Neurodevelopmental Outcomes for Children 0-3 Years with Congenital Heart Disease in an Outpatient Clinic Model

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Background

Surgical and medical advancements for children with congenital heart disease (CHD) result in declining mortality rates, while increasing risk for maturation arrest and neurodevelopmental (ND) delays. To improve ND outcomes, rehabilitation practices must advance with cardiac practice evolutions. Analyzing our clinic model, the Developmental Assessment of Young Children (DAYC-2) was determined to be the optimal standardized assessment.

Objectives

- Investigate the correlation between severity of CHD and ND deficits.
- Refine our clinic model to integrate ND evaluations with cardiology visits, providing patient-family centered care for optimal ND outcomes in our complex population.

Methods

A retrospective study was conducted of patients at MCWHLB Outpatient Cardiac Clinic with a diagnosis of CHD ages 0-3 years (N=80).

Patients were categorized by simple, moderate, and complex cardiac disease. Patients with a genetic disorder were classified separately regardless of their CHD category. (Table 1)

All patients required surgical and/or medical intervention.

Data collected include age, CHD diagnosis, secondary diagnosis as related to ND risk factors, DAYC-2 (physical domain only) raw scores and age equivalence, and therapy history.

Results & Discussion

Percentile ranking for GM and FM skills across all disease severity is lower than the general population; Although no significant difference was noted between groups, results are still indicative that motor skill performance is below age expectations. (Figure 1)

Simple and moderate CHD groups demonstrated change in average values from baseline to six-months, and a trend towards severity dependence, although non-significant. (Figures 2 & 3)

Skill acquisition did occur in simple and moderate groups by six-month reassessment; however, scores remained less than 50th percentile ranking.

Complex and genetic groups showed minimal skill progression.

No significant difference was found between preterm infants with CHD and full-term infants with CHD. Rate of learning was not significantly different between the two groups. (Table 2 & 3)

			N (%)
SIMPLE (N=19, 23.8%)	(Valvular heart disease, left or right sided obstructive lesion, left to right shunt, pulmonary venous anomaly)	Aortic stenosis/COA	1 (1%)
		Large ASD	1 (1%)
		PDA	3 (4%)
		Coarctation of the aorta	2 (3%)
		VSD	8 (10%)
		VSD/COA	1 (1%)
		Ebstein's anomaly	2 (3%)
		TAPVR	1 (1%)
MODERATE (N=10, 12.5%)	Biventricular congenital heart disease repair with moderately complex single stage repair	TOF	9 (11%)
		Complete AVC	1 (1%)
COMPLEX (N=27, 33.8%)	Single ventricle physiology, Complex biventricular congenital heart disease	HLHS	3 (4%)
		Hypoplastic right heart	5 (6%)
		Single ventricle	3 (4%)
		Shone's Complex	1 (1%)
		TGA	5 (6%)
		TOF (requiring neonatal palliation)	4 (5%)
		Truncus arteriosus	3 (4%)
		TAPVR with PS	1 (1%)
		Interrupted aortic arch with VSD	1 (1%)
		Ebstein's anomaly with pulm atresia	1 (1%)
GENETIC (N=24, 30%)	Include simple, moderate, and complex cardiac diagnosis	Truncus arteriosus	1 (1%)
		DORV	1 (1%)
		TOF	5 (6%)
		AVC	7 (9%)
		PDA	3 (4%)
		VSD	4 (5%)
		ASD, VSD, PDA	1 (1%)
		COA	2 (3%)

Table 1. Disease severity.

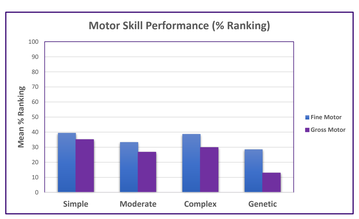

Figure 1. Gross and fine motor percentile ranking at baseline.

	Initial	6 months	Mean Difference	Δ within factor level	Δ depends on factor level
Pre-term:					P=.685
No (≥37 weeks)	26.1 (21.3, 30.9)	32.3 (24.0, 40.5)	+6.2 (-2.5, 14.9)	P=.160	
Yes (<37 weeks)	24.0 (15.1, 32.9)	26.2 (13.5, 38.9)	+0.1 (-13.5, 13.7)	P=.987	

Table 2. Change in **gross motor** percentile ranking from baseline to 6 months examined across demographics.

	Initial	6 months	Mean Difference	Δ within factor level	Δ depends on factor level
Pre-term:					P=.235
No (≥37 weeks)	36.3 (32.5, 40.2)	37.4 (32.1, 42.8)	+1.1 (-5.1, 7.3)	P=.724	
Yes (<37 weeks)	30.1 (22.4, 37.7)	39.3 (29.1, 49.4)	+9.2 (-2.6, 21.1)	P=.128	

Table 3. Change in **fine motor** percentile ranking from baseline to 6 months examined across demographics.

Results

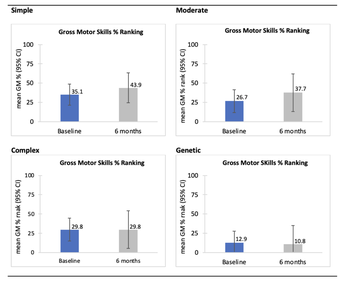

Figure 2. Gross motor skills percentile ranking significantly differed by severity at baseline and 6 months (p<.001). Change in average values showed a trend towards severity dependence, although non-significant (p=.222). GEE analyses with gamma distribution and repeat measures specified.

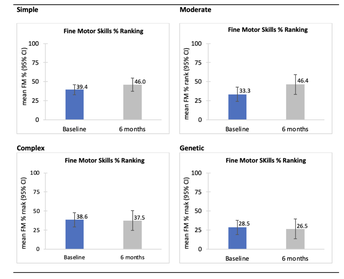

Figure 3. Fine motor skills percentile ranking significantly differed by severity at baseline and 6 months (p=.002). Change in average values showed a trend towards severity dependence, although non-significant (p=.265). GEE analyses with linear distribution and repeat measures specified.

Conclusion

Children with CHD, regardless of disease severity, are at risk for maturation arrest and ND delays.
It is imperative that all have close ND follow-up in infancy.

It is established that premature infants are at high risk for ND delays. This research highlights the need for ND monitoring for all CHD infants, regardless of gestational age, as there was no significant difference between preterm and full-term infants with CHD.

There are various barriers for patients to obtain timely ND follow-up. Early intervention has been proven to help minimize long term developmental delays; however, there is a time-sensitive window of opportunity. We found that with early identification and intervention that there was ND improvement. Our results were not statistically significant however with a larger study population we may have seen more of a measurable change.

We can improve the patient-family experience by implementing a clinic model that addresses cardiac and ND needs during a single visit.

Our model provides an efficient way to capture this at-risk population with less chance for loss to follow-up.

References

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