



Background

- Prenatal palliative care (PPC) is an important component of perinatal management for pregnancies complicated by life limiting or high-morbidity fetal diagnoses.
- Pregnancies are considered high risk when fetal anomalies, maternal comorbidities, or future anticipated complications threaten neonatal survival or long-term quality of life.
- Referrals are initiated at the time of diagnosis by specialists including obstetricians, especially Maternal-Fetal Medicine (MFM) specialists, neonatologists, geneticists, and pediatric cardiologists
- Consultations provide families with education, psychosocial support, and the ability to explore goals of care (GOC) before delivery

Objective

This study describes the role of perinatal palliative care and evaluates factors associated with families' prenatal goals-of-care decisions, as well as how these decisions evolve in the postnatal period.

Methods

- Retrospective chart review of 243 neonates cared for by Phoenix Children's Center for Fetal and Neonatal Care or pregnant mothers referred to the perinatal palliative care team at Phoenix Children's between January 1, 2020 and December 5, 2024
- Diagnoses included: aneuploidies, congenital anomalies such as anencephaly, neurological anomalies, in utero neurologic insults, congenital diaphragmatic hernia, cardiac malformations, chest and abdominal wall malformations, skeletal dysplasia, sacrococcygeal teratoma, pulmonary hypoplasia, hydrops, renal malformations, constriction ring or amniotic band syndrome and extreme prematurity.
- Data collected included fetal and parental demographics and clinical characteristics, fetal perinatal care and fetal postnatal care. Parents who requested any intervention with the purpose of prolonging life whether or not they specified any limitations were included in the life-prolonging care group. Comfort care was defined as care with the sole purpose of providing comfort without the intention of sustaining life.

Results

Table 1: Fetal and Parental Demographics and Clinical Characteristics

	Life-Prolonging N=176	Comfort N=67	p-value
Medical Condition*			
Genetic condition	43 (66.2%)	22 (33.8%)	0.186
Cardiac condition	137 (75.7%)	44 (24.3%)	0.052
Abdominal wall condition	17 (54.8%)	14 (45.2%)	0.019
Infectious disease condition	2 (100.0%)	0 (0.0%)	1.000
Musculoskeletal condition	32 (64.0%)	18 (36.0%)	0.135
Neurologic disorder	41 (56.9%)	31 (43.1%)	<0.001
Oncologic disorder	3 (75.0%)	1 (25.0%)	1.000
Pulmonary disorder	31 (70.5%)	13 (29.5%)	0.746
Renal disorder	26 (72.2%)	10 (27.8%)	0.976
Multisystem condition	17 (73.9%)	6 (26.1%)	0.867

Sex at birth, race, religion, insurance status were non-significant between the groups.

Key Findings

243
Total Patients

72.8%
Chose Life-Prolonging

<5%
Changed GOC After Initial Consult

9.3%
Transitioned to Comfort care

Graph 1: GOC by Medical Condition

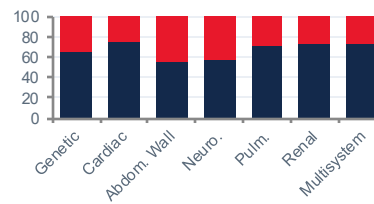


Table 2: Perinatal and Postnatal Care

	Life-Prolonging N=176	Comfort N=67
Family goals of care prior to palliative consult		
Life-prolonging	172/176 (97.7%)	2/66 (3.0%)
Comfort	0/176 (0.0%)	63/66 (95.5%)
Undecided	3/176 (1.7%)	0/66 (0.0%)
Unknown	1/176 (0.6%)	1/66 (1.5%)
Pregnancy outcome		
Live birth	161 (91.5%)	47 (70.1%)
Life-prolonging	139/161 (86.3%)	5/47 (10.6%)
Comfort	15/161 (9.3%)	42/47 (89.4%)
Unknown	7/161 (4.3%)	0/47 (0.0%)
Demise/Termination	15 (8.5%)	20 (29.9%)
Transferred to Phoenix Children's		
Yes	114/161 (70.8%)	5/47 (10.6%)
No	47/161 (29.2%)	42/47 (89.4%)
Discharge disposition		
Home	91/161 (56.5%)	4/47 (8.5%)
Home with home hospice	7/161 (4.3%)	11/47 (23.4%)
Inpatient hospice	8/161 (5.0%)	4/47 (8.5%)
In hospital demise	46/161 (28.6%)	27/47 (57.4%)
Inpatient	1/161 (0.6%)	0/47 (0.0%)
Unknown	8/161 (5.0%)	1/47 (2.1%)

Discussion

- Less than 5% of families who changed their GOC decision following initial consultation.
- No significant difference in GOC based on parental race or religion, gravida, parity, insurance status, or area of deprivation index.
- Fetal diagnoses were found to be associated with GOC decisions, particularly in fetuses diagnosed with a cardiac condition, abdominal wall condition, or neurologic disorder choosing life prolonging care
- With ongoing support, 8 (5%) of families initially requesting life-prolonging care shifted to comfort-focused care prior to delivery
- Based on limitations in interventions from the family or medical team, 6 (4%) babies care transitioned to comfort care after delivery
- In the comfort care cohort, 89.4% remained comfort-focused while 10.6% transitioned to life-prolonging measures.

Conclusions

- Rather than redirecting GOC decisions, the prenatal palliative care team partners with families to assist in prenatal decision-making that aligns with their choices
- After delivery, several families' goals shifted from life-prolonging to comfort-focused care based on limitations. Prenatal and post-natal involvement of the palliative care team involvement is important in preparing and supporting these families as goals and offered interventions evolve
- We did not find parental religion, history of previous pregnancies, or socioeconomic determinants to be associated with GOC decisions. This highlights the importance of not making assumptions regarding the parent's GOC decisions based on their backgrounds