BCM Pediatric Palliative Care Fellowship Rotation: Hospice

Rotation description:

Houston Hospice is a nonprofit hospice organization that cares for both adults and children. They have a home-based hospice program as well as an inpatient hospice unit.

Memorial Hermann Hospice is a nonprofit hospice organization that cares for both adults and children. They have a home-based hospice program.

- 1. The fellow will spend two, 4-week block rotations with hospice, 4 weeks of pediatric hospice (with Houston Hospice) and 4 weeks of adult hospice (2 weeks on the Houston Hospice inpatient unit and 2 weeks with Memorial Hermann on home visits).
- 2. Rotation coordinators:
 - Houston hospice pediatric rotation: Dr. Nancy Glass. Contact: nlglass@texaschildrens.org
 - Houston hospice adult inpatient unit rotation: Dr. Elizabeth Strauch. Contact: estrauch@houstonhospice.org
 - Memorial Hermann rotation: Dr. Patrick Jones. Contact: Patrick.jones3@memorialhermann.org
- 3. Participate in daily hospice visits with representatives from each discipline in the IDT.
- 4. Participate in inpatient visits with patients on the inpatient hospice unit.

<u>Clinical experience</u>: Bedside teaching from hospice physicians and IDT members in the home setting and on the inpatient unit.

<u>Didactic experience</u>: Meeting with hospice medical director about hospice rules and regulations. Directed readings.

Fellow responsibilities:

Daytime: Fellows will participate in home visits and inpatient hospice unit visits with members of the hospice IDT.

Call: No weekday or weekend call.

Evaluation and Feedback:

- 1. Timely verbal feedback provided by faculty throughout rotation.
- 2. Structured written evaluation of fellow by site director using American Academy of Hospice and Palliative Medicine evaluation tools at end of rotation.
- 3. Fellow provides feedback to program director about rotation at end of rotation.

Goals and Objectives for BCM Pediatric Palliative Care Fellowship

Rotation: Hospice

Goals and objectives based on Pediatric Hospice and Palliative Medicine Competencies, version 2.0

Competency 1: Patient and family care: The fellow should demonstrate compassionate, appropriate, and effective care based on existing evidence base in both pediatric and adult 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 who are enrolled in hospice. The fellow should learn about and collaborate with the hospice interdisciplinary team.

- 1. Obtain a comprehensive history and exam including:
 - A. Goals of care and advance care planning
 - B. Detailed symptom history
 - C. Psychosocial and spiritual history
 - D. Functional assessment
 - E. Quality of life assessment
 - F. Developmental age of the child
- 2. Formulate a complete care plan utilizing evidence-based palliative medicine and including all members of an interdisciplinary team.
 - A. Use both pharmacologic and non-pharmacologic pain management interventions
 - B. Assess and manage non-pain symptoms including nausea, vomiting, constipation, fatigue, depression, anxiety, dyspnea, delirium, and pruritus.
 - C. Understand and address the interplay between physical symptoms and psychosocial and spiritual distress.
 - D. Assess and manage psychosocial and spiritual distress in the patient and family.
- 3. Apply knowledge to facilitate key events in palliative care including family meetings, goals of care discussions, advance care planning, and discussions surrounding forgoing or discontinuing life-sustaining therapies.
- 4. Demonstrate ability to respond appropriately to suffering by addressing sources of medical, psychosocial, and spiritual distress, bearing with patient's and family's suffering and distress, and remaining a presence, as desired by patient and family.
 - A. Recognizes and seeks to support the psychosocial and emotional needs of siblings by utilizing appropriate members of the interdisciplinary team.
- 5. Construct plans that balance a patient's level of function and quality of life with concerns for longevity
- 6. Demonstrate effective coordination of patient care, both from within an interdisciplinary palliative care team, with other palliative care providers including hospice teams, and in collaboration with colleagues outside of palliative care.
- 7. Balance a patient's level of function and quality of life with concerns for longevity for patients and families.
 - A. Evaluate changes in functional status over time
 - B. Evaluate quality of life over time
 - C. Demonstrate expertise in maximizing patients' level of function and quality of life over time.
 - D. Recognizes the potential value of meaning making, creating a sense of legacy, and completing

Personal goals to patients and their family members.

- 8. Provide patient, family, caregiver, and staff education.
 - A. Educate families and caregivers in maintaining and improving level of function to maximize quality of care.
 - B. Explain palliative care services, recommendations, and latest developments to patients, families, and caregivers.
 - C. Provides education to various community resources involved in the care of the child and family.
- 9. Recognize signs/symptoms of impending death, prepare patient and family, and appropriately care for dying patients, including care for family members and involved staff.
 - A. Prepare family, caregivers, and other healthcare professionals for the patient's death.
 - B. Provide appropriate assessment and symptom management for the imminently dying patient.
- 10. Provide treatment to the bereaved in collaboration with members of interdisciplinary team.
 - A. Provide support to family members at the time of death and immediately after.
 - B. Refer family members to bereavement programs.

Competency 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 setting.

- 1. Describe the scope and practice of pediatric hospice and palliative medicine including:
 - A. Unique features of suffering for patients, families, and care providers in the care of children with life-threatening conditions.
 - B. Unique features in caring for pediatric patients in regard to physiology, vulnerabilities, development, and decision-making.
 - C. Current standards and best practices of pediatric hospice and palliative medicine.
 - D. 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.
 - E. Role of palliative care in co-management 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.
 - F. History and evolution of pediatric hospice and palliative medicine.
 - G. Settings where hospice and palliative care are provided.
 - H. Barriers faced by patients and families in accessing hospice and palliative care services.
- 2. Recognize the role and importance of an interdisciplinary team in pediatric palliative care.
 - A. Describe the role of the palliative care physician in the interdisciplinary team.
 - B. Identify the various members of the interdisciplinary team and their roles and responsibilities.
 - C. Describe concepts of team process and recognizes psychosocial and organizational elements that promote or hinder successful interdisciplinary team function.
- 3. Describe how to assess and communicate prognosis
 - A. Identify which elements of the patient's history and physical examination are critical to formulating prognosis.
 - B. Describe common chronic illnesses with prognostic factors, expected natural course, and predictable associated symptoms, trajectories, common treatments, and complications.
- 4. Recognize and describe the management of pediatric life-threatening conditions including epidemiology, evaluation, prognosis, treatment, and patterns of progression.

- A. Identify common diagnostic and treatment methods in the initial evaluation and ongoing management of pediatric life-threatening conditions.
- B. Identify signs of advanced disease in pediatric life-threatening conditions.
- 5. Explain principles of assessing and treating common symptoms.
 - A. Describe the concept of "total pain," including the role of the interdisciplinary team in assessing and treating it.
 - B. Explain the relevant basic science, pathophysiology, associated symptoms and signs, and diagnostic options useful in differentiating etiologies of symptoms.
 - C. Describe a thorough, developmentally appropriate assessment of symptoms and functional status, including the use of appropriate diagnostic methods and symptom measurement tools.
 - D. Name common patient, family, healthcare professional, and healthcare system barriers to the effective treatment of symptoms and describes common methods for overcoming these barriers.
- 6. Describe the pharmacologic treatment of symptoms.
 - A. List 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.
 - B. Describe the indications, clinical pharmacology, alternate routes, monitoring of treatment outcomes, appropriate titration, and common side effects for medications commonly used in symptom management (e.g., opioid and non-opioid analgesics, adjuvant analgesics, and other pharmacologic approaches).
 - C. Describe appropriate prescribing in different clinical care settings, such as the home, hospital, intensive care unit, long-term care facility, and inpatient hospice.
 - D. Describe the challenges unique to the use of opioids in symptom management including:
 - 1. Equianalgesic conversions
 - 2. Concepts of addiction, pseudoaddiction, dependence, tolerance, and withdrawal.
 - 3. Legal and regulatory issues surround opioid prescribing.
 - 4. Common barriers to effective use of opioids (e.g., individual, cultural, conceptual misunderstanding; side effects) and common strategies to overcome these barriers (e.g., family education, clear goals of therapy).
- 7. Describe the use of procedural, interventional, and non-pharmacologic approaches to the management of symptoms.
 - A. Identify indications, risks, and appropriate referral for interventional pain management procedures, including surgical procedures, commonly used for symptom management.
 - B. Identify indications, risks, management of common side effects, and appropriate referral for radiation therapy.
 - C. Identify indications, risks, and appropriate referral for commonly used complementary and alternative therapies.
 - D. Explains the role of allied health professions in symptom management.
- 7. Describe the etiology, pathophysiology, diagnosis, and management of common neuropsychiatric disorders encountered in palliative care practice, such as depression, anxiety, delirium, seizures, and brain injury.
 - A. Recognize how to evaluate and treat common neuropsychiatric disorders.
 - B. Describe how to refer appropriately to neurological and mental health professionals.
 - C. Describe the indications, contraindications, pharmacology, appropriate prescribing practice, and side effects of common psychiatric medications.
 - D. Recognize the diagnostic criteria and management issues of brain death, persistent vegetative state, and minimally conscious state.

- 8. Recognize common psychological stressors and disorders experienced by patients and families facing life-threatening conditions, and describes appropriate clinical assessment and management.
 - A. Recognize psychological distress in patients, families, and care providers.
 - B. Describe how to provide basic, supportive counseling, and coaches families and care providers to maintain important developmentally appropriate supports and to strengthen coping skills.
 - C. Recognize the needs of parents and siblings of children who are seriously ill or dying and provides appropriate basic counseling or referral.
 - D. Explain appropriate utilization of consultation with specialists in psychosocial assessment and management.
 - E. Explain 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.
 - F. Describe typical coping mechanisms and important supports specific to each developmental stage.
- 9. Recognize common social problems experienced by patients and families facing life-threatening conditions and describes appropriate clinical assessment and management.
 - A. Assess, counsel, support, and make referrals to alleviate the burden of caregiving.
 - B. Assess, provide support, and make referrals around fiscal issues, insurance coverage, and legal concerns.
- 10. Recognize 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.
 - A. Describe the role of hope, despair, and meaning making in the context of life-threatening conditions.
 - B. Describe the role of development in the patient's understanding of spirituality and death.
 - C. Describe how to perform a basic spiritual/existential/religious evaluation.
 - D. Identify the indications for referral to spiritual care providers or other spiritual counselors and resources.
 - E. Know the developmental processes, tasks, and variations of meaning making for patients at the end of life and their families.
- 11. 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.
- 12. Recognize the components of appropriate management for the syndrome of imminent death.
 - A. Identify common symptoms, signs, complications, and variations in the normal dying process and their management.
 - B. Describe strategies to communicate with the patient and family about the dying process and provide support.
- 13. Recognize the elements of appropriate care of the patient and family at the time of death and immediately thereafter.
 - A. Describe appropriate and sensitive pronouncement of death.
 - B. Identify the standard procedural components and psychosocial elements of post-death care.
 - C. Recognize the potential importance and existence of post-death rituals and how to facilitate them.
 - D. Recognize benefits and challenges posed by a death in different care settings (e.g., hospital, home) and describes resources and strategies to address them.

- 14. Describe the basic science, epidemiology, clinical features, natural course, and management options for normal and pathologic grief.
 - A. Demonstrate knowledge of typical grief patterns and elements of bereavement follow-up, including assessment, treatment, and referral options for bereaved family members.
 - B. Recognize, differentiate, and describe 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.
- 15. Describe ethical and legal issues in palliative and end-of-life care and their clinical management.
 - A. Discuss ethical principles and frameworks for addressing clinical issues.
 - B. Describe federal, state, and local laws and practices that impact palliative care practice.
 - C. Describe professional and institutional ethical policies relevant to palliative care practice.
 - D. Describe the function of the Medicare Hospice Benefit.

Competency 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 relative to hospice care.

Objectives: At the completion of this rotation, the palliative care fellow will be able to:

- 1. Utilize self-evaluation and feedback from interdisciplinary team to appraise his/her performance and continually improve.
- 2. Integrate hospice experience with that already possessed from inpatient palliative care in order to improve process of transition of patients from inpatient care to hospice care.
- 3. Identify knowledge gaps in the course of providing patient care and cultivate the habit of continuous inquiry to expand one's knowledge base.
- 4. Demonstrate a habit of critical thinking, evidence-based decision-making, and continuous quality improvement.

Competency 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.

Objectives: At the completion of this rotation, the palliative care fellow will be able to:

- 1. Initiate informed, relationship-centered dialogues about care.
 - A. Assess 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.
 - B. Assess the developmental level and cognitive understanding of the patient and appropriately include the patient in medical discussions and decision making.
 - C. Assess patients' and family members' decision-making capacity.
 - D. Assess patients' and family members' strengths and limitations of understanding and communication.
- 2. Demonstrate empathy.

- A. Use 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.
- B. Employ 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.
- C. Allow for appropriate emotional expression from patients, families, care teams, and oneself.
- 3. Demonstrate the ability to effectively recognize and respond to one's own emotions and those of others.
 - A. Express awareness of one's own emotional state before, during, and after patient and family encounters.
 - B. Process one's own emotions in a clinical setting in order to focus on the needs of the patient and family.
 - C. Respond 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.
 - D. Identify and correct one's own communication miscues.
 - E. Respond effectively to intense emotions of patients, families, and colleagues.
- 4. Demonstrate the ability to educate patients and families about the medical, social, and psychological issues associated with pediatric life-threatening conditions.
 - A. Demonstrate 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.
 - B. Communicate 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.
 - C. Recognizes ambivalence about care options and treatments and exhibits appropriate strategies to address it.
- 5. Assess and use age-, gender-, and culturally appropriate concepts and language when communicating with patients and families.
 - A. Routinely assess patients and families to identify individuals who might benefit from age, gender-, and culturally appropriate interventions or support.
 - B. Appreciate the need to adjust communication strategies to honor different cultural beliefs.
 - C. Avoid euphemisms in explaining medical issues.
- 7. Collaborate effectively with others as member of an interdisciplinary team.
 - A. Accept and solicit insights from interdisciplinary team members regarding patient and family needs in developing a comprehensive plan of care.
 - B. Accept and effectively incorporate feedback from team members.

Competency 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.

Objectives: At the completion of this rotation, the palliative care fellow will be able to:

1. Demonstrate care that shows respectful attention to age/developmental stage, gender, sexual orientation, culture, religion/spirituality, disability, and family interactions.

- 2. Demonstrate ability to balance the needs of patients, families, and team members with one's own need for self-care.
- 3. Demonstrate knowledge of ethics and law related to the hospice care.
- 4. Recognize his/her own limits and ask for help when needed.

Competency 6: Systems-based practice: The fellow should be able to demonstrate an awareness of and responsiveness to the system of hospice care within the overall realm of the healthcare system.

- 1. Assess the value of care provided and advocate for care that is cost-effective and represents best practices.
- 2. Distinguish between the role of inpatient palliative care physician and hospice physician.
- 3. Describe the unique role of a hospice medical director and his/her function within the healthcare system.
- 4. Demonstrates understanding of financial resources and payment systems for hospice including the Medicare Hospice Benefit.
- 5. Collaborates effectively with colleagues spanning the palliative care continuum including hospitals, nursing homes, long-term care facilities, and hospice agencies.