Level Up: The Utility of the "Advanced Comfort Kit" at End of Life in the Pediatric Population (TH306)

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Objectives

- Recognize pediatric palliative care diagnoses and symptomatology that may require advanced symptom management at the end of life.
- Understand the different mechanisms of action of the varied drug options considered for use at pediatric end of life.
- Develop a multifactorial end of life care plan for pediatric patients in the outpatient hospice or inpatient setting.

Although evidence-based guidelines exist for pain and symptom management and palliative sedation at the end of life, many pediatric cases exhibit refractory symptoms that require a multimodal approach to facilitate a comfortable death. Researchers have documented that the etiology of refractory symptoms tend to be overlapping and variable. These refractory symptoms can include physical, emotional, and existential suffering. Clinical practice patterns have illuminated the need for an innovative approach to pediatric end of life management. Providers should be knowledgeable and flexible in their approach of advanced symptoms at the end of life. A multidisciplinary approach that includes anticipatory planning and access to resources in the face of refractory symptoms at the end-of-life in any setting is also crucial for success.

Many pediatric palliative care (PPC) providers express some distress with managing refractory symptoms at end of life when the cause of the escalating symptoms is not clear-cut and the dosing of medications is atypical. The differing levels of resources and support in the home hospice setting make this situation particularly challenging. As a result, it is important for PPC providers to learn from the experiences and resource utilization from their colleagues. Through the use of didactics, case examples and discussions, this workshop will highlight a practical and step-wise approach to refractory symptom management at pediatric end of life. Practical elements of this process will include a case based review of pain and symptom assessment, a review of pharmacologic tools and mechanism of action, a step-wise approach for pharmacologic escalation in responsive to refractory symptoms, and resource utilization in both the inpatient and home hospice settings. This workshop will also highlight how PPC providers can support one another during and after the emotionally, physically, and morally charged management of these refractory symptoms.

Surgical and Perioperative Palliative Care: Updates from 2018 (TH307)

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Objectives

- Cite recently published literature on evidence and best practices for palliative care interventions in surgical patients.
- Discuss areas of active surgical palliative care investigation in the context of common treatment dilemmas faced while caring for seriously ill patients with surgical disease.
- Describe the application of surgical palliative care research and its impact on patient, family, and caregiver outcomes using concrete examples.

Recent years have seen rapid expansion of the evidence base supporting the implementation of palliative care programs across health systems, ranging from the community to the intensive care unit. Surgical patients face uniquely complex decisions, significant symptom burden, and prognostic uncertainty, and their needs warrant surgery-specific palliative care delivery. Different models have been developed to address these needs, including communication training for surgical providers, embedded inpatient and outpatient surgical palliative care programs, improved prognostication models, and advanced care planning interventions. The core principles of surgery and anesthesiology closely mirror those of palliative care, and the intersection between them is characterized by an increasing annual volume of emerging research. This session will summarize landmark peer-reviewed papers on surgical palliative care published in 2018. The authors will search PubMed and hand-review key journals in surgery, anesthesiology, critical care, and palliative medicine to identify and select articles for inclusion based on journal impact factor and broad interest to the AAHPM/HPNA audience. Using a case-based format to provide clinical context, the panel will present literature drawn from the following topic domains: communication around surgical decision-making, frailty and surgical risk assessment, perioperative advanced care planning, specialty palliative care triggers and delivery models for surgical patients, innovative caregiver and clinician education strategies, and novel symptom management approaches applicable to surgical patient populations. The presenters consist of an HPM fellowship-trained practicing general surgeon and HPM-focused anesthesiologist, an HPM social worker with a specialized practice in surgical oncology and critical care, and an HPM physician whose clinical and academic interests are focused on surgical patient populations. The cross-specialty representation of the panelists ensures a diversity of perspectives that will enrich the audience's appreciation for the role of surgical palliative care research in improving the outcomes of patients and families facing surgical illness across an array of care settings.

Introduction to a Novel Palliative Care Intervention for Family Caregivers of Children and Adolescents Living with Rare Diseases (TH308)

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Objectives

- Establish the need for a family caregiver intervention for parents of children with rare diseases.
- Introduce the intervention and its components.
- Disseminate findings from the piloting of this intervention.

In the U.S. a rare disease is defined as a condition affecting fewer than 200,000 persons. Pediatric patients with rare diseases experience high mortality. Pediatric advance care planning (pACP), a key component of pediatric palliative care, has been proven to improve communication and spiritual and emotional well-being for children with cancer and HIV and their families. For providers, pACP, involves preparation and skill development to facilitate discussions about goals of care and future medical care choices. Due to the uncertainty surrounding a rare disease diagnosis, social isolation and the likelihood of parents being asked to make complex medical decisions for their child, rare diseases exact a severe emotional toll on families. There is an urgent need for interventions to ease the suffering of these families, yet few empirically validated interventions exist to address these issues. Moreover, children with rare diseases are a heterogeneous group who because of co-morbidities are often excluded from research, thereby creating a health disparity. Available research lacks scientific rigor. Our consultation with families of children with rare diseases and with the National Organization for Rare Disorders revealed that basic palliative care needs should be addressed prior to a pACP intervention. Thus, we pilot tested the innovative FACE-Rare intervention, integrating two, previously adapted for pediatrics, evidence-based interventions: Carer Support Needs Assessment Tool (Sessions 1 & 2) *plus* Respecting Choices (Sessions 3 & 4). For acceptability, feasibility and safety purposes, we pilot tested the 4-session intervention, conducted exit interviews, baseline and 2-week post-intervention assessments. This session will review the existing research on the palliative care needs of family caregivers of children with rare diseases, introduce this innovative intervention and its components, disseminate findings from the beta testing and pilot testing, and discuss future directions for research. Video clips will also be presented.

Tear Down the Wall and Build a Bridge: Understanding Latino Cultural and Spiritual Values to Enhance the Delivery of Palliative Care in the Latino Population (TH309)

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Objectives

- Illustrate the complexity of Latino cultural constructs and its impact on the delivery of palliative care services.
- Explore Latinos' perceptions and barriers to seeking palliative care services.
- Appraise how integrating culturally sensitive education could help improve palliative care for Latinos.

The Latino population is currently the largest minority group in the United States and is expected to double by the year 2050. The goal of palliative care is to alleviate physical, psychological, and spiritual pain and suffering. Health systems have an ethical responsibility to provide this service; however, Latinos face significant health disparities and are less likely to receive palliative care in comparison to non-Latino whites. A narrative literature review was conducted to identify unique characteristics, other than language, that contribute to this inequality. Even though Latinos represent a heterogeneous group, they share distinct cultural values, beliefs, attitudes and