Gastrostomy Tube Feeding after Neonatal Complex Cardiac Surgery Identifies the Need for Early Developmental Intervention

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Objective To compare the proportion of developmental delay in early complex cardiac surgery (CCS) survivors with and without gastrostomy tube feeding (GTF). To explore acute care predictors of GTF that might help improve care in CCS survivors.

Study group This comparison study of 2 groups within an inception cohort included 334 CCS survivors after cardiopulmonary bypass at ≤6 weeks of age (2005-2012) who did not require extracorporeal membrane oxygenation or heart transplantation. Children were assessed at 21 ± 3 months with the Bayley Scales of Infant and Toddler Development-Third Edition and the Adaptive Behavior Assessment System-Second Edition: general adaptive composite score. Delay was determined by scores >2 SD below mean. The χ^2 test compared groups. Predictors of GTF were analyzed using multiple logistic regression analysis, results expressed as OR with 95% CI.

Results Of the survivors, 67/334 (20%) had GTF any time before the 21-month assessment. Developmental delays in children with GTF were cognitive in 16 (24%), motor in 18 (27%), language in 24 (36%) vs without GTF in 7 (3%), 8 (3%), and 32 (12%), respectively ($P < .001$). Gastrostomy group had almost 8 times the number of children delayed on the general adaptive composite score. Independent OR for GTF are presence of a chromosomal abnormality, OR 4.6 (95% CI 1.8, 12.0) ($P = .002$), single ventricle anatomy, OR 3.4 (95% CI 1.7, 6.8) ($P < .001$), total postoperative days of open sternum, OR 1.15 (95% CI 1.1, 1.3) ($P = .031$), and total number of hospital days at CCS, OR 1.03 (95% CI 1.1, 1.04) ($P = .002$).

Conclusions GTF identifies CCS survivors at risk for delay, who would benefit from early developmental intervention. The described mostly nonmodifiable predictors may guide counseling of these children's families. *(J Pediatr 2016;169:160-5)*.

Recent improvements in diagnosis, surgical techniques, and overall care of children with congenital heart disease (CHD) have resulted in increased survival rates.[1] More recently, the focus of attention has been shifting to improving developmental outcomes as it is well recognized that children with CHD surviving any complex cardiac surgery (CCS) are at risk for neurodevelopmental disabilities.[2]

In the last decades early developmental intervention (EDI) programs have become a key element in the assistance of children who have, or are at risk of having, developmental delays. EDI provides multidisciplinary services to children from birth to school entry to "promote children's health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or merging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning."[3] EDI is known to positively impact outcomes across developmental domains, including motor, language, cognitive and social/emotional development, overall health, as well as family empowerment.[4-6] Prompt recognition of the need for referral is essential to provide support as early as possible.

The primary goal of gastrostomy tube feeding (GTF) is to enhance growth and nutrition. Indications for GTF usually include children with swallowing difficulties, poor oral intake, feeding disorders, and/or congenital anomalies.[7,8] Studies have shown the positive impact GTF has on the overall health and outcomes of children requiring nonoral feedings.[9-11] A recent study showed benefits included reduced vomiting, increased oral intake, improved parent and child relationship, and satisfaction during meals.[12]

Feeding difficulties are a common obstacle in the postoperative period after CCS for CHD.[13] Nutritional challenges present in children with CHD are

ABAS-II	Adaptive Behavior Assessment System-Second Edition
Bayley-III	Bayley Scales of Infant and Toddler Development-Third Edition
BSID-II	Bayley Scales of Infant Development-Second Edition
CCS	Complex cardiac surgery
CHD	Congenital heart disease
EDI	Early developmental intervention
GTF	Gastrostomy tube feeding

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generally the result of reduced caloric intake, reduced intestinal absorption associated with increased energy loss.[9] It has been estimated that approximately 10%-18% of children require GTF after their initial CCS.[13,14] Feeding difficulties in this population might have different origins including laryngopharyngeal dysfunction, present in approximately 48% of patients after the Norwood procedure, underlying neurologic conditions, and vocal cord paralysis.[15]

The main objective of this study is to compare the proportion of different types of developmental delay in CCS survivors with and without GTF. A secondary objective of the present study is to explore and better understand pre- and post-CCS predictors of GTF that might help improve care and counseling of these children's families.

Methods

This study is part of an inception cohort follow-up project conducted in 6 developmental/rehabilitation referral sites in western Canada: Vancouver, British Columbia; Edmonton and Calgary, Alberta; Regina and Saskatoon, Saskatchewan; and Winnipeg, Manitoba.[16] Infants were identified at the time of first CCS and followed prospectively. At the time of the first CCS, predetermined demographic, preoperative, intraoperative, and postoperative variables were collected. The need for GTF at any time is recorded. At the study center, GTF is indicated when tube feeding extends beyond 30 days; delay in the initiation may be secondary to parental refusal or delayed referral to a surgeon. The health research ethics boards at each site approved the study, and all parents or legal guardians provided written consent.

Participants included infants who had CCS at ≤6 weeks of life requiring cardiopulmonary bypass between 2005 and 2012 at the Stollery Children's Hospital, Edmonton, Canada; and who did not require extracorporeal membrane oxygenation or heart transplantation at any time prior to the 21-month assessment. Children who died prior to the 21-month assessment and those lost to follow-up were excluded. We also excluded children assessed with the Bayley Scales of Infant Development-Second Edition (BSID-II)[17] rather than the Bayley Scales of Infant and Toddler Development-Third Edition (Bayley-III)[18] and those children for whom assessment results were yet not available.

Multidisciplinary assessments were performed at 21 months of age at each of the referral sites. Certified pediatric psychologists and psychometrists administered the Bayley-III[18] (cognitive, language, motor) and the Adaptive Behavior Assessment System-Second Edition (ABAS-II)[19]: general adaptive composite. Delay in both measures was determined by scores >2 SD below mean (ie, scores in the lowest 2.27% of normative population).

The Bayley-III[18] is an individually administered test that assesses the cognitive, language (receptive and expressive communication), and motor (fine and gross motor skills) functioning of infants between 1 and 42 months of age. The child's chronological age is calculated at the time of the testing, adjusting for prematurity until 24 months of age. This widely used tool identifies risk for developmental delay giving useful information to assist clinicians in determining the need for EDI. Each of the 5 subtest results are derived as scaled scores that range from 1-19, with a mean of 10 and a SD of 3. These are then converted into composite scores with a mean of 100 and a SD of 15.

The ABAS-II,[19] a caregiver completed questionnaire, measures the functional and realistic-for-age skills necessary for independent daily living using nine skill areas grouped into 3 composite domains: conceptual, social, and practical, which combined with the motor skill area give the general adaptive composite score, reflective of functional abilities (mean of 100 and a SD of 15).

Family socioeconomic status was determined by the Blishen Index,[20] an indicator dependent on employment, education, and prestige value of an occupation, based on the main family wage earner with a population mean of 43 and SD of 13. Maternal education was recorded in years of schooling at the time of the 21-month assessment.

Acute care information (**Table I**) included birth gestation (37 completed weeks considered term), sex, chromosomal abnormality, antenatal diagnosis; preoperative and postoperative (day 1-5 and day 6-10) highest plasma lactate, inotrope score[21]; total postoperative days with an open sternum; age, weight, single ventricle cardiac defect, cardiopulmonary bypass time, X-clamp time, and use of deep hypothermic circulatory arrest at first CCS; the overall at first CCS presence of pre- or postoperative sepsis, cardiopulmonary resuscitation, vocal cord paralysis, dialysis; and the number of ventilated days and hospital days.

Statistical Analyses

Categorical variables are presented as proportions and continuous variables are presented as means (SD) or medians (IQR). Frequency of gastrostomy tube requirement is given as percentage of assessed survivors, using 95% CIs. Descriptive variables for outcomes were analyzed with Student t test and χ^2 test. Multiple logistic regression analysis included demographic, operative and perioperative predictors of GTF having P value of <.10 after screening for multicollinearity. Results are expressed as ORs with 95% CI; significance considered at <.05. Data analyses were performed using IBM SPSS Statistic Data Editor v 22 (IBM Corporation, Armonk, New York). Results were confirmed with the Akaike model selection using R software v 3.2.1 (R Foundation for Statistical Computing, Vienna, Austria).

Results

Children (n = 407) had neonatal CCS requiring cardiopulmonary bypass; none had extracorporeal membrane oxygenation or heart transplantation prior to the 21-month assessment. Of these 407, 35 (8.6%) died. From the 372 survivors, 18 (5%) were lost to follow-up, 8 (2%) were assessed using the BSID-II[17] rather than the Bayley-III[18], and for 12