



## Original Article

# Prevalence of severe fatigue among adults with cystic fibrosis: A single center study ☆, ☆, ☆

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Received 10 October 2017; revised 13 February 2018; accepted 5 March 2018  
Available online xxxx

## Abstract

**Background:** With life expectancy increasing among patients with cystic fibrosis (CF), the prevalence of complications such as fatigue is also expected to increase. Our aim was to investigate the prevalence of severe fatigue among adults with CF and to identify factors associated with fatigue.

**Methods:** Adult patients with CF receiving treatment at a single center were invited to complete three questionnaires. We then studied the associations between fatigue and clinically measured parameters and between fatigue and patient-reported outcomes.

**Results:** A total of 77 patients (age 19–54 years; 56% males; mean FEV<sub>1</sub>: 63%) completed the questionnaires (43% response rate). The prevalence of severe fatigue among these patients was 26%. The variance in fatigue was explained partially by clinically measured parameters. However, patient-reported outcomes were stronger independently associated with fatigue and included the patients' reported respiratory symptoms, emotional functioning, and social functioning.

**Conclusions:** Fatigue is a clinically important and highly prevalent issue among adults with CF and is associated with a significant reduction in health-related quality of life and participation in society. In addition, fatigue is associated more strongly with the patient's perception of symptoms and well-being than with clinically measured parameters.

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**Keywords:** Cystic fibrosis; Fatigue; FEV<sub>1</sub>; Exercise capacity; Quality of life

**Abbreviations:** CF, cystic fibrosis; FEV<sub>1</sub>, predicted percentage of forced expiratory volume in 1 s; HRQoL, health-related quality of life; CFQ, Cystic Fibrosis Questionnaire; CIS, Checklist Individual Strength; HAES, Habitual Activity Estimation Scale; BMI, body mass index; MST, Modified Shuttle Test; CBT, cognitive behavioral therapy; PRO, patient-reported outcome.

☆ Data earlier presented at: European Cystic Fibrosis Society (ECFS) Conference 2017 in Seville, Spain (7–10 June, 2017). Reference for the abstract: M.M. Nap-van der Vlist, M. Burghard, H.J. Hulzebos, W.R. Doeleman, C.K. van der Ent, E.A. van de Graaf, S.L. Nijhof. The prevalence of severe fatigue in cystic fibrosis. Poster Sessions, Physiotherapy. *J Cyst Fibros*. 2017. Jun; 16, Suppl. 1:S129. [http://dx.doi.org/10.1016/S1569-1993\(17\)30603-3](http://dx.doi.org/10.1016/S1569-1993(17)30603-3).

☆☆ Financial disclosure: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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<https://doi.org/10.1016/j.jcf.2018.03.003>

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Please cite this article as: Nap-van der Vlist MM, et al, Prevalence of severe fatigue among adults with cystic fibrosis: A single center study, *J Cyst Fibros* (2018), <https://doi.org/10.1016/j.jcf.2018.03.003>

## 1. Introduction

### 1.1. Expanding our focus on cystic fibrosis

Thanks to extensive research and improvements in patient care, the life expectancy of patients with cystic fibrosis (CF) now exceeds 50 years [1]. However, as a result of living longer with this chronic, life-threatening condition, many patients develop chronic or intermittent fatigue as they age [2,3]. Persistent fatigue can be highly debilitating, leading to reduced societal participation and increased psychological distress [4]. Therefore, researchers are increasingly interested in developing methods to manage these symptoms and increase the patient's health-related quality of life (HRQoL) [5].

### 1.2. Fatigue in cystic fibrosis

Despite the impact that fatigue can have on daily life, relatively few studies have examined the prevalence or extent of fatigue among patients with CF. We therefore performed a search regarding fatigue and CF in PubMed, Embase, and the Cochrane Library. This search revealed that Sawicki and colleagues reported that 77% of adult patients (age 19–64 years) with CF reported a “lack of energy” [2]. Moreover, Jarad and colleagues found that fatigue is more common among patients with CF compared to healthy subjects [3]. Nevertheless, fatigue as a symptom is a distinct entity from severe, debilitating fatigue; normal fatigue can be experienced by anyone, whereas debilitating fatigue can lead to decreased functioning in daily life. Importantly, the prevalence of severe, debilitating fatigue has not been investigated among patients with CF.

### 1.3. Potential causes of fatigue

Precisely what causes fatigue in patients with CF is largely unknown. Given that fatigue is a complex phenomenon, it is likely that a multifactorial model will be needed in order to understand the cause of fatigue in these patients. Fatigue can be influenced by both biological and psychosocial factors, giving rise to the so-called biopsychosocial model [6]. In other chronic diseases such as rheumatoid arthritis, multiple sclerosis, and diabetes, fatigue was explained only partially by biological factors, requiring the addition of psychosocial factors such as social support and/or feelings of depression [7–9]. Whether decreased pulmonary function can serve as a biological predictor of fatigue in CF is currently a matter of debate [3]. Deconditioning and suboptimal nutritional status are other possible biological factors that may be related to more severe levels of fatigue [10]. Moreover, patients with CF often report poor sleep patterns and increased daytime drowsiness, which have been shown to be associated with reduced physical activity and increased fatigue [11]. Finally, fatigue can be associated with psychological factors, including depressive symptoms and anxiety, both of which are more prevalent among CF patients compared to the general population and have been correlated with fatigue in other chronic diseases [7–9,12].

### 1.4. Aim of the study

The aim of this study was to bridge the current knowledge gap with respect to: *i*) the prevalence of severe fatigue among adults with CF, and *ii*) the putative association between fatigue and clinically measured outcomes and patient-reported outcomes (PROs). Obtaining a better understanding of these factors may provide the foundation for developing future therapies directed at treating and/or preventing debilitating fatigue, thereby improving HRQoL.

## 2. Methods

### 2.1. Study design

In this cross-sectional, single-center study we recruited adult patients ( $\geq 18$  years of age) with CF who were receiving treatment at our outpatient clinic at Utrecht University Medical Center. The following exclusion criteria were applied: patients with a pulmonary infection (defined as requiring supplemental antibiotics upon maintenance treatment and/or hospitalization at the time of inclusion); an active comorbidity that was not related to CF (e.g., active arthritis); and patients who were unable to complete the forms and questionnaires in Dutch.

This study was conducted in accordance with the Declaration of Helsinki and was approved by our institution's Ethics Review Board. All included patients provided written informed consent.

### 2.2. Questionnaires

Participating patients were asked to complete validated questionnaires regarding fatigue, HRQoL, and physical activity. These three questionnaires were sent to the patient's home in August 2016 and were self-administered. If no response was received within four weeks, the non-responding participants received a telephone reminder. Data were collected from August 2016 through December 2016.

The Cystic Fibrosis Questionnaire version 1.2 (CFQ) was used to assess HRQoL. This validated questionnaire provides a CF-specific measure of HRQoL [13]. The CFQ consists of twelve subscales with a score ranging from 0 to 100 points; higher scores represent reduced frequency of symptoms and higher HRQoL. Internal consistency was acceptable for most domains of the CFQ (Cronbach's alpha: 0.43–0.92), and test-retest reliability was high for all domain scores (0.72–0.98).

The well-validated Checklist Individual Strength-20 (CIS-20) was used to assess fatigue [7,14,15]. In this questionnaire, the patient is asked about fatigue experienced in the previous two weeks and consists of the following four subscales: severity of fatigue, concentration, motivation, and activity. This questionnaire has good reliability (Cronbach's alpha: 0.83–0.92) and discriminative validity. A score of 35 or higher on the severity of fatigue subscale is used to define severe fatigue in adults [14].

For physical activity, we used the Habitual Activity Estimation Scale (HAES), a well-validated questionnaire for assessing physical activity in patients with CF [16]. Patients were instructed

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