



Improving Neurodevelopmental Follow-Up in Children with Single-Ventricle Congenital Heart Disease

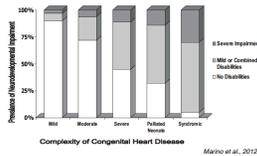
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INTRODUCTION

Surgical and perioperative advances in the field of congenital heart disease (CHD) have increased survival of these patients. A growing body of evidence that affirms the presence of neurodevelopmental morbidity in survivors of CHD (Gerdes & Flynn, 2010). By the age of five, neuromotor sequelae are present in approximately 50% of children with CHD (Gerdes & Flynn, 2010). The disabilities range from those that are barely noticeable, to severe dysfunction that severely impacts quality of life (Gerdes & Flynn, 2010). In addition, the prevalence of disability increases with increasing complexity of CHD.



Disability has been recognized in the following areas:

- Intelligence
- Language (development, expressive, and receptive)
- Executive functioning
- Fine Motor Skills
- Gross Motor skills
- Attention & Behavioral problems (internalizing or externalizing behaviors)

LITERATURE SYNTHESIS

A literature search was conducted to explore the efficacy of early developmental intervention in improving developmental outcomes. An exhaustive search was performed in Cochrane Library, CINAHL, PubMed, and PsycINFO. Synthesis of the evidence revealed:

Early developmental intervention improves outcomes in the following areas:

- Intelligence & academic success
 - Motor
 - Language
 - Personal-Social skills
- Increased efficacy in programs that:
- Began intervention before six months of age
 - Included parental interaction as a key component of therapy
 - Interventions are long-term, throughout infancy & toddlerhood

INTERVENTION

Cardiology Critical Brain Development Program (CCriB)

Objectives:

- Increase acquisition of developmental therapies
- Aid children in acquiring these services as early as possible, goal being by 6 months of age
- Educate parents on the risk of developmental delay, as their participation is essential to the child's success

Program Structure:

- Provides periodic developmental evaluation & monitoring for children with complex CHD
- Minimum yearly evaluation from birth to age 5 by a developmental pediatrician to identify developmental delay and refer for therapy as needed.
- Parental education via handouts and one-on-one instruction with developmental pediatrician

METHODS

Primary Aims:

- #1: Assess CCriB Program effectiveness in improving acquisition of developmental services
- #2: Assess barriers to acquiring developmental services for children

Design:

Prospective chart review & telephone interview of parents

Population:

Single-ventricle CHD s/p stage 2 or 3 palliation AND <4 years of age (48 mo)

Exclusion criteria: Language other than Spanish or English.

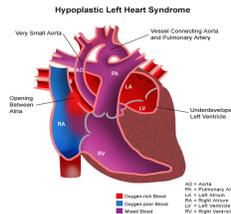
Setting:

Heart Center at Phoenix Children's Hospital
Arizona Pediatric Cardiology Consultants (APCC)

Human Subjects Protection:

Approved by IRB at Phoenix Children's Hospital & Arizona State University

Informed consent & HIPAA authorization obtained from all children included in data analysis



DATA COLLECTION

Demographics:

- Gender
- Cardiac Diagnosis
- Ethnicity
- Primary language spoken at home
- Age at visit

Presence of developmental services:

- Initiation of services prior to CCriB visit
- Initiation of services after CCriB visit
- Which intervention services were initiated?
- Age at acquisition of developmental therapies

Barriers to Care

- Time from referral to appointment
- Attendance

Barriers to care:

- (follow-up phone call)
- Has the child received services and therapies they were ordered? Why not?

RESULTS

ACQUISITION OF SERVICES

- 50% Not receiving any therapies before CCriB
- 63% Ordered additional therapies at CCriB
- 100% of those needing therapy, receiving at least 1 therapy at follow-up

Therapies Before vs. Therapies Ordered

The mean number of therapies before the visit was 0.38 ($sd=0.74$), and the mean number of therapies ordered after the visit was 2.00 ($sd=1.41$). A significant increase from before the CCriB visit to after the visit was found ($t(7)=-2.5, p=.02$).

Therapies Before vs. Therapies Receiving at Follow-Up

The mean number of therapies before the visit was 0.38 ($sd=0.74$), and the mean number of therapies ordered after the visit was 1.25 ($sd=1.04$). A significant increase from before the CCriB visit to after the visit was found ($t(7)=-2.20, p=.06$).

*Paired samples t-test; significance was tested at the $p < .10$ level of significance due to small sample

BARRIERS TO SERVICES

16 therapies ordered, 10 received, 63% acquisition

- Distance/transportation issues
- 25% unable to get services due to AzEIP denial for additional therapies
- 1 needed to get prescription from PCP, rather than specialist
- Lack of parental follow-up

CONCLUSIONS

- Local Impact: CCriB Program @ PCH
 - Presented CCriB Program to parents at Cardiac Day at the Zoo
 - PALs Grant for purchase of equipment
 - Designated clinic in Heart Center for CCriB Program
 - Increased awareness of importance of developmental needs
- Political Impact: Care Coordination for CSHCN
- Developmental care in this population becoming standard of care
- Increased awareness among primary care providers

REFERENCES

Gerdes, M., & Flynn, T. (2010). Clinical assessment of neurobehavioral outcomes in infants and children with congenital heart disease. *Progress in Pediatric Cardiology*, 29, 97-105. <http://dx.doi.org/10.1016/j.pppedcard.2010.06.009>

Marino, B. S., Lipkin, P. H., Newburger, J. W., Peacock, G., Gerdes, M., Gaynor, J. W.,...Mahle, W. T. (2012). Neurodevelopmental outcomes in children with Congenital Heart Disease: Evaluation and management: A scientific statement from the American Heart Association. *Circulation*, 126, 1-30. <http://dx.doi.org/10.1161/CIR.0b013e318265ee8a>