Practice Problem

- >400 pediatric open heart surgeries performed yearly at a large Midwest Children’s Hospital with over a 98% survival rate.1
- Nationally the congenital heart disease population has up to 18.9% discharge mortality rate2
- Patients can have a multitude of post-surgical problems: weight loss, vomiting, vocal cord paresis, increased respiratory effort with increased oxygen demands, medication side effects, other less serious symptoms that can be concerning to parents
- Transitioning care from the acute inpatient setting to home is complex, difficult for the care team, provokes parental anxiety & stress
- No provisions currently in place for a parent focused transition of care for discharged pediatric post-surgical cardiac patients

Project Implementation

- APRN Continuity Clinic proposed to key stakeholders
  Director of The Heart Institute for Children
  Manager of cardiology outpatient services
  Chief Operating Officer
- Safe, Reliable, Effective Care model from the Institute for Healthcare Improvement guided this QI project: family & patient engagement, teamwork, communication, improving work processes & patient outcomes
- Patient inclusion criteria
  Underwent complex congenital heart surgery
  Anticipated to require close follow up due to parental anxiety
  Marginal health status
  Nutritional or weight gain concerns
  Heart failure symptoms
  Echocardiograms, CXR &/or lab work
  Under the age of 18 years
- Inter-professional team approach to meet patient’s needs
  Speech therapy
  Occupational therapy
  Physical therapy
  Dietician
- Challenges
  APRN assigned to continuity clinic also an inpatient APRN with concurrent inpatient responsibilities
  Cardiac surgical service with high census during implementation & evaluation period
- Tool to measure parental satisfaction only available in English
- Many non-English speaking patients in Continuity Clinic

Outcomes

- Evaluation
  Parental adherence to discharge instructions
  Parental recall of red flags, medication schedule, F/U appointments
- Parental satisfaction measured
  Parents’ Perceptions of Satisfaction with Care from Pediatric Nurse Practitioners (PPSC-PNP) survey tool7
- 14 patients seen in APRN Continuity Clinic from 1/2019-4/2019
  6 questionnaires returned
  9 out of 14 patient’s primary language was English
  3 out of 9 questionnaires distributed not returned

- Parents reported anxiety secondary to:
  - Difficulty developing a routine
  - Financial strain
  - Lack of sleep
  - Directions & need for medications
  - Limited food intake
  - Continued NG intakes

- Documented satisfaction using the PPSC-PNP tool was high
- Clinic visit times ranged 40 min- 2 hours
- No readmissions from time of discharge to APRN Continuity Clinic visit

Clinical Implications for Practice and Next Steps

- Adherence to discharge instructions & parental satisfaction with an APRN Continuity Clinic contributed to best practices in care for this vulnerable population: children with complex congenital heart disease
- Parents of this vulnerable population continue to need support, guidance & reassurance after discharge
- APRN most familiar with patient's unique needs is best to guide continuity of care from inpatient to outpatient settings
- Adequate APRN staffing must be ensured for inpatient ICU coverage and Continuity Clinic coverage
- Inter-professional team approach recommended during Continuity Clinic to meet child's complex healthcare needs
- Maintain regular communication with stakeholders by scheduling standing meeting times throughout the year
- Cost benefit ratio of staffing, continuity of patient care & both parental and stakeholder satisfaction should be explored

Summary of the Supporting Literature

- Challenges for transitioning care
  Feelings of discontinuity of care, lack of communication, parents’ perception of losing their familiar care givers34
- Pediatric complex care clinic implementation
  Improved parental empowerment, improved continuity of care, improved healthcare team's attentiveness to their needs5
- Parents of children with congenital heart disease experience
  Emotional stress, financial strain, relationship instability, uncertainty of their family’s future3
- Preventing readmission to the hospital
  Contact with care providers who had extensive knowledge of their child’s condition & established relationship with family5
- APRN continuity of care clinic for complex patients
  Having the same APRN from inpatient to outpatient clinic reduced fragmented care, provided a structured process & parental education6

Key References

W19  Patient Satisfaction of an Acute Care Continuity Clinic for Pediatric Patients who have Undergone Congenital Heart Surgery

Background: Within the setting of a large children’s hospital in the Midwest, there were more than 400 congenital heart surgeries performed per year with over a 98% survival rate. Patients can have a multitude of post surgical problems presenting as weight loss, vomiting, vocal cord paresis, increased respiratory effort with increased oxygen demands, medication side effects, and other less serious symptoms that can be concerning to parents. Transitioning these children safely and supporting their parents adequately from the acute care inpatient setting to the family’s home following congenital heart surgery is a complex and difficult task for the care team. Parents sought and needed both support and information regarding their child’s medical care from providers who were most familiar with their child’s unique healthcare needs. It was anticipated that parents would be more satisfied attending a post-hospitalization clinic visit with a familiar APRN versus phone triage care, and that positive post-surgical outcomes would remain high.

Aims of service change: This quality improvement project provided and evaluated continuity of care via an acute care continuity clinic staffed by an APRN who was familiar with both specialized post-operative care and the patient’s unique post-surgical healthcare needs. This inter-professional healthcare model for patients with acute postsurgical cardiac healthcare needs aimed to improve the child’s transition to home and examine parental satisfaction of the APRN Continuity Clinic.

Details to innovation: Within the chosen setting, there were no provisions for continuity of care for discharged acute cardiac patients other than routine follow-up medical appointments. A pre-implementation assessment was done by performing a retrospective chart review of 112 patients seen in the routine pediatric cardiovascular post-operative clinic from July through November of 2017. Out of the 112 total patients, 21 patients needed extended time during their cardiovascular post-operative clinic appointment. They also needed earlier follow up after discharge, labs and imaging, and collaboration with other service lines at the time of the appointment. These patients were scheduled for return visits, ranging from one to four additional visits, in order to manage all their medical needs.

Methods: Evaluation of parental adherence to patient follow up discharge instructions was measured by parental ability to recall and state: red flags, dates for follow up appointments, and medication schedules. Parental satisfaction was measured by using the Parents’ Perceptions of Satisfaction with Care from Pediatric Nurse Practitioners (PPSC-PNP) survey tool. The author of the tool granted permission to both modify and use the PPSC-PNP tool.

Outcome: Fourteen patients were seen in the APRN Continuity Clinic between January to April 2019. None of the fourteen patients needed readmission prior to or during their acute care visit. Results of a post APRN Continuity Clinic questionnaire revealed that parents rated their satisfaction high regarding the care that was provided by the APRN within the clinic.

Evaluation of change: Examining both parental adherence to patient follow up discharge instructions and parental satisfaction in the care of their child with a complex post-surgical cardiac condition furthered the inter-professional team’s ability to develop best care practices for this vulnerable population.

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