Creation of a Comprehensive Clinic for Preterm Infants with Patent Ductus Arteriosus

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**Background:** The cardiac catheterization laboratory at Le Bonheur Children’s Hospital in Memphis, TN is performing transcatheter PDA closure (TCPC) on an increasing number of premature, extremely low birth weight (ELBW) infants. To date, we have performed TCPC on 160 ELBW infants weighing <2 kg at the time of the procedure, 65 of whom were <1 kg with the smallest weighing 640 grams. The median gestational age is 25 weeks (range 22-27 weeks). We receive referrals from four neonatal intensive care units (NICU) in the Memphis area and from four additional NICUs within the city’s 100-mile radius. The institution’s reputation for having the most experience with this procedure in the United States has spurred referrals from three cities over 300 miles away.

**Methods:** ELBW infants who have undergone TCPC have unique follow-up needs that are not easily provided in a general cardiology clinic or NICU follow-up clinic. A nurse practitioner developed and directed outpatient multi-specialty clinic for ELBW who have undergone TCPC was established to deliver the comprehensive care and services that these high-risk infants require. A multidisciplinary team approach including neonatology, cardiology, pulmonology, nursing, developmental specialists, nutrition, speech therapy, social work, research collaborators and other health care specialists are integral partners dedicated to the care and promotion of wellness of these ELBW infants.

**Results:** Patients are scheduled for clinic initially at 1 month post discharge, then at corrected ages of 6, 12, 24, and 36 months or more frequently if clinically necessary. Annual appointments are subsequently made at 4 and 5 years of age. Patients are then seen at ages 7, 10, 15, and 18 years until transition to adult congenital cardiology. A detailed schedule of which evaluations, testing, consultations, and services are to be implemented at each visit was created.

**Conclusions:** Comprehensive follow-up of ELBW infants who have undergone TCPC can be provided in a multi-specialty clinic developed and directed by a nurse practitioner. Communication and co-management of interrelated medical problems that require input from multiple sub-specialties are provided in this unique setting. Establishing a clinic is a dynamic process which requires continuous evaluation and adaptation of the model to facilitate overall advancement and improvement.

**References:**

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METHODS

• Collaboration and coordination with multi-specialty and multi-disciplinary teams was necessary to develop the clinic.

• Visit schedules were created for each cohort.

• Input from each specialty was considered when developing the clinic protocol.

• NICU discharge follow-up recommendations were also considered.

• Follow-up rates for the NICU discharge clinic are at 72%-100%.

• Follow-up rates for the PDA Clinic are at 72% for 2018.

• Patients were managed into cohorts which determined each group’s unique follow-up needs.

RESULTS

High-Risk Infants and Children

• Visit schedules were created for each cohort.

• Input from each specialty was considered when developing the clinic protocol.

• NICU discharge follow-up recommendations were also considered.

• Follow-up rates for the NICU discharge clinic are at 72%-100%.

• Follow-up rates for the PDA Clinic are at 72% for 2018.

• Patients were managed into cohorts which determined each group’s unique follow-up needs.

INSTITUTIONAL BACKGROUND

• Le Bonheur Children’s Hospital has performed TCPC on more ELBW infants weighing less than 2 kg at the time of the procedure than any other center in the United States:

  - 160 < 2 kg
  - 65 < 1 kg
  - Smallest infant 640 grams
  - Mean procedural age 25 weeks gestation (22-27 weeks)

• With a large number of ELBW infants who have undergone TCPC at Le Bonheur Children’s Hospital, a comprehensive clinic for follow-up was needed.

• TCPC eliminates the risks associated with pharmacotherapy and surgical ligation in fragile and high-risk extremely low birth weight (ELBW) infants.

• TCPC is a new procedure for ELBW infants; however, long-term outcomes are not yet known.

• ELBW infants require specialized follow-up at discharge which can be provided in multi-specialty outpatient clinics.

• Buy-in from key stakeholders was important.

• Multi-specialty team included:

  - Cardiology
  - Pulmonology
  - Neonatology
  - Developmental Pediatrics

• Multi-disciplinary team included:

  - Nursing
  - Registered Dietitian
  - Sonographers
  - Speech Therapy
  - Social Work

• Patients were managed into cohorts which determined each group’s unique follow-up needs.

• Le Bonheur Children’s Hospital has performed TCPC (Transcatheter patent ductus arteriosus closure) is minimally invasive and provides immediate closure of the PDA.

• Persistence of PDA can be provided in multi-specialty and multi-disciplinary teams was important.

• Comprehensive follow-up may reduce these risks and can be provided in a multi-specialty clinic developed specifically for ELBW infants who have undergone TCPC.

• Seamless communication and co-management of interrelated medical problems that require input from multiple sub-specialties are provided in this unique forum.

• Establishing a clinic is a dynamic process which requires continuous evaluation and adoption of the model to facilitate overall advancement and improvement.

• A wholistic approach that targets the needs of a specific patient population is a model that can be replicated and supported well by nurse practitioners.

• An established clinic for a new patient population allows for measurement of long-term outcomes.

• Collaboration among nurse practitioners in specialty areas is instrumental in the success of initiating and sustaining a multi-specialty clinic.

FUTURE IMPLICATIONS

• ELBW infants are at a higher risk for hospital readmission and death during the first year of life compared to healthy term infants.

• Comprehensive follow-up may reduce these risks and can be provided in a multi-specialty clinic developed specifically for ELBW infants who have undergone TCPC.

• Seamless communication and co-management of interrelated medical problems that require input from multiple sub-specialties are provided in this unique forum.

• Establishing a clinic is a dynamic process which requires continuous evaluation and adoption of the model to facilitate overall advancement and improvement.

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BACKGROUND

• Patent ductus arteriosus (PDA) is a common pathology in preterm infants.

• A hemodynamically significant PDA may require intervention for closure.

• Transcatheter patent ductus arteriosus closure (TCPC) is minimally invasive and provides immediate closure of the PDA.

• TCPC eliminates the risks associated with pharmacotherapy and surgical ligation in fragile and high-risk extremely low birth weight (ELBW) infants.

• TCPC is a new procedure for ELBW infants; however, long-term outcomes are not yet known.

• ELBW infants require specialized follow-up at discharge which can be provided in multi-specialty outpatient clinics.

CONCLUSION

• A wholistic approach that targets the needs of a specific patient population is a model that can be replicated and supported well by nurse practitioners.

• An established clinic for a new patient population allows for measurement of long-term outcomes.

• Collaboration among nurse practitioners in specialty areas is instrumental in the success of initiating and sustaining a multi-specialty clinic.