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Original Article

Prediction of preschool functional abilities after early complex cardiac surgery

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Abstract *Background:* It is important to identify early predictors of functional limitations in children after congenital heart surgery to optimise their independence as they prepare for school. The purpose of this study is to determine potentially modifiable predictor variables of functional abilities in pre-school children who underwent complex cardiac surgery at 6 weeks of age or earlier. *Methods:* This prospective inception cohort study comprised a sample of 165 survivors (63% boys) who had complex cardiac surgery (75% biventricular repairs) at Stollery Children's Hospital, Edmonton, Alberta. We excluded children with chromosomal abnormalities. When children were 4–5 years of age, the parents completed the Adaptive Behavioral Assessment System II. Regression analysis was used to assess the association between multiple risk factors and each of the four continuous composite scores. *Results:* The mean scores for the practical domain and general adaptive composite score of the Adaptive Behavioural Assessment System were lower than the conceptual and social domains, with 13.3% of the children having a delay in the practical domain. There was a significant association between the general adaptive ($p = 0.003$; 0.012), conceptual ($p = 0.0004$; 0.042), social ($p = 0.0007$; 0.028), and the practical ($p = 0.046$; 0.003) domain composite scores with the mother's education and preoperative plasma lactate, respectively. *Conclusion:* Maternal education may be a marker for the social context of children, and warrants societal attention to improve functional outcomes. Preoperative lactate as a potentially modifiable variable may warrant increased attention to early diagnosis and aggressive resuscitation of young infants with congenital heart disease.

Keywords: Adaptive behaviour; congenital cardiac surgery; pre-school function; prediction; outcomes

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As sustained progress on early diagnosis and developing technologies to repair complex congenital cardiac defects has led to an increasing number of survivors among children undergoing complex cardiac surgery: investigations of late sequelae and factors modifying their risks are emerging.[1] These children are at risk for fine and gross motor delay, physical growth abnormality, behaviour problems, learning difficulties, deficits in language skill, below-average cognitive abilities, and delays in activities of daily living.[2–4] It is not enough to report just the neurodevelopmental sequelae as early studies in the functional outcomes of children after complex cardiac surgery in early life have shown.[4–8] Some studies report that children surviving complex cardiac surgery are at risk for impaired quality of life and emotional and behavioural maladjustment as they reach school age.[9,10] A range of risk factors associated with lower functional outcomes in children with neonatal cardiac surgery have been identified to include genetic predisposition,

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gender, chromosome abnormalities, surgical group, health status, and socio-economic status.[6–8,11–13]

Functional outcomes for young children have been traditionally measured by multidimensional parent-completed questionnaires[14] such as the Adaptive Behavioural Assessment System.[15] Adaptive behaviour has been defined as the level to which individuals meet the standards of personal independence and social consciousness expected for their age and culture.[14] Measurement of adaptive behaviour supplements cognitive assessment in the diagnosis of a cognitive disability to provide a comprehensive assessment.[16,17] An age-appropriate independent skill level in daily living activities is necessary to facilitate a smooth transition at all stages in the child's developmental trajectory.[4]

The purpose of this study is to determine potentially modifiable predictor variables of functional outcomes in pre-school children with congenital heart disease who underwent complex cardiac surgery at 6 weeks of age or earlier.

Materials and methods

Programme

The children were part of a larger study within the Registry and Follow-Up of Complex Paediatric Therapies Programme as previously described.[3,18] The children were from six centres in western Canada: Vancouver, British Columbia; Edmonton and Calgary, Alberta; Regina and Saskatoon, Saskatchewan; and Winnipeg, Manitoba.

Subjects

This prospective inception cohort included 260 neonates identified at the time of complex cardiac surgery for congenital heart disease performed at 6 weeks of age or earlier, between 2000 and 2005. Of the 260 neonates, 17 had chromosomal abnormalities and were excluded. Of the remaining 243 patients eligible for follow-up, 52 died before 5 years of age, 17 were lost to follow-up, and 16 had not yet been assessed, leaving 165 patients for assessment at the age of 54.5 (5.3) months. No child had a vision or hearing loss. Socio-economic status, as calculated for the main and highest income earner, was determined using the Blishen Index – dependent on employment, education, and prestige value of an occupation, with a population mean of 43 and standard deviation of 13.[19] Maternal education was measured in total years of schooling at the time of the 4.5-year assessment. Acute care variables were preoperative plasma lactate, lowest PaO_2, cardiopulmonary bypass time, deep hypothermic arrest time, postoperative lowest PaO_2, highest plasma lactate, highest inotrope score, all ventilator days – preoperative and postoperative – all hospital days of admission, single-ventricle physiology, and age at surgery.

Ethics and consent

Follow-up procedures were discussed with parents and written consent was obtained. Institutional health research ethics boards approved the project.

Outcome functional measure

To ascertain the functional abilities of the children, parents completed the Adaptive Behavioural Assessment System II parent report form for children 0–5 years 11 months, at the time of the 4–5-year assessment. Although other tests could be used to assess the functional abilities in children, the Complex Therapies Follow-Up Programme has chosen the well-accepted Adaptive Behavioural Assessment System II.[15] The standardisation sample for the Adaptive Behavioural Assessment System II comprised 2100 individuals at birth to 5 years of age according to gender, race, and different levels of disabilities. The average reliability coefficient for the adaptive domains ranged from 0.91 to 0.98. The test–retest reliability coefficients ranged from 0.70 to 0.90.9. Validity has been indicated in all instrument scores by an internal consistency of 0.90.9. Established test administration protocols were followed and the same individual scored all of the forms.

The Adaptive Behavioural Assessment System II is an instrument intended to measure and assess realistic, independent behaviours of individuals, and the effectiveness of interactions with others, while including consideration of community contexts.[15] This measure consists of nine skill areas grouped into three composite domains: conceptual – communication, functional pre-academics, and self-direction; practical – home living, health and safety, community use, and self-care; and social – leisure and social. The motor skill is separate and included with the nine skilled areas in the total general adaptive composite score. The composite scores have age-based population scores with a mean of 100 and a standard deviation of 15. Each age-based skill area-scaled score has a mean of 10 and standard deviation of 3.

Statistics

Continuous variables are shown as mean (SD), and dichotomous variables are presented as count (percentage, %). Collinear predictors were identified before building the multiple regression models. Purposeful selection method was performed to select the best subset of predictor variables. Linear regressions were run for each of the continuous outcomes and each of the explanatory variables to determine significance at 0.15 α level. Multiple regressions were fitted separately for each of the four continuous outcome variables and each of the significant predictor variables in the univariate analysis, with the exception of multicollinear variables. Clinically important variables were also included in the models regardless of their p-values in the univariate analysis. Effect size deviations from reference means were used to assess the clinical relevance. In the purposeful model, the cut-off point was a p-value under or equal to 0.05. All statistical analyses were performed using statistical software SAS version 9.2 (SAS Institute, Cary, NC, USA) and SPSS version 16 (SPSS Inc., Chicago, IL, USA).

Results

Table 1 presents the demographic, preoperative, operative, and postoperative variables collected for this study. The population consisted of 63% males and 75% children with biventricular repairs. Outcomes are presented in Table 2. The mean scores for the practical domain and general adaptive composite score of the Adaptive Behavioural Assessment System were lower than the conceptual and social domains, with 13.3% of the children having a delay in the practical domain (Table 3).

Table 1. Description of the cohort of 165 survivors of infant cardiac surgery.

	Mean or n (SD or %)
Preoperative/demographic variables	
Gender (male)	104 (63%)
Single-ventricle anatomy	41 (24.8%)
Birth gestation (weeks)	38.9 (1.8)
Mother's years of schooling	13.2 (2.8)
Lowest PaO_2 [arterial blood gas (mmHg)]	37.5 (15.6)
Highest plasma lactate (mmol/L)	4.3 (4.5)
Operative variables	
Age at surgery (days)	12.8 (10.7)
Cardiopulmonary bypass time (minutes)	123.6 (64.5)
Deep hypothermic circulatory arrest used	113 (68.5%)
Postoperative variables	
Highest inotrope score	18.3 (14.0)
Highest plasma lactate (mmol/L)	6.4 (3.3)
Lowest PaO_2 (mmHg)	47.2 (13.4)
Overall perioperative variables	
All ventilator days	18.3 (17.5)
All hospitalisation days	34.2 (35.5)

Prediction of general adaptive composite

In the multiple regression analysis (Table 4), there was a significant association between the general adaptive composite with preoperative plasma lactate, mother's education, and gender. Preoperative lactate is a potentially modifiable variable; each 1 mmol/L higher plasma lactate before surgery was associated with a lower general adaptive composite score of 0.72 points (p = 0.013).

Prediction of the conceptual domain

Table 5 shows the significant relation between the conceptual domain and mother's education, ventilator days, gender, and preoperative lactate. Preoperative lactate and ventilator days are potentially modifiable variables. Each 1 mmol/L higher preoperative plasma lactate was associated with a lower conceptual score of 0.55 points (p = 0.043). Each day that the children were ventilated during their hospital stay for cardiac surgery was associated with a lower conceptual score by 0.16 points (p = 0.024).

Prediction of practical domain

A significant relation was found between the practical domain and preoperative plasma lactate, mother's education, and single-ventricle anatomy (Table 6). Preoperative lactate is a potentially modifiable

Table 3. Frequency of the outcome of functional delay (outcome score <70) in 4.5-year-old children undergoing infant cardiac surgery.

Outcome	n (%)
ABAS – GAC <70	23 (13.9%)
ABAS – conceptual <70	15 (9.1%)
ABAS – social <70	10 (6.1%)
ABAS – practical <70	22 (13.3%)

ABAS = adaptive behaviour assessment system; GAC = general adaptive composite score of the ABAS

Table 2. Description of outcomes in 4.5-year-old children undergoing infant cardiac surgery.

Outcome	n	Minimum	Maximum	Mean	SD
ABAS – GAC	165	41	130	89.7	17.0
ABAS – conceptual	165	45	129	93.2	16.7
ABAS – social	165	48	130	93.9	17.1
ABAS – practical	165	35	127	85.8	16.2

ABAS = adaptive behaviour assessment system; GAC = general adaptive composite score of the ABAS

Table 4. Univariate and multivariable linear regression for general adaptive composite in 165 4.5-year-old children undergoing complex cardiac surgery at 6 weeks of age and less.

	Univariate regression		Multiple regression	
Label	**Effect size (95% CI)**	**p-value**	**Effect size (95% CI)**	**p-value***
Mother's education (years)	1.22 (0.41, 2.03)	0.003	1.21 (0.42, 2.00)	0.003
All hospitalisation days	– 0.11 (–0.18, – 0.03)	0.004	–	–
Preoperative highest lactate (mmol/L)	– 0.75 (–1.33, – 0.17)	0.011	– 0.72 (–1.28, – 0.16)	0.013
All ventilator days	– 0.17 (–0.32, – 0.02)	0.024	–	–
Postoperative lowest PaO_2 (mmHg)	0.22 (0.03, 0.42)	0.025	–	–
Female	5.21 (–0.17, 10.59)	0.058	5.68 (0.51, 10.84)	0.031
Norwood/single-ventricle anatomy	– 4.97 (–11.00, 1.06)	0.105	–	–
Postoperative highest lactate (mmol/L)	– 0.64 (–1.43, 0.15)	0.114	–	–
Age at surgery – days	– 0.17 (–0.42, 0.07)	0.165	–	–
Birth gestation (weeks)	0.97 (–0.47, 2.41)	0.184	–	–
Postoperative highest inotrope score	– 0.09 (–0.27, 0.10)	0.369	–	–
DHCA	2.24 (–3.41, 7.88)	0.435	–	–
Cardiopulmonary bypass time (minutes)	– 0.01 (–0.06, 0.03)	0.473	–	–
Preoperative lowest PaO_2 (mmHg)	0.05 (–0.12, 0.22)	0.547	–	–

DHCA = deep hypothermic circulatory arrest
*p-value < 0.15 in univariate regression considered as significant candidates for the multivariate analysis

Table 5. Univariate and multivariable linear regression for conceptual score in 165 4.5-year-old children undergoing complex cardiac surgery at 6 weeks of age and less.

	Univariate regression		Multiple regression	
Label	**Effect size (95% CI)**	**p-value**	**Effect size (95% CI)**	**p-value***
Mother's education at (years)	1.53 (0.75, 2.31)	0.001	1.40 (0.64, 2.16)	0.001
All hospitalisation days	– 0.12 (–0.19, – 0.05)	0.001	–	–
All ventilator days	– 0.19 (–0.34, – 0.05)	0.009	– 0.16 (–0.29, – 0.02)	0.024
Postoperative: overall lowest PaO_2 (mmHg)	0.24 (0.05, 0.43)	0.014	–	–
Female	6.25 (1.01, 11.49)	0.020	7.22 (2.31, 12.13)	0.004
Preoperative highest lactate (mmol/L)	– 0.64 (–1.22, – 0.07)	0.027	– 0.55 (–1.09, – 0.02)	0.043
Norwood/single-ventricle anatomy	– 5.98 (–11.86, – 0.1)	0.046	–	–
Birth gestation, completed (weeks)	1.23 (–0.17, 2.64)	0.085	–	–
Postoperative: overall highest lactate (mmol/L)	– 0.64 (–1.41, 0.14)	0.107	–	–
Postoperative: overall highest inotrope score	– 0.14 (–0.33, 0.04)	0.126	–	–
Age at treatment/surgery (days)	– 0.18 (–0.42, 0.06)	0.134	–	–
Cardiopulmonary bypass time (minutes)	– 0.01 (–0.05, 0.03)	0.555	–	–
Preoperative lowest PaO_2 (mmHg)	0.01 (–0.16, 0.17)	0.914	–	–
DHCA	– 0.19 (–5.73, 5.34)	0.945	–	–

DHCA = deep hypothermic circulatory arrest
*p-value < 0.15 in univariate regression considered as significant candidates for the multivariate analysis

variable; each 1 mmol/L higher preoperative plasma lactate was associated with a lower practical score of 0.81 points (p = 0.003).

Prediction of social domain

There was a positive association between the social composite domain (Table 7), and preoperative plasma lactate, mother's education, and gender. Preoperative lactate is a potentially modifiable variable; each 1 mmol/L higher preoperative plasma lactate was associated with a lower social score of 0.63 points (p = 0.028).

Discussion

Functional abilities are a very important consideration in neurodevelopmental evaluations of children assessed for school readiness. This study is the first to present predictors of functional limitations in children 4.5 years of age following neonatal open-heart surgery. Several instruments have been developed and utilised to measure various components of functional health aspects in children with congenital heart surgery.[5,6] This study is the first to use the Adaptive Assessment Behavioural System II for a

Table 6. Univariate and multivariable linear regression for practical score in 165 4.5-year-old children undergoing complex cardiac surgery at 6 weeks of age and less.

	Univariate regression		Multiple regression	
Label	Effect size (95% CI)	p-value	Effect size (95% CI)	p-value*
Preoperative highest lactate (mmol/L)	– 0.83 (–1.38, – 0.28)	0.004	– 0.81 (–1.35, – 0.27)	0.003
Postoperative: overall lowest PaO_2 (mmHg)	0.24 (0.06, 0.43)	0.010	–	–
All hospitalisation days	– 0.09 (–0.16, – 0.02)	0.013	–	–
All ventilator days	– 0.16 (–0.30, – 0.02)	0.030	–	–
Norwood/single-ventricle anatomy	– 6.01 (–11.73, – 0.2)	0.039	– 6.31 (–11.85, – 0.7)	0.026
Mother's education (years)	0.81 (0.03, 1.60)	0.043	0.77 (0.01, 1.53)	0.046
Postoperative: overall highest lactate (mmol/L)	– 0.58 (–1.34, 0.17)	0.130	–	–
Age at treatment/surgery (days)	– 0.15 (–0.38, 0.09)	0.216	–	–
Female	2.33 (–2.85, 7.50)	0.376	–	–
DHCA	1.80 (–3.58, 7.19)	0.509	–	–
Postoperative: overall highest inotrope score	– 0.06 (–0.24, 0.12)	0.514	–	–
Preoperative lowest PaO_2 (mmHg)	0.04 (–0.12, 0.20)	0.616	–	–
Cardiopulmonary bypass time (minutes)	– 0.01 (–0.05, 0.03)	0.684	–	–
Birth gestation, completed (weeks)	0.15 (–1.23, 1.53)	0.828	–	–

DHCA = deep hypothermic circulatory arrest
*p-value < 0.15 in univariate regression considered as significant candidates for the multivariate analysis

Table 7. Univariate and multivariable linear regression for social score in 165 4.5-year-old children undergoing complex cardiac surgery at 6 weeks of age and less.

	Univariate regression		Multiple regression	
Label	Effect size (95% CI)	p-value	Effect size (95% CI)	p-value*
Mother's education (years)	1.39 (0.58, 2.20)	0.001	1.39 (0.60, 2.18)	0.001
Preoperative highest lactate (mmol/L)	– 0.67 (–1.26, – 0.08)	0.0251	– 0.63 (–1.19, – 0.07)	0.028
Female	6.01 (0.62, 11.40)	0.0291	6.52 (1.37, 11.67)	0.013
All hospitalisation days	– 0.08 (–0.15, – 0.01)	0.032	–	–
All ventilator days	– 0.13 (–0.28, 0.02)	0.084	–	–
Postoperative: overall highest lactate (mmol/L)	– 0.59 (–1.39, 0.20)	0.144	–	–
Postoperative: overall lowest PaO_2 (mmHg)	0.13 (–0.06, 0.33)	0.187	–	–
Age at treatment/surgery (days)	– 0.15 (–0.40, 0.10)	0.231	–	–
Preoperative lowest PaO_2 (mmHg)	0.08 (–0.08, 0.25)	0.323	–	–
Birth gestation, completed (weeks)	0.65 (–0.80, 2.10)	0.379	–	–
Norwood/single-ventricle anatomy	– 2.35 (–8.44, 3.75)	0.448	–	–
Cardiopulmonary bypass time (minutes)	– 0.01 (–0.05, 0.03)	0.509	–	–
DHCA	1.78 (–3.89, 7.46)	0.535	–	–
Postoperative: overall highest inotrope score	– 0.02 (–0.21, 0.17)	0.840	–	–

DHCA = deep hypothermic circulatory arrest
*p-value < 0.15 in univariate regression considered as significant candidates for the multivariate analysis

heterogeneous group of children following congenital heart surgery. We determined that increased preoperative plasma lactate, gender, and mother's education were associated with lower scores in all of the four domains – conceptual, social, practical, and general adaptive composite – of functional outcomes in the study.

Influence of preoperative plasma lactate on functional outcomes

A significant association between higher preoperative plasma lactate with lower functional scores, in all domains, of 4.5-year-old children was found in the present study. Increased preoperative lactate levels have been found by others to be associated with mental and/or motor delay in children undergoing arterial switch operations for transposition of great arteries,[20] survival, and adverse neurological outcomes in children with intracardiac surgery aged 6 weeks or less.[18,21] This is important, because preoperative plasma lactate may be a modifiable variable; it is possible that increased attention to early diagnosis and aggressive resuscitation may improve preoperative lactate levels and thus outcomes. How to reduce preoperative lactate levels cannot be answered

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by this study. In general, optimising pulmonary to systemic flow in single-ventricle physiology patients, and rapid resuscitation and transport to cardiac intensive care of these critically ill infants are needed. Specific strategies to achieve this goal should be the topic of future clinical trials.

Influence of gender on functional outcomes

Male children were identified in the current study to have significantly lower functional abilities, as scored in the areas of general adaptive composite, conceptual, practical, and social domains, when compared with female children. Being male has been reported by others to be associated with lower physical functioning and social limitations[6] and greater risk for functional limitations such as self-care, communication, and mobility in a group of cardiac children not including those having Norwood surgery.[12] This could reflect differential over-protection or differences in pathogenesis of brain injury, as reported by Majnemar et al[12] Further study is required.

Influence of mother's education on functional outcomes

Mother's education significantly affects all domains of functional outcomes in children undergoing complex cardiac surgery at 6 weeks of age or earlier. Each year, increase in mother's education is significantly associated with better functional abilities of 4.5-year-old children with congenital cardiac surgery. Several studies have reported an association between socio-economic status and mental outcome in children.[6,22–25] Larsen et al[6] found that parent education is an important factor in the psychosocial well-being of children with congenital heart surgery. McCusker et al[26] found that maternal factors contribute to later adjustment in children with congenital heart surgery. Children who are perceived as vulnerable by their parents have lower adaptive development,[9,27] and Lipstein[27] suggests that preoccupation with the child's health could contribute to poorer developmental and behavioural outcomes. Social support is very important for this group of families and helps to build on functional skill levels by being part of groups with similar developmental age levels. We hypothesise that maternal education may be a marker for the social environment of the child, including social supports, and coping skills in caring for a vulnerable child.

Influence of single-ventricle heart defect on functional outcomes

The current study determined that there is a considerable relation between single-ventricle anatomy and practical scores of children at 4.5 years of age. In a previous publication, Alton et al[4] reported that the children with single-ventricle anatomy had lower self-care scores on the Adaptive Behavioural Assessment System II than the comparison arterial switch surgical group. Interestingly, in the current study, preoperative PaO_2 was not associated with any of the Adaptive Behavioural Assessment System II outcomes on univariate analyses, and postoperative PaO_2 was associated with practical, conceptual, and general adaptive composite scores on univariate analyses. However, on multiple regressions, postoperative PaO_2 was not an independent predictor, whereas single-ventricle physiology was an independent predictor of practical score. This suggests that it may not be the low PaO_2 that is responsible for adverse practical score in the single-ventricle patients.

Strengths

This study is part of a larger cohort follow-up project that prospectively follows up children who undergo complex cardiac surgery for congenital heart disease at 6 weeks of age or less. Therefore, data in this study were collected prospectively that ameliorate recall bias. This provided a large number of children registered in the database with at least 4.5 years of follow-up and minimal loss to follow-up. Moreover, this study offers an extensive geographic base, tracking children from across western Canada who underwent complex cardiac surgery at the same centre. Finally, all parents completed the same Adaptive Behavioural Assessment form that was scored by the same person.

Limitations

The results should be interpreted with caution owing to several study limitations. First, this is an observational study: researchers had limited control over confounding factors and could only control recognised and measured factors. The associations found are hypothesis generating and cannot be said to be conclusively causal. Second, the questionnaires were filled out by parents who may be inclined to answer questions optimistically, which may affect the accuracy of the results. Third, as this is an observational study on a particular defined group, results cannot be applied to other congenital heart disease populations operated upon at different ages. Fourth, functional outcomes in children have been traditionally measured by the Vineland Adaptive Behavioural System[28] and the Adaptive Behavioural Assessment System. It is unlikely that the use of a different functional measure such as the Vineland Adaptive Behavioural System would have found significantly different results.[28] It is essential to understand that the Adaptive Behavioural Assessment System II is a functional measure and does not measure intelligence, neuropsychological outcomes, or academic achievement. Studies on intelligence or underlying cognitive skills as the outcome may well uncover different predictors.

Conclusion

It is important to identify early predictors of functional limitations in children after congenital heart surgery to optimise their independence as they prepare for school. This information is needed to counsel, educate, and support parents regarding understanding the everyday activities that the children will require as they prepare for school, and to promote early intervention that may be beneficial to their child's psychological stability. Preoperative lactate is a potentially modifiable variable that predicts adverse functional outcome; this may warrant increased attention to early diagnosis and aggressive resuscitation of young infants with congenital heart disease. Maternal education may be a marker for the social context of children, may be modifiable, and warrants societal attention to improve functional outcomes of children with complex disease.

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Conflicts of Interest

None.

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