are equipped or trained to care for children
 - 6.3.5. Demonstrates the ability to ascertain the needs of an organization wishing to provide palliative or hospice care to infants and children, including staffing, training, equipment, and pharmacy needs
 - 6.3.6. Demonstrates the ability to respond to gaps in infrastructure and programs that provide services to children and their families
 - 6.3.7. Effectively uses supporting services that provide support to children with life-threatening conditions and their families, including “wish foundations,” camp and respite programs, and bereavement services
- 6.4. Demonstrates knowledge of the various settings and related structures for organizing, regulating, and financing care for patients with palliative care needs
 - 6.4.1. Describes differences in admission criteria for various settings, such as hospitals, palliative care units, skilled-nursing and assisted-living facilities, acute/subacute rehabilitation facilities, and long-term acute care settings, as well as traditional home hospice
 - 6.4.2. Describes the models for financing hospice and palliative resources for children, including state Medicaid waiver programs, federal Title 5 programs, and charity care
- 6.5. Collaborates with all elements of the palliative care continuum, including hospitals, palliative care units, nursing homes, long-term care facilities, home and inpatient hospice, schools, and other community resources
 - 6.5.1. Utilizes members of the interdisciplinary team to create smooth and efficient transitions across healthcare settings for patients and families

- 6.5.2. Communicates with care managers and appropriate staff across sites to enable seamless transitions between settings
- 6.5.3. Communicates with clinicians at the time of care transitions to clarify and coordinate the care plan across settings
- 6.5.4. Demonstrates approaches to help school staff address and care for children who receive palliative and bereavement services and who may need individualized plans that include emergency responses and requests for limits to resuscitation
- 6.5.5. Identifies challenges to providing palliative care and related services for children in the context of specific organizational policies and the laws of the local community and state
- 6.6. Advocates for quality patient and family care and assists patients and families in dealing with system complexities
 - 6.6.1. Communicates and supports patient and family decision-making about discharge planning, including settings of care, service options, and reimbursement and payer systems
 - 6.6.2. Coordinates and facilitates dialogue among patients and families and service provider representatives (eg, hospice liaison nurses; nursing home administrators; and interhospital departments including but not limited to ICU, intermediate care, and the emergency department)
 - 6.6.3. Identifies targets for advocacy (organizational, governmental, and nongovernmental) to improve the lives of children and families who can benefit from palliative care
 - 6.6.4. Describes methods for effective advocacy to assist patients and families dealing with system complexities
- 6.7. Partners with healthcare managers and healthcare providers to assess, coordinate, and improve patient safety and health care and understands how these activities can affect system performance
 - 6.7.1. Describes hospital and palliative care program continuous quality improvement programs and their goals and processes
 - 6.7.2. Demonstrates ability to work with professionals and care providers of varying disciplines to improve patient safety and system-based factors that affect care delivery

NOTES and REFERENCES

1. Definition of a pediatric patient: In P-HPC the term “patient” refers to all ages of pediatric patients, whether the patient is a fetus in the perinatal period, infant, child, adolescent, or young adult.
2. Definition of family: “The term family is used broadly to encompass all those persons of importance to the patient, as defined by the patient.”¹ The term includes persons who have the best interests of the child in mind and may include caregivers other than family (eg, parents who are divorced, extended family members, foster parents, guardians).
3. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*. 3rd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2013. Available at http://nationalconsensusproject.org/Guidelines_Download2.aspx. Accessed November 14, 2014.
4. National Hospice and Palliative Care Organization. *Standards for Pediatric Palliative and Hospice Care Advancing Care for America’s Children*. Washington, DC: National Hospice and Palliative Care Organization; 2009. Available at <http://www.nhpco.org/i4a/pages/index.cfm?pageID=5874>. Accessed November 14, 2014.
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6. Committee on Psychosocial Aspects of Child and Family Health. The assessment and management of acute pain in infants, children, and adolescents. *Pediatrics*. 2001;108(3):793-797.
7. American Academy of Pediatrics Committee on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics*. 2013;132:966. Originally published online October 28, 2013 (doi: 10.1542/peds.2013-2731)
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11. Klick JC, Friebert S, Hutton N, et al. Developing competencies for pediatric hospice and palliative medicine. *Pediatrics*. published online: November, 17th, 2014 (doi: 10.1542/peds.2014-0748)