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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.
- FHC database reviewed for cross reference.

Results

Underlying Diagnoses:
- Cardiac: 41%
- Neurological: 12%
- Renal: 11%
- Pulmonary: 1%
- Genetic: 11%
- Congenital Anomalies: 24%

Outcomes for PaCT FHC referrals:

- Totals: 1,926 consults in FHC
- 323 mothers met by PaCT
- 870 infants delivered in FHC
- 1,026 consults in FHC
- 37 live born infants at CMH
- 272 live born infants at FHC
- 16 IUD
- 135 deaths
- 60 lived < 24hrs
- 20 lived < 1 wk
- 21 lived < 1 mo
- 30 lived < 1 yr
- 3 lived > 1 yr

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.