IMPACT: Early Lessons from the Toronto Perinatal Palliative Care Pilot

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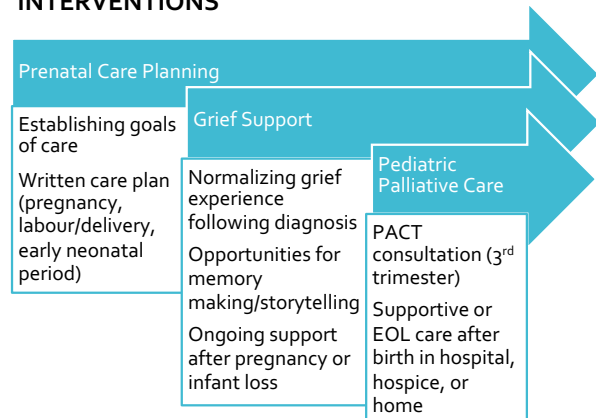
BACKGROUND

- Technological advances have resulted in earlier diagnosis of life-threatening fetal conditions
- In spite of pre and post-natal medical advances, there is still a high degree of potential morbidity and mortality for babies born with the most serious fetal conditions[1]
- American College of Obstetricians and Gynecologists (ACOG) defines perinatal palliative care as a strategy that "comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy"[2]
- In 2018, the MOHLTC funded a pilot program to strengthen perinatal palliative care supports in Toronto – collaboration among Women's and Infants' Program, Sinai Health System; Paediatric Advanced Care Team (PACT), SickKids; Emily's House
- Whereas most programs focus only on supporting parents who make the decision to continue pregnancy and pursue comfort-focused care, the aim of ours was to broaden support regardless of goals of care and outcomes

Objective:
Provide perinatal palliative care supports to any family facing a life-threatening fetal diagnosis for which comfort-focused care at birth is one ethically reasonable option, not necessarily the chosen plan of care

INTERVENTIONS

Prenatal Care Planning
- Establishing goals of care
- Written care plan (pregnancy, labour/delivery, early neonatal period)

Grief Support
- Normalizing grief experience following diagnosis
- Opportunities for memory making/storytelling
- Ongoing support after pregnancy or infant loss

Pediatric Palliative Care
- PACT consultation (3rd trimester)
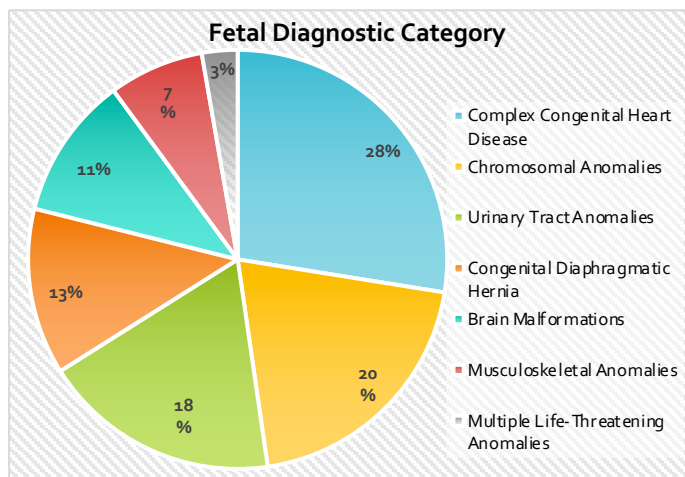- Supportive or EOL care after birth in hospital, hospice, or home

IMPACT CLINICAL TEAM

- Clinical Nurse Specialist, Women's and Infant's Program, Sinai Health System
- Grief Support Coordinator, Emily's House
- Nurse Practitioner, PACT, SickKids
- Grief Support Coordinator, PACT, SickKids
- Physician Lead, PACT, SickKids

PILOT OUTCOMES

Total # of Patients Referred= 107
- Year 1: 66
- Year 2: 43

Fetal Diagnostic Category

- Complex Congenital Heart Disease — 28%
- Chromosomal Anomalies — 20%
- Urinary Tract Anomalies — 18%
- Congenital Diaphragmatic Hernia — 13%
- Brain Malformations — 11%
- Musculoskeletal Anomalies — 7%
- Multiple Life-Threatening Anomalies — 3%

Flow diagram:
- Total Patients (107)
  - Pregnancy Continuation (88)
    - Intensive Care (48)
      - Intrauterine Fetal Demise (5)
      - Neonatal Death (16)
      - Survival Beyond Neonatal Period (27)
    - Comfort-Focused EOL Care (40)
      - Intrauterine Fetal Demise (15)
      - Neonatal Death (18)
      - Survival Beyond Neonatal Period (6)
      - Pregnancy Ongoing (1)
  - Pregnancy Termination (19)

LESSONS LEARNED

- Program name changed from "perinatal hospice" to IMPACT (Infant Maternal Perinatal Advanced Care Team) to minimize referral barrier
- Prognostication often challenging and dynamic in this population (eg. Due to advanced imaging, fetal interventions) – need flexible approach to potentially shifting treatment options and goals of care
- Inclusive approach captures more families who experience fetal or neonatal loss compared with focusing only on those with goals of care focused on comfort
- Combination of in-person and virtual visits due to pandemic, but also because team members span multiple institutions
- Memory making/storytelling items compiled into take-home kit – families can begin engaging with materials at home during pregnancy, involve partner and other family members who may be restricted from visiting hospital
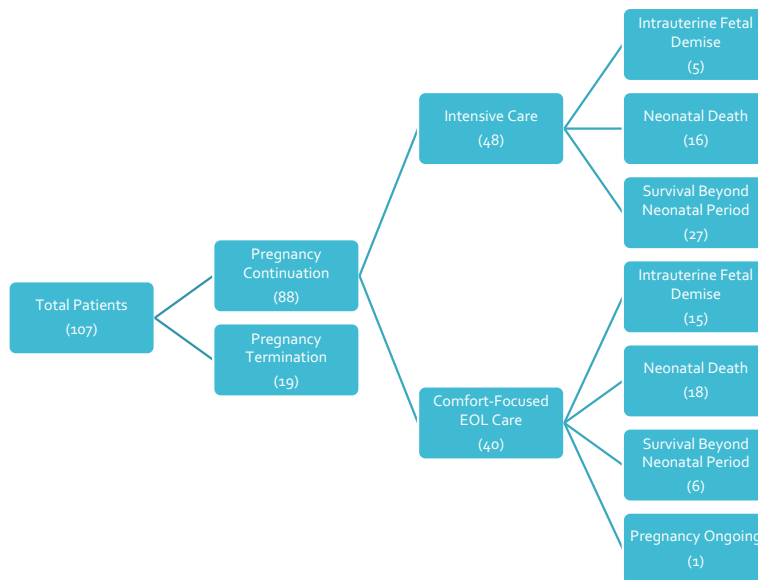
NEXT STEPS

- Ongoing feedback and revision regarding optimal use of resources and populations served
- Addressing challenges of collaborating across institutions (eg. data sharing)
- Expanding creative grief support initiatives
- Needs assessment to guide expansion of support and consultation efforts to broader Greater Toronto Area region
- Evaluation – patient and provider perspectives

REFERENCES & ACKNOWLEDGEMENTS

1. Center for Disease Control and Prevention. National Center for Health Statistics: Birth Defects or Congenital Anomalies. https://www.cdc.gov/nchs/fastats/birth-defects.htm.
2. Perinatal Palliative Care, ACOG Committee Opinion, Number 786. Obstetrics & Gynecol 2019;134(3):e84-e89.

SickKids   emily's house · a special place for kids · a project of Philip Aziz Centre   Mount Sinai Hospital · Sinai Health System · Joseph & Wolf Lebovic Health Complex   Ontario · Toronto Central Local Health Integration Network