Heart Failure/Transplant and Palliative Care and Collaborative Practice
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Introductions and Disclosures (none)
Objectives for Session

• Participants will be able to define pediatric palliative care
• Participants will be able to summarize the evidence of the benefits of early integration of palliative care
• Participants will be able to describe the benefits to patients/families/staff in various patient situations with various outcomes
What is Palliative Care?
Myths and Misconceptions

- Palliative care is only for those who are dying
- Palliative care is only for those with no chance for cure
- Palliative care is for people with cancer or old people
- Palliative care means giving up hope
- Patients who chose palliative care die faster
- Pain relief from palliative care creates addiction
Pediatric palliative care is care designed to meet the unique and special needs of children living with life-threatening conditions such as cancer, muscular dystrophy, cystic fibrosis, severe brain problems, complications from prematurity and birth defects and rare disorders, among other conditions. Unlike many other forms of medical care, pediatric palliative care recognizes that everyone in the family is affected when one member is ill. Therefore, pediatric palliative care focuses on the needs of the patient and family: parents, brothers and sisters and other members of the members of your support system. The focus of pediatric palliative care is to enhance the quality of life for all involved, in large part by preventing and alleviating suffering using the skills and knowledge of a specialized care team that includes doctors, nurses, social workers, chaplains, child life therapists, and others. Pediatric palliative care focuses on pain and symptom management, information sharing and advance care planning, practical, psychosocial and spiritual support, and coordination of care.

Our patient population

• Transplant Patients
• Heart Failure Patients
CHD

• CHDs are the leading cause of birth defect associated infant illness and death
• 1 in 100 is the popular slogan
• 40,000 infants affected each year
  – Compared to 1 in 3000 infants affected by CF
  – 1/6250 children diagnosed with cancer

• 2012 Congenital Heart Public Health Consortium
CHD

- The CDC estimates that there are 1 million children and 1.4 adults with CHD in the US
  - **more adults than kids**
Causes Leading to Transplant

90% of the pediatric transplants are due to cardiomyopathy or congenital heart disease according to the ISHLT (1996-2005)
Pediatric Heart Transplants
Diagnosis Distribution by Location
(Transplants: January 2004 – June 2015)
Causes of Heart Failure

- Congenital Heart Disease
- Cardiomyopathy
- Myocarditis
- Arrhythmias
- Drug/toxin Exposure
- Valvular Disease
- Arteriovenous malformation
- Non cardiac Causes
  - Sepsis
  - Renal Failure
  - HIV infection
Other Implications of AHD

- Financial
- Emotional
- Cost to parents
- Cost to siblings
Patterns of EOL in children with advanced heart disease

- Most pediatric deaths associated with AHD occur in the first year of life after a prolonged hospital stay.
- Most children with ADH who die in hospital do so in the ICU setting.
- Half of those have mechanical circulatory support
- 92% have mechanical ventilator support.
- In this study at BCH, nearly 25% die a long distance from home.
- Most patients died after discontinuation of disease directed care.
- Nearly 25% died during active resuscitation.

~Children who are admitted with AHD tend to die while receiving highly intensive care.

*This population is different from the oncology population which is the most often studied group of children at EOL

Disease trajectory in non cancer diagnoses
The Terrible Model
Dr. Death Model

Curative/Disease Controlling Therapy

Hospice
Palliative Care

Diagnosis of Life Threatening Illness
Death
Continuum of Care Model

Diagnosis of Life Threatening Illness

Curative/Disease Controlling Therapy

Palliative Care

Hospice

Bereavement Care

Death
Impact of Palliative Care

- Additional support is associated with reduced sense of need for information
- Greater sense of family functioning
- Decreased long term stress led to improved self care and health of caregiver and other family members
- Disease severity played a limited role in perceived stress
- In this study, despite disease progression, the levels of stress and worry decreased with palliative care support.

Impact of palliative care on patients with advanced heart disease

- Decreased symptom burden
- Decreased depression
- Improved quality of life as rated by the Minnesota Living With Heart Failure Questionnaire

- LS Evangelista, et al. Examining the Effects of an Outpatient Palliative Care Consultation on Symptom Burden, Depression, and Quality of Life in Patients With Symptomatic Heart Failure. *Journal of Cardiac Failure* Vol. 18 No. 12 2012
ImPACT! of Palliative care on the caregivers’ experience

• Improvement in worry and stress scores on a QOL tool.
  – Stress measured as difficulty sleeping
  – Worry measured as worry about the ability to care for their child’s health/disease.

• Ability of PACT to reduce caregiver’s perception of their child’s pain–major implication for emotional well being

• Surviving siblings have different parent after a child's death.
Pediatric versus adult cardiomyopathy and heart failure-related hospitalizations: a value-based analysis

- Value-based health care is a as outcomes divided by cost. Data on value-based health care in pediatric heart failure are scarce. METHODS AND RESULTS: A retrospective analysis of the Healthcare Cost and Utilization Project Kids' Inpatient Database and Nationwide Inpatient Sample was performed for pediatric and adult cardiomyopathy and heart failure-related hospitalizations. The study included 5,689 pediatric and 473,416 adult hospitalizations. Pediatric cardiomyopathy and heart failure hospitalizations were significantly longer than adult hospitalizations (mean ± SE 16.2 ± 0.7 days vs 6.8 ± 0.1 days; P < .001). Overall mortality was greater for pediatric hospitalizations (7.7% vs 5.6%; P < .001), although it decreased over time for both pediatric and adult hospitalizations. Charges were greater for pediatric hospitalizations, both overall ($116,483 ± $5,735 vs $40,662 ± $1,419; P < .001) and for all years evaluated. CONCLUSIONS: In a value-based model, pediatric cardiomyopathy and heart failure-related hospitalizations are associated with worse outcomes and greater charges than adult hospitalizations. More research is needed to understand the cost effectiveness of pediatric heart failure treatment and to reduce the burden on the health care system.

- Wittlieb-Weber, Carol A; Lin, Kimberly Y; Zaoutis, Theoklis E; O'Connor, Matthew J; Gerald, Ken; Paridon, Stephen M; Shaddy, Robert E; Rossano, Joseph W Journal of Cardiac Failure (J CARD FAIL), Jan2015; 21(1): 76-82. (7p)
Carolinas Medical Center

- Flagship facility of Carolinas Healthcare System which includes more than 30 affiliated hospitals in North and South Carolina. *One of the largest public not for profit healthcare system in the US.*
- An 874 bed hospital that includes a Level 1 Trauma Center, Levine Cancer Institute, a research institute and numerous specialty services
- Serves as one of five of North Carolina’s Academic Medical Teaching Hospitals
- 234 bed children's hospital, LCH, on campus
Program history

- First pediatric heart transplant 1989
- 37 transplants with more than half that volume in last 3 years...
- Designated physician leader and coordinator 2014
- Collaborated with PACT to establish a palliative consult as part of transplant evaluation
- Established a Pediatric Heart Failure Clinic/Program
- Attained Accreditation as a Pediatric Heart Failure Institute by Battelle Healthcare Colloquium May 2016-first in the Carolinas, 11th in country
Surgical cases

• 2014- 452
• 2015- 483
• 2016 - 528

• Our 5 year goal is to be a 600 case/year program
Cath program

[Bar chart showing SHVI/LCH Combined Congenital Cath & EP Program Volume from 2011 to 2016.]
CASE PRESENTATIONS
Case #1

- Toddler w/ new diagnosis of ostial atresia of LMCA not amenable to surgical repair 2nd to LV dysfunction; Teen parents, Live 1.5hrs away from LCH
- Extended hospital stay to include initiation of continuous milrinone infusion, transplant evaluation and listing
Case #1

• Quality of life for pt and parents while waiting in hospital
• Young parents - underage mother, father somewhat hands off and struggling w/ his mother not present; both missing school
• 'Active' toddler w/ continuous IV infusion
ImPACT!

• Impartial listening
• Support of this family's unique experience
• Family Check ins
• Safe space for parents/father to verbally process QOL for 2 y/o "living in hospital" vs waiting at home. No fear of "retribution or hurting transplant MD/team feelings."
• Improved QOL and level of activity for 2 y/o and further hospitalizations—acquisition of portable pump and back pack for this one and future patients
Action Items

• To inquire about ongoing school support for parents
• To encourage/teach healthy behaviors and parenting skills
• Encourage child to remain active, but keep safe
Case #2

- 17 y.o male with DMD
- EF of 20%, on asa, coreg, aldactone, enalapril and Lasix
Case #2

- Quality of Life
- Complexity of his care (for mom)
- Help mom needs/care coordination
- Now turning 18, need for HCPOA vs guardianship
ImPACT!

- When chronic condition remains unchanged/stable, the primary medical team may not address/assess quality of life, changes of needs/support needs, family's understanding and acceptance of disease complexity.

- And families of chronically ill children whose condition remains unchanged/stable seem to minimize/forget the looming questions and problems that are on the horizon.

- The patient may need new or different information as he ages.
Action Items

• Research resources available to mom to help with his increasingly labor intensive care/needs
• Encourage healthy behaviors (leaving CPAP on)
• Meeting to discuss healthcare power of attorney
• PACT f/u appointment to discuss specific scenarios of disease trajectory in more detail
  – What happens if
    • You need CPR at home
    • You get PNA
    • You need milrinone...or a VAD (destination therapy)
Case #3

- 5 y/o CHD listed for OHT, admitted with 2 weeks N/V, FTT
- Met as OP 2 mo. prior during txp eval
- Extended code event (x 45 min) with pulm hemorrhage
- Hemodynamically stabilized on ECMO
- Anoxic brain injury
Case #3

- Unexpected complications
- Prior discussion of Quality of Life goals
- Emotional support
ImPACT!

- "Oh I'm so glad to see you."
- Familiar face when discussing EOL decisions and plans.
- A conversation we had already had.
Action Items

- Family support
- End of Life symptom management
- Facilitating Memory Making, family visitation
- Bereavement follow up
'I'm living a fairytale': Spanish girl, 17, whose 'OMG' picture Justin Bieber posted online reveals how she went from a £3 an hour babysitter to a catwalk model

- Cindy Kimberly, 17, earned £2.90 an hour working as a babysitter in Spain
- Bieber shared her picture to his 47.5m followers asking: 'OMG who is this!'
- Cindy has had lots of job offers and calls offering her things since the post
- She will now make her catwalk debut at fashion show in Madrid next month
- Said Bieber's attention was even bigger deal because she loves his music
What do your ideas look like?
Ideas are the source of all things.

Plato
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References

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8. Momen, N.C. Barclay, SIG., (2011) Addressing the 'elephant on the table': barriers to end of life care conversations in heart failure-a literature review and narrative synthesis. *Lippincot Williams & Wilkins*
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11. Wittlieb-Weber, Carol A; Lin, Kimberly Y; Zaoutis, Theoklis E; O'Connor, Matthew J; Gerald, Ken; Paridon, Stephen M; Shaddy, Robert E; Rossano, Joseph W *Journal of Cardiac Failure (J CARD FAIL), Jan2015; 21(1): 76-82.* (7p)
12. [https://www.cdc.gov/ncbddd/heartdefects/data.html](https://www.cdc.gov/ncbddd/heartdefects/data.html)