

Family Centered Care for Patients with Congenital Heart Defects: Enhancing the Role of Palliative Care

BACKGROUND

- **Children** with critical congenital heart defects (CHD)
- Multiple surgeries
- Prolonged cumulative hospitalization stays
- Complications/prognostic uncertainties
- Parents & families of these patients
- Disrupted family life; increased stress
- Challenging medical decision
- Pediatric Palliative Care (PPC) teams
- support families antenatally and postnatally
- help parents clarify goals of care
- Hesitation to involve PPC in patients with CHD

OBJECTIVE

Increase the percent of patients with critical CHD who receive a PPC consult by 50% by November 2019.

DESIGN/METHODS

- November 2018 to November 2019
- Stakeholders: surgeons, cardiologists, palliative care providers, pediatric and neonatal intensive physicians, residents, advanced practice care providers, and nurses
- IHI model for improvement
- 1) clarify current use of pediatric palliative care
- 2) explore common causes of low use (Figure 1)
- 3) provide education about pediatric palliative care
- 4) clarify location/timing of ideal PPC consult
- subpopulation CHD 5) identify deemed appropriate for palliative care involvement

OUTCOME & PROCESS MEASURES

Outcome measure was percentage of patients hospitalized for critical CHD who received a PPC consult analyzed using a run chart.

Process measure was number of cases of critical CHD between consults analyzed using a Shewhart G-chart.

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RESULTS

- Baseline six months (May 2018-October 2018, n=42): **1 PPC consult per 11 infants and neonates**
- Intervention period (November 2018-November 2019; n=80):
 - **Percentage** of infants with a consult **trended upward** (Figure 2)
- Number of eligible patients between consults improved from 5.1 to 1 (Figure 3)
- One parent of a prenatally diagnosed patient was seen antenatally by the PPC team.

in our PICU. Causes targeted for improvement shown in yellow.





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Department of Pediatrics SCHOOL OF MEDICINE AND PUBLIC HEALTH

Cardiology, Pediatric Palliative Care, and Pediatric Hospitalist teams

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