Beyond the Horizon: Providing Palliative and End-of-Life Care for Undocumented Immigrants in the United States (TH368)

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Objectives

- Investigate factors that complicate caring for seriously ill undocumented immigrants.
- Discuss options for quality end-of-life care for undocumented immigrants.
- Design or revise institutional policies to protect undocumented patients/families and healthcare providers.

Approximately 11 million undocumented immigrants (UI), accounting for 14.6% of the uninsured population living in the United States are not eligible for insurance under the Affordable Care Act, limiting options for palliative and end-of-life (EOL) care. Though the Universal Declaration of Human Rights includes the right to dignity-conserving care for all, access to quality EOL care eludes UI, with limited access to charity hospice care. UI experience many challenges when seeking healthcare including language/cultural barriers, limited social support, financial stressors, lack of access to care and insurance, discrimination and general mistrust in the healthcare system. Some mistrust can be mitigated through developing institutional policies to protect UI and their families when ICE officers are present in health care settings. UI rely on hospitals, including safety-net institutions for healthcare; unfortunately, they often present with advanced illness due to limited access (with delayed diagnosis, fragmented care and lack of advance care planning). While some barriers can be overcome through development of institutional policies to protect UI and their families, palliative providers are confronted with challenges in providing continued symptom management with limited charity care and resources available to this vulnerable patient population.

Using case-based presentations, experts from different states will provide insight into the current plight of the seriously ill UI and the healthcare personnel caring for them. We will identify strategies and outline ways to advocate for access to medical and hospice services. Through an interactive immersive learning structure we will identify best practices in different geographical regions of the US as a collaborating practice to protect the basic human rights of the seriously ill and their families including approaches to medical repatriation.

Expanding Palliative Care Accessibility: Models for Palliative Care delivery in Primary Care and Hospital-Based Settings (TH369)

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Objectives

- Compare and contrast primary palliative care and consult based care delivery.
- Describe interdisciplinary peer education strategies.
- Describe longitudinal support system from academic center to rural community hospital to improve palliative care access for patients in rural communities.
- Evaluate successes and barriers in supporting palliative care planning and implementation in rural ICU setting.

Primary palliative care is a model to deliver palliative care that can be used by treatment teams without access to full palliative care consult teams. This includes primary care offices which are the center of care for many patients with serious illness, especially those in rural and underserved regions. Ensuring excellent palliative care delivery within these models is critical to improving quality of care across the trajectory of serious illness.

Primary palliative care benefits patients and families by decreasing symptom burden, suffering, conflict and non-beneficial treatments while increasing quality of life, comprehension and satisfaction. It similarly benefits clinicians and health systems by decreasing conflict, costs, length of stay and delivery of non-beneficial therapies. Primary palliative care can use triggers, guidelines and decision support tools to aid primary providers in palliative interventions and communication. This is increasingly recognized in value-based payment models such as Accountable Care Organizations (ACOs) and the Comprehensive Primary Care Plus program, thus creating an opportunity for palliative care clinicians.

This concurrent session will present unique, multidisciplinary approaches to enhance primary palliative care delivery. These models vary from providing training for hospital-based and primary care clinicians to integrating palliative specialists in primary care. They include:

1. Focused geriatrics and palliative care skills training for primary care physicians within an ACO.
2. A trial of home-based palliative care embedded within a primary care practice vs. usual office-based care enriched with palliative care training for primary care clinicians.
3. A systematic intervention to improve serious illness communication in primary care.
4. A curriculum on best practice approaches to delivering primary palliative care for hospital-based teams with community education and outreach.

Both primary care and palliative care needs and resources vary widely by region and practice. Each model presented will emphasize the process of needs assessment and stakeholder engagement preceding program design and implementation. This will equip attendees to return to their own communities and begin to engage with primary care practices around developing models of care.

The Epidemiology of Community-Based Pediatric Palliative Care: A Descriptive Study (TH370A)

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Objectives

- Describe the demographics of the pediatric population served by a community-based palliative care program.
- Recognize survival data of the pediatric population served by a community based palliative care program and its implications on the care needs and support for these children and their families.

Original Research Background. Pediatric Palliative Care (PPC) is a rapidly-growing pediatric subspecialty. While there is ample literature characterizing children receiving inpatient palliative care services, little is known about the children enrolled in community-based pediatric palliative care programs.

Research Objectives. To characterize a large cohort of children in upstate NY cared for by CompassionNet, a community-based pediatric palliative care program.

Methods. Children were identified by reviewing the CompassionNet database from 2008-14. Children were eligible for the program if they were <22 years old and had an illness that put them at risk of dying before age 21. Demographic data, time on the program, disease categories, overall survival, and date of death were extracted from the database. Disease type was defined by ICD9 codes for complex chronic conditions (CCC).

Results. 713 children were enrolled and followed during the study period. The median time children were on the program was 3.5 years (range 0-15 years). Median age at time of enrollment was 6.5 years (0-24). 379 (53%) were male. 426 (60%) were white, 102 (14%) black, 38 (5%) were Hispanic and 49 (7%) were other. The most common CCC's were malignancies 265 (37%), cardiovascular disease 81 (11%), and neonatal disease 58 (8%). 546 (77%) of children enrolled in the program are alive. At 1 and 2 years, 82% and 56% of children are still being served by the program, respectively.

Conclusion. These data suggest there is a role for community-based pediatric palliative care programs in caring for children with CCC's and that with many of these children surviving a long time, that role can continue over many years.

Implications for Research, Policy, or Practice. Children with complex chronic conditions live a long time and spend much of that time in the community. Broader support for community-based programs is needed to provide these children and their families support at home, not just in the hospital.

Improving Moral Distress and Provider Perceptions with an Integrated Palliative Care Conference in the Neonatal Intensive Care Unit (NICU) (TH370B)

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