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# Lost in translation? How adults living with Cystic Fibrosis understand treatment recommendations from their healthcare providers, and the impact on adherence to therapy

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### ABSTRACT

**Objective:** This study builds on the limited research documenting Cystic Fibrosis (CF) patients' understanding of treatment recommendations and how this may impact adherence to therapy.

**Methods:** We surveyed adults with CF and their healthcare professional (HCP) to capture treatment recommendations provided by the HCP, and patients' knowledge, and frequency of performance, of these recommendations. We classified CF participants' understanding of treatment recommendations (correct/incorrect) as compared to the actual recommendations made by the HCP. We computed CF participants' adherence in relation to HCP treatment recommendations and to their own understanding of treatment recommendations (adherent/non-adherent).

**Results:** Complete HCP and patient data were available for 42 participants. The recommended treatment frequency was correctly understood by 0%–87.8% of CF participants. Adherence to HCP treatment recommendations ranged from 0 to 68.3% (mean 45.4% ± 21.5), and rates were low (<33%) for acapella, percussion/postural drainage, tobramycin nebulization and insulin. Participants' adherence was greater when calculated in relation to participants' understanding of treatment recommendations (62.4% ± 25.1) than when calculated in relation to actual HCP treatment recommendations (45.4% ± 21.5%) ( $p = 0.009$ ).

**Conclusion and practice implications:** Adults with CF misunderstand treatment recommendations; this likely affects treatment adherence. Interventions to ensure HCPs use effective communication strategies are needed.

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## 1. Introduction

Over the past few decades, significant medical advances in the management of Cystic Fibrosis (CF) have resulted in the median age of survival in Canada increasing from 27.5 years in 1986 to 50.9 in 2014 [1,2]. Daily management of CF requires adherence to a range of time-consuming and complex treatments [3]. A person with CF can spend the equivalent of four months per year of full-

time work [4] carrying out life-sustaining treatments. A cross-sectional survey of adults with CF [5] suggested that the mean number of daily therapies was 7 and the mean time spent on self-care activities was 108 min per day.

As with other chronic medical conditions [6], patient adherence to treatment regimens in CF is suboptimal and can vary by type of treatment recommended [7–10]. Poor adherence rates in children and adults have been associated with a greater number of CF-related hospitalizations and higher health care costs in a large database study [11], although a smaller study in children only did not replicate this association [12]. Findings on the relationship between adherence in CF and pulmonary exacerbations remain mixed [13,14]. Researchers have commented on the factors influencing adherence to CF treatments, including socio-demographics [15,16], regimen characteristics (e.g. time-consuming

**Abbreviations:** CF, Cystic Fibrosis; HCP, Health Care Professional; FEV1, Forced expiratory volume in 1 s; PEP, positive expiratory pressure; HFCOD, high-frequency chest wall oscillating device.

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treatments) [17], relationship with HCPs [15], psychological (e.g. depression) [15], cognitive (e.g. treatment beliefs) [16], family functioning (e.g. family support) [15,17], health status (e.g. illness severity) [15], coping strategies (e.g. avoidance) [15], and locus of control [18].

Several papers have described common misconceptions and misunderstandings patients living with CF may have about treatments recommended to them by their healthcare professionals (HCPs) [19–23]. Bailey and colleagues [24] underlined that CF patients' correct understanding of HCPs' treatment recommendations is a key necessary condition for successful treatment adherence. There is a paucity of research examining the relationship between CF patients' level of understanding of their treatment recommendations and treatment adherence. One study [21] found that 12% to 32% of mothers of children living with CF had an inaccurate understanding of the CF treatment recommendations made by the physician. In this study, lower levels of knowledge of treatment among mothers and their children with CF were associated with poor treatment adherence.

The objective of this study is to examine how well adults living with CF understand the treatment recommendations given to them by their HCP and how this information may play a role in impacting self-reported adherence to therapy. We hypothesized that CF patients' level of self-reported adherence to their understanding of treatment recommendations will be greater than their self-reported adherence to actual HCP recommendations.

## 2. Methods

This study is part of a larger project entitled "The Ottawa Cystic Fibrosis Treatment Knowledge and Adherence Program" that included an observational cohort study at a multidisciplinary adult CF outpatient clinic in Ottawa, Canada. All study procedures were approved by the Ottawa Health Science Network Research Ethics Board (Protocol #2011046-01H).

## 3. Participants and procedures

Study participants were recruited from a multi-disciplinary adult CF clinic in Ottawa, Canada, between May 2011 and June 2013. Inclusion criteria were English-speaking adults expected to continue receiving care at the CF clinic for 1 year who were able to provide consent. Participants were excluded if they had a life expectancy of less than one year, or if they were lung transplant recipients. Consenting participants were asked to complete a questionnaire package on the day of their appointment that included an assessment of their understanding of HCP treatment recommendations and a CF treatment self-reported adherence measure.

## 4. Measures

### 4.1. Participants' characteristics

Socio-demographic data were collected in the questionnaire. Medical data (FEV<sub>1</sub>%) was obtained by chart review.

Participants living with CF completed a range of measures (described previously [25]); this included a disease specific form to systematically collect data on their understanding of CF treatment recommendations and self-reported treatment adherence. Simultaneously, HCPs were asked to complete the same items on treatment recommendations in order for data on actual treatment prescriptions to be available. The CF treatment recommendations covered in these forms were: 1. Chest physiotherapy (percussion/postural drainage, positive expiratory pressure devices (PEP), high-

frequency chest wall oscillating device (HFCOD), acapella), 2. Oral medications and supplements (ADEK vitamins/source CF, vitamin D, pancreatic enzymes, azithromycin), 3. Nebulizers (tobramycin, hypertonic saline, dornase alfa), 4. Insulin injections, and 5. Puffers (or inhalers).

### 4.2. HCP treatment recommendations

The CF nurse coordinator was asked to use participants' medical charts to indicate the frequency at which each treatment was prescribed by the healthcare team. Response options included '2 times per day', '1 time per day', '3–5 times per day', 'Occasionally', 'Only when the patient feels worse', 'With every meal and snack' (for pancreatic enzymes only), and 'As needed' for nebulizers, puffers (or inhalers), azithromycin and insulin (the latter response option is less applicable for azithromycin, it was included for consistency with the patient version of the form). The option 'Not applicable' was available for instances in which the HCP did not recommend a treatment.

### 4.3. Participants' self-reported understanding of the treatment recommendations

Study participants completed the form and indicated their understanding of 'recommended frequency by my CF team' for each CF treatment. Participants were given the same response options as those provided in the HCP version of the form and two additional options ('I don't know' and 'Never').

### 4.4. Participants' self-reported frequency of treatment performance

In order to measure self-reported adherence to treatment recommendations, study participants were asked to use the same response options as above to indicate the frequency with which they had performed each CF treatment in the past 4 weeks.

Supplementary File 1 shows the layout of the CF Treatment Regimen and Adherence Form of both the healthcare provider and CF participant versions using the percussion and postural drainage item as an example.

## 5. Data analysis

We examined characteristics of study participants using central tendency and dispersion measures. The data captured in the CF Treatment Regimen and Adherence Form was used to compute the participants' understanding and self-reported adherence variables presented in this paper. Participants' self-reported understanding of treatment recommendations was coded as correct or incorrect depending on whether it matched the recommendation reported to have been made by the HCP.

Two measures of self-reported adherence were computed:

- *Self-reported adherence to HCP treatment recommendations:* We categorized participants as adherent or non-adherent according to whether they performed the treatment at the frequency recommended by the HCP.
- *Self-reported adherence to participants' own self-reported understanding of treatment recommendation:* We categorized participants as adherent or non-adherent according to whether they performed the treatment at the frequency they had understood it to have been recommended by the HCP.

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