Higher Levels of Education Are Associated With Full-Time Work in Adults With Cystic Fibrosis

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BACKGROUND: This study sought to explore factors in adults with cystic fibrosis (CF) that predicted whether (i) someone was engaged in full-time paid work, and (ii) those engaged in paid work reported problems with absenteeism and/or presenteeism. **METHODS:** Adults with cystic fibrosis who live in Western Australia completed absenteeism and presenteeism questions from the World Health Organization's Health Performance Questionnaire. The participants were grouped by work status (full time vs part time or unemployed) and by self-reported absenteeism and presenteeism (evidence of vs no evidence of). We explored whether factors such as air-flow obstruction, level of education, health-related quality of life (measured by using the Cystic Fibrosis Questionnaire–Revised), and treatment adherence predicted group membership. **RESULTS:** Of the 50 participants for whom data were available (median [interquartile range] age 30 [25–36] y; mean $\pm$ SD FEV₁% predicted, 60 $\pm$ 18%); 34 (68%) worked full time. A higher education level increased the odds of working full time (odds ratio 1.74, 95% CI 1.36–1.89). Among the employed participants, problems with absenteeism and presenteeism were reported by 20 (47%) and 7 (16%), respectively. Both those who reported problems with absenteeism or presenteeism were characterized only by lower scores on the role domain of the Cystic Fibrosis Questionnaire–Revised ($P = .02$). **CONCLUSIONS:** In this study, the majority of adults with cystic fibrosis worked full time and a low percentage of the sample reported problems with absenteeism and presenteeism. *Key words:* cystic fibrosis; absenteeism; presenteeism; productivity; work; employment. [Respir Care 2019;64(9):1116–1122. © 2019 Daedalus Enterprises]

Introduction

The life expectancy of people with cystic fibrosis (CF) has substantially improved in the past decade, and it is

now estimated that up to 90% of children born with CF will survive into adulthood.¹ Because people with CF are living longer, they are facing issues related to the responsibilities of adulthood, including the need to support themselves financially. Earlier research reported that adults with CF have the desire or intention to work.² However, few studies have reported on issues related to employment in this population, with most studies having been conducted more than a decade ago.^{3–5} The findings of these older studies are likely to be of limited relevance because new treatments (eg, hypertonic saline solution, ivacaftor, and

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Orkambi) lumacaftor/ivacaftor are now available for the management of CF, which reduce exacerbation frequency and are likely to improve the capacity to work.^{6,7}

To our knowledge, over the past decade, only one relatively small study ($N = 23$) investigated issues related to employment in this population.⁸ This study reported that, despite the high daily symptom and treatment burden associated with this disease, most adults with CF were engaged in paid employment.⁸ However, this study⁸ did not report associations between employment and other outcome measures, and only collected data from participants who lived in rural Western Australia. This limits the applicability of the findings to people with CF who lived in metropolitan regions, which is where the majority of adults with CF reside.

The aims of the present study were to explore factors in adults with CF living in Western Australia that predicted; (i) whether someone was engaged in full-time work, and (ii) whether those who were engaged in paid work reported issues with absenteeism and presenteeism. Understanding issues related to employment are important in this population because the capacity to successfully engage in work provides greater financial security and is associated with reduced social isolation, and greater self-esteem.⁹⁻¹¹

Methods

This study presented a secondary analysis of data collected for a randomized controlled trial (RCT) that explored the effect of using a smartphone application to self-report symptoms on measures related to exacerbation frequency and health-care utilization.⁸ Secondary outcomes for this RCT were absenteeism and presenteeism, FEV₁, health-related quality of life, and feelings of anxiety and depression. Approval to conduct the RCT was obtained from the human research ethics committees at Sir Charles Gairdner Hospital and Curtin University (registration 12615000599572). For the RCT, before randomization, baseline data were collected by a senior physiotherapist (JW) during a 1-h visit at Sir Charles Gairdner Hospital. Questionnaires were administered to collect data on work status, absenteeism and presenteeism, health-related quality of life, level of education, treatment burden, and feelings of anxiety and depression. Spirometric measures of resting lung function were collected, and descriptive measures of age, sex, height, and weight were recorded.

To be eligible to enroll in the RCT, adults diagnosed with CF who were living in Western Australia needed to be under the clinical care of the CF team at Sir Charles Gairdner Hospital and to have experienced at least one respiratory exacerbation in the past 12 months that required intravenous antibiotics. The primary outcome of the RCT was the number of exacerbations that required intra-

QUICK LOOK

Current knowledge

The life expectancy for people with cystic fibrosis (CF) has improved substantially in the past decade. It is estimated that the majority of children born with CF will survive into adulthood. Because people with CF live longer, they face issues related to adulthood, including the need to support themselves financially. Earlier research has indicated people with CF have the desire to work and that, despite high disease and treatment burden, most adults with CF are engaged in paid employment.

What this paper contributes to our knowledge

In this sample of people with moderate CF, most had completed post-high school education and worked full time. Compared with the participants who were unemployed or worked part time, those who worked full time were older and had higher levels of education. Both relative absenteeism (absence from work due to illness) and presenteeism (loss of work performance due to illness) demonstrated large variability. Based on these findings, full-time work and high levels of education are realistic goals for most people with CF, despite severe respiratory disease.

venous antibiotics, and the number of participants with an exacerbation in the previous 12 months who were more likely to have an exacerbation in the following 12 months. At the time of recruitment, the participants needed to have been exacerbation-free for at least 2 weeks. Exclusion criteria comprised current or previous listings for lung transplantation, a lack of access to a smartphone, and any impairment or disability that prevented correct use of the smartphone application. To be included in the analyses reported in the current study, the participants needed to have completed the absenteeism and presenteeism questions of the World Health Organization's Health Performance Questionnaire.^{12,13} Further, to ensure that our data pertained only to paid work, the participants who indicated that they were engaged in volunteer work, caregiving responsibilities, or formal study were excluded because we were unable to determine if these commitments were included in estimates of working hours.

Measures Related to the Current Study

Work status was assessed by using the Cystic Fibrosis Questionnaire-Revised.¹⁴ In this questionnaire, the participants were asked to select the work and/or study status

that best described their current situation, with response choices, including studying, homemaker (ie, carer), volunteering, or working (either full time or part time).¹⁴ Absenteeism was defined as the number of hours absent from work due to illness. Presenteeism was defined as the reduction in work performance, despite being present at work,¹² and reflects the decreased productivity that occurs when employees are not able to function optimally at work due to illness. These data were collected by using the Health Performance Questionnaire, which is a self-complete, valid, and reliable tool.^{12,13}

Given recent data that ~40% of Australian adults with CF in the labor force were working part time,¹⁵ relative measures of absenteeism and presenteeism were used. Relative absenteeism was calculated by subtracting the number of hours that employees worked from the number of hours that they were expected to work, then dividing this by the hours expected to work. Values for relative absenteeism over the past 4 weeks ranged from negative values, which indicated that the employee worked more than expected, to 1.0, which indicated that the employee was always absent from work.¹⁶ This measure is useful when evaluating the different impact of absenteeism on people who work full time versus part time.

To measure relative presenteeism, the participants were asked to rate their performance on a 10-point Likert scale relative to the usual performance of most workers with a similar job over the past year or two. Relative presenteeism was then calculated by dividing the average work performance of the employee by the average performance of co-workers. Values were capped between 0.25 and 2.0, with 2.0 indicating that the participants perceived their performance at work to be twice that of their co-workers.¹⁶ Measures of FEV₁ and FVC were collected by using a calibrated spirometer (Medgraphics [MGC Diagnostics, St Paul, Minnesota] or Easyone [Ind Medical Technologies, Andover, Massachusetts]), according to published guidelines.¹⁷ Data were expressed as absolute values and as a percentage of the predicted value in the healthy population.¹⁸

Health-related quality of life was measured by using the Cystic Fibrosis Questionnaire-Revised. This is the most widely accepted method for assessing health-related quality of life in people with CF and is valid and reliable.¹⁴ This self-complete questionnaire comprises 50 questions that assess 12 domains of health, including respiratory symptoms.¹⁴ Each domain was scored of 100, with higher scores indicating better quality of life. In addition, the Cystic Fibrosis Questionnaire-Revised measures the highest level of education attained on a 5-item ordinal scale that ranges from the lowest level (some secondary school or less) to the highest (professional qualification or post-graduate study).

Treatment adherence was measured by using the Treatment Adherence Questionnaire-Cystic Fibrosis, which has high inter-test reliability and is a well-established tool for measuring adherence to treatment in this population.¹⁹ The Treatment Adherence Questionnaire-Cystic Fibrosis is a self-completed questionnaire that lists 12 common CF treatments and asks the participant to report how many minutes he or she spent performing each treatment over the past 7 days. Feelings of anxiety and depression were measured by using the Hospital Anxiety and Depression Scale.²⁰ This questionnaire has high reliability and validity.²⁰ This self-complete questionnaire comprises 14 questions and asks the participant to rate his or her feelings of anxiety and depression over the previous 7 days. Responses to each question were provided on a 4-point Likert scale (ranging from 0 to 3), with higher scores indicating greater feelings of anxiety and depression.

Data Analysis and Sample-Size Calculation

Statistical analyses were undertaken by using the Statistical Package for Social Sciences 24.0 (SPSS, Chicago, Illinois). The distribution of continuous data were examined by using frequency histograms and the Shapiro-Wilk test. Data that approached a normal distribution were expressed as mean $\pm$ SD, with data that did not approach this distribution being expressed as median (interquartile range). For all analyses, a *P* value of $<.05$ was considered statistically significant.

To address the first aim, the participants were first grouped by their work status into 2 categories; (i) working full time, or (ii) not working full time, which included participants who were working part time or were unemployed. Differences between groups in age; body mass index; FEV₁; FVC; treatment time per day; Hospital Anxiety and Depression Scale scores; the physical, social, role, and respiratory domain scores of the Cystic Fibrosis Questionnaire-Revised; and the level of education (grouped into the following: did not complete tertiary education, completed tertiary education, or completed post-graduate tertiary education) were explored by using either independent-samples *t* test (parametric data), the Mann-Whitney test (non-parametric and ordinal data), or the chi-square test (nominal data). Thereafter, if significant between-group differences were found in more than one variable, then logistic regression was undertaken with group membership as the dependent variable.

To address the second aim, the participants were grouped according to their relative absenteeism over the past 4 wk and relative presenteeism as (i) impaired or (ii) unimpaired. Specifically, for relative absenteeism over the past 4 wk, the participants who reported a score of >0 were considered impaired (ie, had evidence of relative absen-

teeism over the past 4 weeks) and those who reported a score of ≤ 0 were considered unimpaired (ie, had no evidence of relative absenteeism over the past 4 wk). For relative presenteeism, the participants who scored ≥ 0.25 (the lower bound threshold for relative presenteeism scores) and < 1 were considered impaired (ie, had evidence of relative presenteeism), and those who scored ≥ 1 and ≤ 2 were considered unimpaired (ie, had no evidence of relative presenteeism). Thereafter, differences between groups and logistic regression were undertaken as described for the first aim. Because this was an analysis of an existing data set, prospective sample-size calculations were not performed.

Results

At the time of recruitment, a total of 180 adults with CF were managed by the CF team at Sir Charles Gairdner Hospital. Of these, 70 (39%) were eligible and invited to participate in the RCT and 60 individuals agreed to participate and completed the Health Performance Questionnaire before randomization. Data from 10 participants were excluded from the analyses because 6 reported being a student and 4 reported being a homemaker. The characteristics of the 50 participants who contributed data to these analyses are presented in Table 1.

Compared with the participants who were not working full time, those who were working full time were older (median [IQR] 33 [27–38] vs 26 [22–32] y, $P = .048$) and were characterized by a higher percentage of tertiary education graduates (79% vs 31%, $P = .002$) (see the supplementary materials at <http://www.rcjournal.com>). Level of education was the only variable that contributed significantly to the model used to predict the odds of working full time (Table 2).

Of the 50 participants included in this study, 43 (86%) reported being employed and their data were included in the assessment of absenteeism and presenteeism (Table 3). Of these 43 participants, 9 (21%) were working part time, with most (7/9 [78%]) reporting poor health as the reason for working part time rather than full time. Full-time workers reported working on average $\pm$ SD 34 ± 14 h/week, with part-time workers reported working 16 ± 7 h/week. The most frequently reported job classification was “professional” (30%); the least frequent was “laborer” (2%). Four-week relative absenteeism was median (IQR) 0.0 (0.0–0.1), which suggested that the participants were attending work when expected. Relative presenteeism was median (IQR) 1.0 (1.0–1.1), which suggested that the participants rated their work performance to be similar to their co-workers.

Compared with the participants who described problems with relative absenteeism over the past 4 wk, those who did not describe problems with relative absenteeism

Table 1. Characteristics of the Participants

Variable	Value	Range (minimum–maximum)
Males, <i>n</i> (%)	29 (58)	
Rural location, <i>n</i> (%)	9 (8)	
Work, <i>n</i> (%)		
Full time	34 (68)	
Part time	9 (18)	
Unemployed	7 (14)	
Age, median (IQR) y	30 (25–36)	18–53
BMI, median (IQR) kg/m ²	22.1 (20.4–25.9)	16.2–36.4
FEV ₁ % predicted, mean $\pm$ SD	60 $\pm$ 18	25–93
FVC % predicted, mean $\pm$ SD	75 $\pm$ 15	42–104
FEV ₁ /FVC, mean $\pm$ SD	65 $\pm$ 11	40–84
<i>Pseudomonas aeruginosa</i> , <i>n</i> (%)	49 (98)	
No. different treatments per day, median (IQR)	8 (7–9)	0–11
Time spent on treatment per day over the past wk, median (IQR) min	60 (34–97)	0–215
HADS score, median (IQR)		
Anxiety	4 (2–7)	0–15
Depression	3 (1–4)	0–9
CFQ-R score, median (IQR)*		
Physical	75 (60–92)	8–100
Social	72 (61–83)	33–100
Role	83 (73–92)	22–100
Respiratory, mean $\pm$ SD*	71 $\pm$ 16	22–100
Level of education, <i>n</i> (%)		
Some secondary school or less	8 (16)	
Completed year 12	10 (20)	
Other higher education	14 (28)	
University degree	7 (14)	
Professional qualification or post-graduate study	11 (22)	

N = 50.

BMI = body mass index

* From a total score of 100, with higher scores indicating better quality of life.

IQR = interquartile range

HADS = Hospital Anxiety and Depression Scale

CFQ-R = Cystic Fibrosis Questionnaire-Revised

over the past 4 wk scored higher on the Cystic Fibrosis Questionnaire-Revised role domain (median [IQR] 92 [75–100] vs 83 [60–90], $P = .02$ (see the supplementary materials at <http://www.rcjournal.com>). Compared with the participants who described problems with relative presenteeism, those who did not describe problems with relative presenteeism scored higher on the Cystic Fibrosis Questionnaire-Revised role domain (median [IQR] 83 [75–98] vs 83 [58–92], $P = .02$) (see the supplementary materials at <http://www.rcjournal.com>). No between-group differences were found for FEV₁, FVC, feelings of anxiety and depression, or treatment adherence (see the supplementary materials at <http://www.rcjournal.com>). Because between-

Table 2. Univariate Logistic Regression to Identify Predictors That Changed the Odds of Working Full Time

Independent Variable	OR (95% CI)
Age (5-y increments)	1.26 (0.92–1.49)
Body mass index	1.12 (0.95–1.26)
Sex (female)	1.24 (0.43–1.77)
FEV ₁ % predicted (5% increments)	1.04 (0.86–1.19)
Level of education (completed tertiary education)*	1.74 (1.36–1.89)†
Treatment time (10-min increments)	1.07 (0.94–1.19)
HADS: Anxiety	1.03 (0.86–1.18)
HADS: Depression	1.02 (0.75–1.23)
CFQ-R: Respiratory‡	0.99 (0.95–1.03)

Note: The reference group was of the participants who were not engaged in full-time work.

* Grouped into the following for analysis: (i) participants who did not complete tertiary education, (ii) those who completed tertiary education, or (iii) those who completed post-graduate tertiary education.

† Denotes $P < .05$.

‡ Of a total score of 100, with higher scores indicating better quality of life.

OR = odds ratio

HADS = Hospital Anxiety and Depression Scale

CFQ-R = Cystic Fibrosis Questionnaire-Revised

Table 3. Characteristics of Participants Included in the Analyses Related to Absenteeism and Presenteeism

Variable	Value
Full-time work, n (%)	34 (79)
Part-time work, n (%)	9 (21)
Job classification, n (%)*	
Manager	4 (9)
Professional	13 (30)
Technician or trader	7 (16)
Community and personal service worker	8 (19)
Clerical and administrative worker	7 (16)
Sales worker	1 (2)
Machinery operator or driver	2 (5)
Laborer	1 (2)
Hours worked per week, mean $\pm$ SD (range [minimum-maximum])	
For full-time workers	34 $\pm$ 14 (0–64)
For part-time workers	16 $\pm$ 7 (6–27)

$N = 43$.

* Job classifications according to the Australia and New Zealand Standard Classification of Occupations (Australian Bureau of Statistics. Australian and New Zealand Standard Classification of Occupations. Canberra: ABS Publication 1220.0.2013. Available at <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/1220.0Main%20Features2013,%20Version%201.2?opendocument&tabname=Summary&prodno=1220.0&issue=2013,%20Version%201.2&num=&view=>). Accessed on September 29, 2017.

group differences were found in only one variable, logistic regression was not undertaken.

Discussion

Of the adults with a diagnosis of CF who lived in Western Australia and who were not engaged in study or care-

giving activities, 68% ($n = 34$) reported working full time. Compared with those working part time or were unemployed, full-time workers were older and had higher levels of education, with education level being the only predictor of work status. More participants reported having problems with relative absenteeism than presenteeism; however, there was considerable variability in both measures within the sample. Those without problems with absenteeism and presenteeism had higher scores on the role domain of the Cystic Fibrosis Questionnaire-Revised.

Despite moderate disease severity, the majority of the participants worked full time. This was comparable with a previous study that demonstrated that 63% of adults with CF worked full time.²¹ The comparatively older age of the participants who worked full time was unexpected because we postulated that older participants would have greater respiratory impairment and, therefore, be less likely to work full time. However, respiratory impairment, expressed as FEV₁ % predicted, did not differ between the groups. This was consistent with previous literature that found FEV₁ % predicted to be a poor predictor of work status.³⁻⁵ Our finding of older age among those who worked full time may reflect a “survivor effect” in older adults with CF. That is, it is possible that the older adults included in this study were “survivors,” with a potentially less-aggressive disease course and were able to attain high levels of education and also engage in full-time work.

Results of previous research indicated that people with CF who work part time report higher daily treatment time when compared with those who work full time (mean $\pm$ SD 70 $\pm$ 45 min vs 49 $\pm$ 43 min, $P = .02$).²¹ This finding was not supported in the current study, which found that those who worked full time had a treatment time that was double that of those who worked part time. Although this difference did not reach the threshold for statistical significance ($P = .07$), this was likely to reflect inadequate power. We hypothesized that those who spend more time on treatment have greater control over their disease and thus can engage in full-time work. However, this needs investigation in a larger study.

This study also demonstrated that higher levels of education were associated with increased odds of being employed full time (odds ratio 1.74, 95% CI 1.360–1.89), which was in agreement with previous studies.^{3,21,22} Specifically, Targett et al²² previously reported that attainment of “higher than high school education” was associated with greater odds of being employed (odds ratio 2.96, 95% CI 1.40–6.27). We hypothesized that attaining higher levels of education affords people with cystic fibrosis greater flexibility in their choice of employment and thus increases the likelihood of being employed. If the aim of vocational counseling is to reduce the likelihood of a person with cystic fibrosis working part time or being unemployed, then, according to these findings, people with cys-

tic fibrosis should be encouraged to attain an education level higher than secondary education.

Given that the majority of participants (64%) had attained post-secondary education, it was unsurprising that most participants were employed in skilled jobs. Unskilled laborers represented a low proportion of participants (2%), which was comparable with previous studies in France (<5%)²¹ and North America (6%).³ Hours worked per week (mean $\pm$ SD 30 $\pm$ 14 h/week) by the participants in this study were comparable with observations made by Burker et al³ (mean $\pm$ SD 32 $\pm$ 13 h/week) and Targett et al²² (37 [22–40] h/week). Despite their disease and associated treatment burden, the working hours of people with cystic fibrosis approximate those of Australia's general population (31 h/week).²³

More participants reported having problems with relative absenteeism over the past 4 weeks (47%) than relative presenteeism (16%), which suggested that cystic fibrosis may have had a greater impact on absenteeism. Both outcomes displayed large variability, which revealed large disparities in absenteeism and presenteeism across the sample. This finding was comparable with a previous study that demonstrated variable rates of absenteeism and presenteeism in adults with CF who live in rural areas.⁸ With regard to relative absenteeism over the past 4 wk and relative presenteeism, only the role domain of the Cystic Fibrosis Questionnaire-Revised differed between those who reported problems and those who did not. However, this was expected because the role domain questions of the Cystic Fibrosis Questionnaire-Revised asked participants about absence from work and loss of work performance in the past 2 weeks due to illness or treatment.¹⁴ Although neither absenteeism nor presenteeism were influenced by measures collected as part of this study, it was possible that factors such as work entitlements (ie, access to sick leave), motivation, and the acceptability in individual workplaces of people who presented to work when unwell may have played a role.

The main strength of this study was that it used questions from the Health Performance Questionnaire, a valid and reliable tool,^{12,13} to quantify absenteeism and presenteeism. To our knowledge, this study was the first to administer the absenteeism and presenteeism questions from the Health Performance Questionnaire in people with cystic fibrosis who lived in metropolitan areas. This limited the applicability of the findings to people with cystic fibrosis who lived in rural areas, where work and study status and/or opportunities may have differed from metropolitan areas. However, at least in Western Australia, the majority of adults with cystic fibrosis reside in metropolitan areas. One limitation of this study was a selection bias introduced by the study criteria for the larger RCT. That is, the RCT required the participants to have had an exacerbation in the past 12 months and not have a previous or

current lung-transplantation listing. This potentially excluded people with CF with mild or severe disease. It was also possible that our sample size lacked the power to detect meaningful between-group differences in some variables, such as FEV₁ and FVC. Another limitation was the minor risk of recall bias for questionnaires in this study. However, the questionnaires have all been validated in cystic fibrosis or other chronic lung disease populations and do not have long recall periods, with the maximum being 4 weeks in the Health Performance Questionnaire.^{12,13}

The primary benefit of these findings for future clinical practice is that clinicians are now able to confidently assert that full-time work and high levels of education are realistic goals for most people with CF, despite severe respiratory disease. The primary benefit of these findings for future clinical practice is that clinicians are now able to confidently assert that full-time work, and high levels of education are realistic goals for most people with CF, despite severe respiratory disease. Encouragement may also be given to children and adolescents with CF to attempt to obtain higher levels of education because this is associated with greater odds of working full time.

Conclusions

In this sample of people with moderate severity of cystic fibrosis, most participants had completed post-high school education and were engaged in full-time work. With the continued increase in age of survival due to improved treatment options, this study indicated that it was realistic for adolescents with CF to plan goals for study and employment beyond high school and much further into adult life. Both relative absenteeism and presenteeism demonstrated large variability, which suggested that CF affected the work behaviors of some, but not all, in this population. Future studies of absenteeism and presenteeism in people with CF should consider using larger sample sizes and investigate to what extent work-specific factors, such as job flexibility (ie, flexible working hours), role flexibility (ie, reassignment to less physically demanding roles), workplace beliefs (ie, social acceptability of working while sick), and entitlements to sick leave, influence these outcomes.

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