

Maria Broadstreet R.N., MSN, CPNP AC/PC, Sue Horner MS, APN/CNS, RNC-NIC, Candace Harvey BSN, RN, Jenna Badour RN, Leslie Rodman-Uher OT, MS, Jessica Frantz MS, CCC/SLP, Jeanette Hill PT, MS, Lynn Boswell PT, MS, Raye Ann O'de Regnier MD, Nguyenvu Nguyen MD
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Research

- Neurodevelopmental impairments (NDI) are pervasive and persistent in children with congenital heart disease (CHD)¹.
- Approximately 50% of children with CHD have impaired executive function, cognition, motor, visual motor, language or behavior.
- Approximately 30% require remedial school program or specialized services.
- Impairments may not be recognized until a child reaches school age.
- Early evaluation, intervention, and long term follow up are recommended by the American Heart Association (AHA).¹

Purpose

A combined model of neonatology and cardiac intensive care follow up program was created to identify, monitor, and provide developmental supports for children with CHD who are at increased risk for neurodevelopmental deficits.

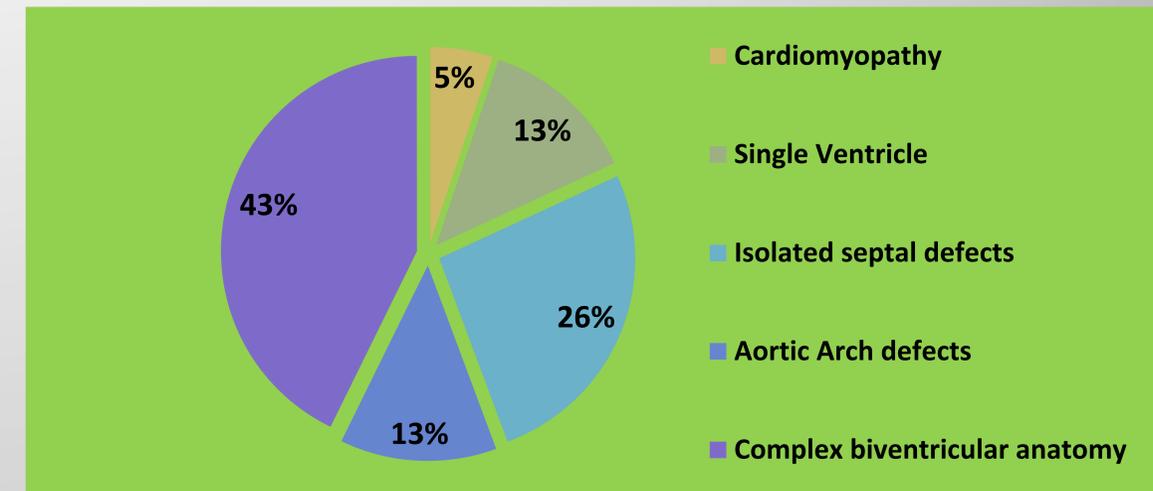
Method

- A multi-disciplinary clinical and administrative team was created since June 2012 at Ann & Robert H. Lurie Children's Hospital of Chicago to support developmental needs for children with heart disease.
 - Cardiology, Neonatology, Cardiovascular surgery, Rehabilitation services (OT/PT/ST), Child life, and Audiology
- Inpatient developmental rounds occur weekly to provide:
 - Integrated evaluation of patient clinical status alongside with non-cardiac risk factors for NDIs based on the AHA 2012 guidelines.¹
 - Standardized referral for inpatient PT/ST/OT evaluation or interventions
 - Standardized referral for early interventions (EI) as indicated
 - Review progress on current rehabilitation therapies
 - Standardized referral for outpatient neurodevelopmental follow up
- Nursing-driven developmental committee provides educational supports for unit staff and parents.

Target Population

- Age < 5years (current program with plans to expand)
- Severe CHD requiring open heart surgery before the age of 12 months
- Signs of neurologic injury, chromosomal/genetic abnormalities, learning disability and behavioral/social-emotional abnormalities

Results



- Bayley Infant Developmental Scale (BIDS –III) at 6-12 months
 - Normal cognitive score 98.6, ± 11
 - Lower language and motor scores 89.4, ± 9.4 and 87.4, ± 13.8
- Late preterm gestational age (<37 weeks) was associated with lower motor scores, p=0.023
- Early inpatient occupational, physical, & speech therapy and parent-directed home therapy lead to significant improvement in PT/OT/Speech findings P=0.001

Conclusions

- Multi-disciplinary approach is necessary to provide comprehensive developmental care to children with CHD throughout early childhood.
- Early initiation of PT, ST and OT interventions show promising preliminary results of improvement in all areas of potential delay.

References

- ¹ Marino, Bradley S., et.al "Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management : A scientific statement from the American Heart Association." *Circulation*. 2012.126.1143-1172.