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A Unique Model for Palliative Care in a Level IV Neonatal Intensive Care Unit

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Background

- The Fetal Health Center (FHC) at Children’s Mercy Hospital (CMH) allows onsite delivery for infants with prenatally known life threatening or surgical conditions at a freestanding children’s hospital.
- Mothers referred to the FHC have a prenatal Integrated Consult (IC) with a multidisciplinary team including specialists relevant to patient diagnosis.
- PaCT involvement within the IC allows the team to meet patients prenatally and follow the family throughout pregnancy, delivery and post-natal course.

Objective

To describe and quantify the relationship between the FHC and PaCT for program development purposes.

Methods

- Reviewed PaCT database
- Identified all prenatal consults from FHC inception (2010) to 12/31/2017
- FHC database reviewed for cross reference

Results

- 1,926 consults in FHC
  - 323 mothers met by PaCT
- 272 live born infants at FHC
- 37 live born infants at CMH
- 16 IUD
- 135 deaths
  - 56 lived < 24hrs
  - 23 lived < 1 wk
  - 21 lived < 1 mo
  - 30 lived < 1 yr
  - 3 lived > 1 yr

Underlying Diagnoses
- Pulmonary: 41%
- Congenital Anomalies: 24%
- Neurological: 12%
- Renal: 11%
- Genetic: 11%
- Cardiac: 11%

Outcomes for PaCT FHC referrals

- Totals
  - Active = 127
  - Deaths = 151
  - Discharged = 47
- Yearly:
  - 2010: 1
  - 2011: 3
  - 2012: 10
  - 2013: 23
  - 2014: 27
  - 2015: 31
  - 2016: 60
  - 2017: 61

Neonatologists’ Reflections

- Unanimously valued the continuity offered by PaCT
  - “Being on the journey with the family”
  - “Providing an extra layer of support throughout the hospital”
- Growing trust in palliative care approach
  - “Provides a partnership … in delivering difficult news”
- Normalizes involvement in more than just “the ‘bad’ cases”

Conclusions

PaCT provides as integral service to families seen in the FHC as evidenced by:

Volume: increasing number of consults over time

Variety:
- A wide range of underlying diagnoses
- A variety of types of support: during an acute crisis, during end of life, or long term continuity

Value:
- Reflected in neonatologists’ insights
- Prenatal relationship allows time to build rapport and trust with the family and becomes important when making decisions