Patient Education to Increase Cystic Fibrosis Nutrition Assistance Program Participation

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Introduction

Cystic fibrosis (CF) is a chronic, progressive, genetically inherited disease affecting multiple organs throughout the body, in particular the lungs and pancreas. Genetic mutations cause thick mucus to build up throughout the body. Medical management of the disease comes at a significant burden due to:

- Frequency of clinic appointments & hospital stays
- Medications and supplies
- Vitamins
- Special diet and/or nutritional supplements
- Time requirements for breathing treatments & airway clearance

There are nutritional assistance programs that aim to assist patients with CF with these out-of-pocket costs and copays. Programs are based on type of insurance or income level. Pharmaceutical company enzyme assistance programs (Care Forward, Live2Thrive, Care Direct) aim to help those who are privately insured, whereas patients with any type of insurance who fall within 500% of the Federal Poverty Level may qualify for the Hashwell Foundation Cystic Fibrosis fund. Many patients are not aware of these programs or how to apply. Education and/or help with the application process has the potential to increase patient participation in these programs.

Methods

Recruitment

- Caregivers of children, and adults who have not yet transferred out of pediatric service, treated at the UNM Pediatric CF Clinic, who meet program qualification requirements, yet are not enrolled in a CF nutritional assistance program
- Education on the specified programs, and/or help with the application process will be offered either in person at clinic appointments, or by telephone

Screening

- Nutrition graduate students will screen patients on the UNM Pediatric CF Clinic roster to determine eligibility via electronic medical record

Data Collection

- Age, ethnicity, pancreatic status and enzyme brand (if applicable), and insurance type will be collected via electronic medical record
- Survey (completed either in person or by telephone) to assess assistance program participation
- Educational handout to be designed and provided in-person by a nutrition graduate student
- Handout will describe nutrition assistance program benefits and the process to apply
- Data will be stored REDCap secure web application
- All data will be collected February – May 2019

Implications

- The aim of this project is to increase nutritional assistance program enrollment in the UNM Pediatric CF Clinic population
- Helping patients access available resources is an important aspect of CF
- The development of an effective educational handout has the potential to be utilized by other CF Centers throughout the country

References