Creating Opportunities for Optimal Nutritional Experiences for Infants With Complex Congenital Heart Disease

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ABSTRACT

Introduction: To our knowledge, successful breastfeeding in the population with single ventricle congenital heart disease has not been reported in the literature, particularly during the interstage period.

Method: A retrospective case study including inpatient nutrition and a complete history of daily logs with the home surveillance monitoring program was performed.

Results: Successful full breastfeeding (exceeding prescribed weight growth goals) after Stage I surgery was achieved during the interstage period. The infant was discharged at 3.41 kg, not consistently breastfeeding, and progressed to 7.05 kg at 5 months of age, fully breastfeeding.

Conclusion: Supporting breastfeeding for infants who have undergone repairs for single ventricle anatomy can be challenging but can be accomplished. It requires a concerted team effort, clear communication, and collaboration among caregivers, the mother, and her supporters. J Pediatr Health Care. (2016) ■, ■-■.

KEY WORDS

Breastfeeding, home surveillance monitoring programs (HMP), interstage period, Patient- and family-centered care, single ventricle heart disease

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Congenital heart disease (CHD) is the most common birth defect and occurs in 1% of live births, or approximately 40,000 infants per year, in the United States (Hoffman & Kaplan, 2002; Reller et al., 2008). Of these, nearly 25% of patients have critical congenital heart defects (Oster et al., 2013). The management of CHD has rapidly progressed since the introduction of pediatric cardiopulmonary bypass and advances in the medical, surgical, and nursing care have enabled "blue babies" to not only survive childhood but successfully transition to adulthood (Gurvitz & Saidi, 2014).

For single ventricle anatomy, there is a heightened risk for mortality within the first year of life, specifically between Stage I and Stage II palliations (Oster et al., 2013). Infants typically undergo one of three types of Stage I surgical interventions (Norwood, Sano, or Hybrid) to balance pulmonary and systemic blood flow. After discharge, families engage in extensive home surveillance monitoring that includes recording

oxygen saturations, daily weights, and close monitoring of physiologic status (e.g., color, fluid retention, respiratory effort, activity level). The period of greater risk continues through stage II palliation secondary to factors associated with the cardiac anatomy, alterations in fluid status, and respiratory infection issues of infancy (Ghanayem et al., 2003). Data from the Society of Thoracic Surgeons congenital heart surgery database identified improvement in hospital survival after first stage palliation from 68% in 2002 to 81% in 2009 (Feinstein et al., 2012) because of improvements in perioperative care (Tweddell et al., 2002). The interstage period risk remains high, with 10% to 20% mortality as of 2014 (Rudd et al., 2014).

Routine nutritional support for infants with complex CHD involves the nurse practitioner, dietician, cardiologist, and pediatrician, who individually and collaboratively assess clinical progress and make recommendations to optimize nutritional intake. The infant's tolerance of feedings and ability to achieve targeted weight gain goals is followed. In addition, during hospitalization daily weight, caloric intake, mode of feeding, and daily intake and output totals are monitored.

A literature review showed no references that discussed full breastfeeding (BF) for an infant with single ventricle physiology during the interstage period. Anderson et al. (2009) reported on 100 infants from neonatal discharge after initial Stage I palliation to the time of Stage II palliation and found evidence that lower weight-for-age *z* score and younger age at the time of the Stage II palliation affected the length of hospital stay. Most patients were fed formula, with only 24% receiving breast milk at neonatal discharge and only 9% at the time of the Stage II procedure (Anderson et al., 2009). Slicker et al. (2013) identified the preference of breast milk for nutrition and acknowledged that there are benefits to BF despite limited BF because of physiologic instability.

This case study highlights a nutritional journey and opportunities to provide care that support both patient and family during the interstage period for an infant through 5 months of age.

In this article, BF is defined as feeding exclusively from the mother's breast without bottle supplementation. To our knowledge there are no descriptions in the current literature of practical interventions to successfully transition infants to full BF during the interstage period; however, there are anecdotal reports of BF success in this fragile population. None of the reports mention nutritional support using colostrum, breast milk, and other supplements throughout the early newborn period to provide the infant with optimal nutrition. This case study highlights a nutritional journey and opportunities to provide care that support both patient and family during the interstage period for an infant through 5 months of age.

PRENATAL AND BIRTH HISTORY

A male was prenatally diagnosed at 18 weeks' gestation with double inlet left ventricle (LV) and no outflow tract obstruction. At 38 weeks' gestation induction was scheduled because of concern of maternal hypertension. A subsequent cesarean birth was performed secondary to failure to progress. The infant was delivered at a large tertiary care hospital with a birth weight of 3.41 kg. Apgar scores were 8 and 9, and the infant was brought to the neonatal intensive care unit, where his oxygen saturation percentages were in the mid to upper 90s on room air, no blood pressure gradient was noted between the upper and lower extremities, and blood glucose level was normal.

The patient was transferred to a quaternary pediatric freestanding children's hospital cardiac intensive care unit. Upon arrival, chest radiography, electrocardiography, and bedside echocardiography were performed. A prostaglandin infusion was started after the echocardiography, which confirmed the prenatal diagnosis of double inlet LV; a congenital cardiac anomaly in which both atriums empty into the LV and the right ventricle (RV) is hypoplastic. The ventricles are reversed in location (LV under right atrium and RV under left atrium). The arteries are situated with the aorta arising from the RV and the pulmonary artery from the LV. This infant had other related defects, including a small atrial septal defect, coarctation of the aorta at the isthmus and a size discrepancy between the semilunar valves (Figure 1b). This anomaly results in mixed oxygenated and desaturated blood flowing to both the lungs and systemic circulation, with a greater volume flowing to systemic circulation than to pulmonary circulation. Figure 1a shows the normal heart anatomy, and Figure 1c shows this infant's anatomy after Stage I surgical repair.

FAMILY ASSESSMENT

The mother was a 32-year-old married primipara. She lived in rural New England, with no local extended family for support. The mother was a veterinarian who had been in practice for 8 years. She believed strongly in the power of colostrum and breast milk during early infancy. Her supportive work environment allowed her an extended maternity leave secondary to the high-risk CHD diagnosis and treatment plan. The father, a devoted and supportive husband, worked fulltime in a professional role at a local company with no travel constraints.