

**IMPACT**Infant Maternal Perinatal  
Advanced Care Team

# Antenatal Counselling through a Palliative Care Lens

Sarah Lord, MD, FRCPC, Paediatric Advanced Care Team, Hospital for Sick Children  
Lindsay Pollard, RN, BScN Women's and Infants' Health Program, Mt. Sinai Hospital

**SickKids****IMPACT**Infant Maternal Perinatal  
Advanced Care Team

# Conflicts of Interest

- No disclosures

**SickKids**

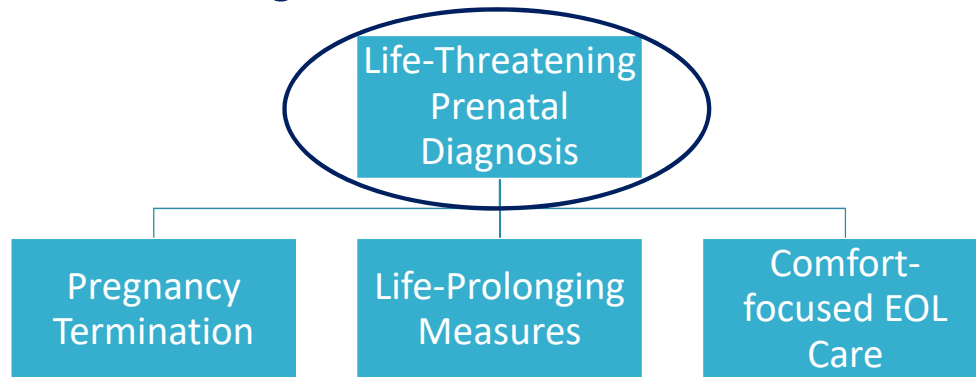


## Objectives

- To discuss our approach to perinatal palliative care support through a case example
- To explore aspects of palliative care counselling that can be applied across varied circumstances faced by families with life-threatening fetal diagnoses



## Evolving Model of Perinatal Palliative Care



IMPACT Goal: Provide equitable opportunities to support all families who experience a life-threatening fetal diagnosis **regardless of their care choices – if comfort-focused end of life care is ONE ethically reasonable choice (regardless of the chosen plan of care)**

## Case Example - Maya

- Maya is a 35 year-old G5P1 patient who is pregnant with a fetus who was identified as having growth restriction, microcephaly, cleft palate, a large VSD and overlapping digits. Based on counselling the family went on to have amniocentesis which confirmed the suspected diagnosis of Trisomy 18.
- Parents have consults with MFM, Clinical genetics, and Neonatology who have discussed the diagnosis and spectrum of disease including the high probability of a shortened lifespan, neurodevelopmental disability and other potential medical complexities.
- Parents decline option of pregnancy termination but are leaning towards focusing care on the baby's comfort when she's born and allowing a "natural" death, avoiding attempts at invasive life-prolonging interventions.
- Family referred to IMPACT



## What does palliative care look like?

- Discussion with CNS about Values/Goals
  - Who is this family? How are they thinking about things? What are their values/beliefs around these difficult situations? Who supports them during difficult times?
  - Validate those goals while challenging them to think of other parallel ones
  - The focus really is building a trusting relationship – first built on the foundation of expressing care about their situation and for their family
- Education about L&D care planning
  - Before writing a care plan, educate families about what kinds of things to think about when imagining the labour/delivery process and start to form some wishes for that experience
- Introduction to Grief Support Coordinator
  - Normalizing grief following a life-threatening fetal diagnosis
  - Discussion about bonding, storytelling/legacy building during pregnancy
  - Ongoing support in the event of fetal loss
- Introduction to PACT
  - Can revisit values/goals, how those inform care planning
  - What does palliative care look like after birth (varies depending on setting/goals of care)
  - Further supports (eg. Siblings)



## Case Example - Maya

- They ask for a visitor exception for grandparents to meet the baby after delivery. Although their son cannot come in the delivery room, they plan to have him join virtually on their smartphone just after Ruby is born and then visit later with grandparents if possible.
- A fetal heart tracing of 2-5 minutes is requested for the family to add to their memory book.
- They agree to meet with Spiritual Care who plan a Blessing for baby.
- They will bring in a special outfit for photos.
- Parents would like legacy/memory items including hand and foot imprints, bead bracelet of her name, impression molds of her hands/feet.
- They work together with the IMPACT CNS to create a care plan that includes the above details as well as symptom management plans for the baby. They also work with the IMPACT grief support coordinator to do some legacy work together as a family while Maya is still pregnant.
- In the third trimester, they also meet with paediatric palliative care team NP (PACT) and discuss more specifics about comfort care after birth, as well as preferred location of care if the baby survives the first 24h (or when mother safe for discharge) and care remains focused on comfort
- As time passes during the pregnancy, the family expresses increasing hope that they will be able to spend some time together with their baby alive



