Transforming the Nutrition Care Model for Infants with Cystic Fibrosis: a qualitative study of clinicians' perspectives

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Abstract

Clinician perspectives may inform health service strategies to meet optimal nutrition needs for infants with cystic fibrosis (CF). We conducted a qualitative study with CF-specialized dietitians (RDs) and physicians between July to December 2020 to characterize the current state of infant nutrition care delivery and organize input into a conceptual model to inform CF care program strategies. Among 42 participants, 36 completed survey responses and 6 completed interviews; 93% were RDs. Three global themes emerged in the current care model: nutrition management, family-centered connections, and collaborative care delivery. Within nutrition management clinicians emphasized providing education, setting goals, and maintaining adequate follow-up with families. Under family-centered connections clinicians expressed the need to foster relationships with families and link families to resources for assistance to social stressors such as food insecurity. Collaborative care delivery for clinicians interviewed was defined by sharing expertise from across the interdisciplinary team. Based on the timing of this study, clinicians reported compelling examples for various modes of telehealth and home weight monitoring to facilitate and support these domains of nutrition care, including potential advantages for education, supporting family needs, and communication. We integrate these themes to propose a conceptual model for integration of in-person and telehealth activities to enhance quality infant CF nutrition care delivery. Future implementation can refine this model through testing of practical telehealth interventions to optimize nutrition outcomes for infants with CF.

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Nutrition Care Inputs	In-Person Standard Activities	Telehealth Activities	Goal Outcomes
NUTRITION MANAGEMENT Education Goals Follow up FAMILY-CENTERED	GUIDELINES OF CARE • Multidisciplinary CF care team approach • Anticipatory nutrition guidance Initiation & maintenance of	VIDEO VISITS Opportunities for education & teach-back Assessments for home environment Team communication HOME WEIGHT MONITORING	CLINICAL OUTCOMES Optimize growth & eliminate malnutrition for all infants diagnosed with cystic fibrosis FAMILY-CENTERED CARE
• Relationships • Resources	therapies • Frequent growth measures • Monthly visits in first 6 months, bimonthly 6-12	PROGRAM Routine weight monitoring Shared decision-making with families	Foster positive family care experiences through shared goals and transparent expectations
COLLABORATIVE CARE DELIVERY Dietitian expertise Shared team experience	months, quarterly 12+ months • Routine laboratory monitoring	REMOTE MESSAGING • Address social determinants & barriers to care • Shared agenda setting with families	WORKFORCE CAPACITY Sustain clinician capacity and performance for health services

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