“It Can’t Be the Dialysis that Kills the Child…” Partnering Pediatric Palliative Care with Care for Children with End-Stage Renal Disease (TH366)

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Objectives

- Explain key issues in end-stage renal disease in the pediatric population.
- Summarize dialysis care, including the various forms, eligible populations, contraindications, and complications.
- Identify opportunities and challenges for palliative care and hospice collaboration in the care of pediatric patients with end-stage renal disease.

As chronic kidney disease progresses to end-stage renal disease (ESRD), important discussions regarding when and if to initiate dialysis occur. ESRD affects more than 660,000 Americans, less than 10,000 (1.5%) of those are pediatric patients whose time on dialysis is typically meant as a bridge to transplant. In rare circumstances, comorbidities, such as multiorgan failure, progression of other life-threating medical conditions, congenital anomalies, and size restrictions limit pediatric candidates’ access to transplant. In addition, dialysis-related infections and thrombosis can limit patients’ access to future transplant. Overall, this leads to a 5-year mortality for children with ESRD of 11%. Despite these mortality rates, very little has been published on pediatric palliative care (PPC) and hospice in ESRD.

How can nephrology and PPC teams partner with each other, patients and caregivers to optimize care in pediatric ESRD? In this session, our multidisciplinary team will use recent cases, clinical literature, and Medicaid/Medicare regulations to inform attendees about shared challenges and solutions supporting patients with ESRD and their families. An overview of modes of renal replacement therapy, their limitations, and complications will be provided by pediatric nephrologists. Strategies to introduce the broad complement of PPC options and maintain open lines of communication between families and nephrology colleagues will be reviewed by PPC experts with experience caring for patients with ESRD. Finally, presenters will discuss challenges to implementing and maintaining palliative care principles, including those beyond end-of-life discussions, within the context of ESRD care. In this concurrent session, participants will have an opportunity to learn about ESRD care options and hear our centers’ experiences caring for these complex patients, highlighting the various roles of PPC, some challenges and ethical concerns we have encountered, and strategies to introduce palliative care within the pediatric ESRD population.

Evaluating Quality of Pain Treatment Among the Seriously-Ill Populations (TH367)

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Objectives

- Understand the benefits and challenges of broadening the eligible population for hospice and palliative care quality measures to include those with serious-illness.
- Identify suggested ideas for implementation of the measure using real-world case examples
- Apply and translate this measure to other work that’s been done and to be able to replicate it in future work

Quality measurement for palliative care is limited by the “denominator problem,” or the inability to identify distinct populations of patients with serious illness in large health data sources, thus limiting the potential for broad system-based measurement of quality. Using claims and clinical data in the OptumLabs Data Warehouse, our goal was to identify seriously ill populations and evaluate the feasibility of assessing a pain-related quality measure in these populations.

We accomplished this through the following aims:

1. Develop claims-based technical specifications for patients with serious-illness, and two population subsets with:
   a. Dementia
   b. Multiple chronic conditions (MCC)
2. Assess the validity/reliability of the AAHPM’s Measuring What Matters (MWM) Pain Treatment quality measure in each of the eligible (sub) populations above.