Supporting Optimal Growth in Infants with Chronic Conditions: How Are We Doing and What Can We Do?

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SUPPORTING OPTIMAL GROWTH in infants with chronic conditions has never been so important. Outcomes for many chronic conditions, such as cystic fibrosis (CF), necrotizing enterocolitis (NEC), and congenital heart disease (CHD), are improving, but undernutrition remains an all too common problem. Current challenges in treating patients with chronic conditions include the prioritization of breastfeeding, identification of the most effective nutritional interventions, and the prevention or recovery of acquired growth failure.

Cystic Fibrosis

Over the past 3 decades, the median age of survival for patients with CF has risen from ~29 to 43 years.¹ Clinical outcomes, such as weight gain, have also been steadily improving. These improvements are, in part, due to a combination of new therapies for CF and the implementation of newborn screening programs.² The recent identification of small-molecule therapies, such as ivacaftor, that target specific mutations in the CF transmembrane conductance regulator gene is also associated with improved nutritional status, possibly due to a reduction in energy expenditure, reduced gut inflammation, and an increase in fat intake and absorption.^{3,4} Despite these advances, the prevalence of undernutrition remains unacceptably high in infants with CF, and improvements in weight and, in particular, length have stagnated in recent years (Fig. 1).^{1,2} The impact of undernutrition during infancy in CF patients has been shown to have negative long-term effects, including poorer growth, worse lung function, and more severe chest abnormalities at 12 years of age.^{5,6} Breastfeeding can support optimal growth in infants with CF and is associated with fewer exacerbations and reduced risk of *Pseudomonas aeruginosa* infection.^{2,7,8} However, breastfeeding rates are low for infants with CF, and most of these infants receive formula as the primary source of nutrition or as a supplement to breastfeeding (Fig. 2).¹ Parents may choose

not to breastfeed due to the overarching urgency to improve weight and a lack of confidence that breast milk can support good growth. Stress from the diagnosis may also factor into the decision or the success of breastfeeding. Furthermore, infants requiring surgery (e.g., stoma formation) will have different nutritional needs and may experience periods of static growth. Multiple nutritional interventions may be required to support optimal growth in infants with CF, such as parenteral nutrition and specialized formulas.

Necrotizing Enterocolitis

Nutrition also plays a crucial role in the management of NEC. Breast milk contains a variety of factors that may be protective against NEC, such as immunoglobulins, prebiotics, bioactive proteins, and growth factors. For patients requiring surgical intervention post-NEC, breast milk is preferred for enteral feeds after surgery;⁹ however, a recent retrospective analysis of infants aged <6 months who underwent intestinal

FIG. 1. Median WHO nutritional outcome percentiles for infants aged <24 months with CF.¹ CF, cystic fibrosis. Source of data: Cystic fibrosis patients under care at CF Foundation-accredited care centers in the United States, who consented to have their data entered. Cystic Fibrosis Foundation Patient Registry 2017 Annual Data Report, Bethesda, Maryland ©2018 Cystic Fibrosis Foundation.

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FIG. 2. Form of feeding by age in infants with CF.¹ Source of data: Cystic fibrosis patients under care at CF Foundation-accredited care centers in the United States, who consented to have their data entered. Cystic Fibrosis Foundation Patient Registry 2017 Annual Data Report, Bethesda, Maryland ©2018 Cystic Fibrosis Foundation.

surgery reported that infants with NEC received breast milk in only 7% of hospitalized days.¹⁰ If breast milk is not available or the patient is intolerant to standard preterm formulas, hydrolyzed formulas (e.g., semielemental and amino acid based) may be used, but there is limited evidence on which type is best for infants recovering from NEC.^{9,11} Feeding strategies should aim to support growth, encourage adaption, and prevent parenteral nutrition—associated liver disease, yet the perfect nutrition to support optimal growth may not always be clear. Although breast milk is recommended, breastfeeding may be very difficult due to stress, loss of confidence, and other negative psychological effects parents experience when their infant is hospitalized in the neonatal intensive care unit (NICU).¹²

Congenital Heart Disease

Mortality associated with CHD has been declining, yet the prevalence of growth restriction in infants and young children with CHD has remained at ~20% since the 1960s, despite advances in research, methodology, education, and feeding strategies.^{13,14} Poor growth in infants with CHD can result in more frequent hospitalizations, poorer surgical outcomes, and higher rates of mortality, as well as long-term adverse effects such as cognitive impairment and persistent growth retardation.^{15,16} Similar to other chronic conditions, challenges in treating infants with CHD include supporting breastfeeding and appreciating the infant's limitations. Infants with cardiac conditions are unpredictable, unstable, and unique; the return to optimal growth can be long and associated with consequences.

In summary, breastfeeding has a pivotal role in treating chronic diseases, yet it can be challenging due to the medical and emotional complexities associated with these conditions. Parents experience stress with diagnosis and having a child in the NICU. They also face pressures from the wider multidisciplinary team to prevent growth failure and may lose confidence in their ability to maintain or promote growth with breast milk. Furthermore, infants with chronic conditions have inherent absorption/malabsorption issues and additional nutritional requirements. Dietitians and nutritionists must work to balance these issues to support optimal growth in all of these vulnerable patient groups.

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