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# Cystic fibrosis-related education: Are we meeting patient and caregiver expectations?

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### ABSTRACT

**Objective:** The purpose of this study was to improve patient education in clinic by evaluating patient perceptions of education provided, as well as patient self-confidence related to topics within cystic fibrosis (CF). The study assessed whether self-confidence matched knowledge and defined patient-specific goals for education timing and information sources.

**Methods:** Age specific questionnaires were distributed over four months to patients 11 years of age and older and caregivers of patients of all ages at a single CF Foundation accredited care center.

**Results:** Participants reported frequent education on all topics except for reproductive effects of CF and mental health. A positive correlation was seen between overall confidence in CF-related knowledge and performance on a validated knowledge scale in adolescent caregivers only. Participants expected all educational milestones to be met by 13–14 years of age.

**Conclusions:** Gaps in CF education remain and educational models should deliver information by the early teens without overlooking reproductive effects and mental health.

**Practice Implications:** The educational model for CF clinics should become more comprehensive by including education on topics such as mental health and reproductive effects. Providers are an important pathway for information and should not disregard the value of education provided during clinic visits.

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## 1. Introduction

Cystic fibrosis (CF) is a complex disease state which requires education related to a variety of topics including lung health, nutrition, treatment, and genetics. Proper management of the CF patient requires thoughtful provision of patient education to both patients and their caregivers. New therapies and improved management have greatly increased life expectancy with the latest reported median survival age reported at 47.7 years [1]. It is therefore imperative that CF education is provided not only to the parents and caregivers of these patients but to the patients themselves.

Prior research has elucidated certain gaps in the knowledge of both CF patients and their families. A common theme amongst these earlier studies is that patients often lack a full grasp of the genetics behind the disease, the reproductive ramifications (e.g. common male infertility), and the effects that CF plays outside the lungs (e.g. CF-related liver disease) [2–5]. Areas in which CF

patients are interested in learning more have also been identified. Patients expressed interest in learning more about everyday life with the disease as well as future issues related to employment and marriage [3]. Parents expressed concern with the psychosocial aspects of the disease, and patients reported needing more information regarding new therapies [6]. A recent survey found the highest unmet needs amongst adult CF patients to be coping strategies for decreased energy, future unpredictability, and changes to the disease as well as new therapies and medication side effects [7]. The study highlighted less interest in a discussion of CF inheritance and diet strategies (e.g. gaining weight).

CF patients and their families obtain needed information in a variety of ways. Parents and caregivers are often the primary sources of information for younger patients, but medical staff and literature are other important sources [2,4,5]. The Internet is becoming increasingly important as a source of information with its use for CF material by patients ranging anywhere from 35% of patients up to 73% [4,8]. Information is important to patients and families because knowledge and understanding have been tied to a variety of positive outcomes. Several studies have tied lower rates of adherence with decreased understanding of a provider's recommendations [9,10].

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National guidelines have established educational goals for both the infant and preschool age groups. Education for caregivers of infant patients with CF focuses on infection control, consent for the CF Foundation patient registry, airway clearance therapies (ACT), and tobacco smoke avoidance [11]. Education for pre-school aged patients focuses on infection control, clinical research and the CF Foundation patient registry, tobacco smoke avoidance, and energy goals [12]. Adult guidelines are less specific and highlight the need for successful education during the adolescent period in order to promote adequate self-management and care as an adult [13]. Previous research has also identified the importance of programs designed to assist patients with the transition to adult care [14]. However, there is little guidance on best practices for education amongst CF patients in the 6–17 year old age group in considering both their health literacy and stage of development. More research is needed into defining patient and caregiver wishes regarding their educational milestones as well as the best means of providing this information. The following research was designed as a quality improvement initiative of a local Cystic Fibrosis Foundation (CFF) accredited affiliate center in order to best provide educational services to patients and their families. The specific aims of this project were to: 1) identify the proportion of patients and caregivers who report having received education from the medical team on CF-related topics, 2) determine the level of caregiver/patient confidence in CF-related knowledge, 3) determine if a correlation exists between patient confidence in knowledge and knowledge on a validated CF knowledge scale, 4) describe sources of CF information utilized by patients/caregivers, and 5) describe patient/caregiver perspectives on when educational goals related to CF should be met.

## 2. Methods

### 2.1. Study site

The current project took place at a CF Foundation accredited affiliate CF center. Center staff includes two pediatric pulmonologists, two nurses, a dietitian, a respiratory therapist, a social worker, and a pharmacist. The center sees both pediatric and adult patients. Based on 2015 CF Foundation Registry data, this includes 137 patients (55 children between 0 and 10 years of age, 33 adolescents aged 11–18 years of age, and 49 adults over the age of 18). Per CF Foundation guidelines, patients are expected to attend quarterly clinic visits.

### 2.2. Participants

Participants were recruited between January 2017 and April 2017 on presentation for a normal CF care visit. Patients were included if they were at least 11 years of age and caregivers of all patients were included. Exclusion criteria included a primary language other than English, a history of lung transplantation, or a diagnosis of CF transmembrane conductance regulator-related metabolic syndrome (CRMS) or CF screen positive, inconclusive diagnosis (CFSPID). If a patient was coming in for an acute visit (i.e. not seeing all providers in clinic), they were excluded from participation at that visit. These patients could be included if they had an additional normal clinic visit during the data collection period. Informed consent was given by all participants prior to inclusion.

### 2.3. Survey development

A questionnaire was developed in order to answer questions related to the five specific study aims. Experts in CF created questions to assess core content areas related to CF education

(pathophysiology, lung health, medications, nutrition, etc.). The education section survey specifically addressed general education by clinic personnel. A separate section asked participants to report on other sources of education they might utilize. As the study wanted to compare participant confidence and knowledge, the questionnaire incorporated previously validated knowledge scales [15,16]. In order to use these validated scales in the ages in which they were validated, researchers created five versions of the survey (adolescent patient, adolescent caregiver, child caregiver, adult patient, and adult caregiver). The child caregiver survey version can be found in the Supplementary. Caregiver versions of the survey included two additional demographics question related to relationship with the child and whether or not the individual was a primary caregiver. For the purposes of this research, adolescent was defined as a child between 11 and 18 years of age. The child and adolescent knowledge scale included subscales for general health, lung health, nutrition, and treatment [16]. Questions in the adult scale were assigned one of these four areas for further assessment. Questionnaires underwent a brief pilot period to assess clarity of questions and survey intent and included patients from a separate CF center to prevent loss of potential data points. The pilot period resulted in elimination of four questions related to adherence that were deemed to be inconsistent with the rest of the survey by pilot participants. The final questionnaires included 72–77 items divided into five sections (education frequency, confidence, educational timing, knowledge, and information sources). There were two open-ended questions seeking insight about overall opinions regarding clinic-based education and items for a potential CF clinic website. The study was approved by the University of Oklahoma and St. Francis Healthcare System Institutional Review Boards.

### 2.4. Survey procedures

Questionnaires were given to participants during normal clinic workflow. For patients able to perform lung function tests (spirometry), this occurred after the respiratory therapist worked with the patient. For younger patients, caregivers were given the questionnaire after being roomed by a nurse. The questionnaire was given to participants by a pharmacist, and participants were given an initial 10 min to complete it. Participants could request additional time if needed to finish all questions. Participants were also given an opportunity to address any follow-up questions after turning in the survey. Clinic personnel did not directly observe survey completion, but participants were instructed to complete the surveys individually without assistance from each other. Participants were assigned a number on survey completion with no identifying information maintained on the survey. A running list of participants was maintained solely to prevent duplication of responses.

### 2.5. Measures

Education frequency and confidence items were rated on four-point scale. Frequency choices included never, at some visits, at most visits, and at every visit. Confidence options included not at all, not very, somewhat, and very confident. Participants ranked the age for particular educational goals to be met by circling a number between 6 and 18 years of age. Educational sources were assessed using a rank-order question with eight possible sources of information. The adult versions used a knowledge scale validated by Balfour and colleagues with true, false, and don't know as answer options [15]. The child and adolescent versions used the multiple choice Knowledge of Disease Management-CF (KDM\_CF) scale validated by Quittner and colleagues [16].

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