

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