Improving family-centered care through standardization of cystic fibrosis nutrition interventions in 0-2 year olds

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Introduction

Cystic Fibrosis (CF) is a rare genetic disease that affects the lungs, pancreas, and other organs and impacts about 30,000 people in the U.S. The CF Foundation (CFF) has established an accreditation process resulting in over 120 nationally recognized CF Centers focused specifically on improving CF population health through a multidisciplinary care team model. CFF accreditation provides critical leverage for improvements in CF care and ongoing clinical research - resulting in a median CF patient life expectancy of 47 years in 2017, up from 6-7 years in the 1960s.

In December 2018, Atrium Health received designation from the CFF to become an accredited center providing care to both pediatric and adult patients. As of July 2019, there are >125 children and 80 adults followed for CF. We anticipate continued growth as our Center establishes Charlotte as a world-class destination for CF care across the southeast.

Case for Change

Because of different nutritional needs, psychosocial maturity levels, and use of aggressive interventions, we sought to develop a standardized algorithm to implement across our center based on age groups and patient/family acceptance of interventions. We are a new center with largely a young CF population. We found wide variability of nutrition interventions in use among providers at different times in the disease process and in different settings. We wanted to be conscious of the different maturity levels of our patients and patient/family acceptance of interventions, and tailor interventions accordingly. We developed our algorithm to provide family- and patient-centered care based on the different needs of diverse age groups while adhering to known successful interventions appropriate per age. For the greatest impact on long-term nutritional and pulmonary outcomes, our algorithm is more aggressive with our younger subset.

Goal

All children with cystic fibrosis deserve optimal nutritional health achieved through implementing latest evidence-based care per CFF Guidelines. The goal of this initial project was for >50% of our patients 0-2 years old to have a weight for length (W/L) >50th percentile (%ile) on the WHO growth chart.

Process

Several Change Concepts continue to be tested (see Key Driver Diagram for entire list). Major concepts include:

1) Interdisciplinary team-based care, co-location, real-time provider coaching with team
2) Pre-clinic huddle to identify gaps in care
3) Nutritional pathway based on CF Foundation Guidelines, collaboration with other centers and team consensus
4) Clinical decision aid with interventions completed
5) Patient-centered Action Plan with follow-up care

Co-location of CF team for team-based approach to care:
- Real-time consult w/ other team members
- Seamless handoff between team members
- Multidisciplinary approach to addressing barriers
- Workflow & throughput efficiency (~reduction in cycle time)

Pre-Clinic Huddle: Identify barriers to or gaps in care, assess overall health and well-being of child, identify required interventions

Nutritional Pathway

Through several PDSA cycles, we created a nutritional pathway decision aide with check boxes and progressive interventions to allow different providers to easily see interventions already tried and those yet to be implemented.

Data: The data demonstrate shift after Feb 2018 with 11 consecutive data points above the median. The next steps in our improvement process will be to focus on bringing more stability to the process to assure consistent meeting of our W/L goal.

Conclusions: Our initial data show that algorithm use in our 0-2 year old population has resulted in improved standardization of interventions, more consistent use by different providers in different care settings, and increased percentage of patients with W/L >50th %ile. This tool enables us to improve the nutritional outcomes of all patients in a consistent and efficient manner. Additionally, our patients and families are beginning to see greater emphasis on growth and nutrition and their importance to overall CF care and outcomes.

References


Contact Info

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