

Self-efficacy and Social Support in Cystic Fibrosis Patients

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ABSTRACT

Introduction and Background: Increased survival of patients with cystic fibrosis (CF) has prompted interest toward coping with chronic disease. Self-efficacy, the confidence the people have to be able to perform a certain task, is considered crucial for self-management of chronic diseases when the patient has to follow a demanding therapeutic approach. **Patients and Methods:** It has been explored in 117 patients 7–39 years old, together with the social support, considered a relevant factor of coping as well. The constructs were assessed with self-report questionnaires and measured with a 0–100 score. **Results:** The self-efficacy median score was lower in younger patients (61.1) and particularly in those with a BMI <10th, and higher in older ones (71.1); in these patients, self-efficacy was directly, significantly related with age at diagnosis. Older patients perceived a high social support from the family (91.7); it was inversely related to the time elapsed from diagnosis. **Conclusions:** Coping with CF should be monitored from the age of diagnosis, possibly with psychological support

Key words: Cystic fibrosis, self-efficacy, social support

INTRODUCTION

Life expectancy for children affected by cystic fibrosis (CF) has improved, extending from infancy to adult life, and medical regimens are demanding, including chest physical therapy, diet, and multiple medications. Educational programs have been devised to empower self-management of patients,^[1,2] a critical issue in adolescent care, and transition to adult care.^[3]

Self-efficacy, a construct introduced from social cognitive theory,^[4] has been suggested as the most important factor predicting self-management behavior for monitoring and treating respiratory problems.^[5] This construct is related to the beliefs about how capable a subject is of performing

the behavior that leads to the desired outcomes, and can contribute to a successful treatment. Perceived self-efficacy plays a central role in the process of self-management because it affects actions directly and through its impact on cognitive, motivational, and affective determinants.^[6] It is a critical issue in adherence,^[7] but few studies are addressed to CF.^[1,2]

An individualist approach should not neglect the social and environmental conditions of health behavior,^[6] especially when family is heavily involved in the treatment; moreover, the social support - SS - has been shown to influence psychological adjustment of adolescents with CF.^[8-10]

The primary objective of this study is to describe attitude to self-management in Italian CF patients of different ages, from childhood to adult life, together with SS.

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METHODS

Subjects and methods

Patients affected by CF (positive sweat test) were recruited at the CF unit of the Bambino Gesù Hospital, a large pediatric hospital in Rome, Italy.

The inclusion criteria were as follows: At least 7 years of age, ability to read Italian, and absence of severe mental illness. Patients completed the study instruments during the planned day care or hospital admission.

Clinical characteristics

Social and demographic data, age at diagnosis, presence of chronic lung colonization by pathogens, chronic complications, height and weight, and number of exacerbations in the past year, together with patients' and families' sociodemographic variables were collected. Pulmonary function test (percentage of predicted forced expiratory volume at 1 s [FEV1]) results were retrieved from clinical charts.

Health-related self-efficacy

The self-efficacy CF medical regimen scale (SCFS) has been developed to measure the individual's confidence about his or her ability to perform behaviors prescribed for patients with CF. The questionnaire includes 15 items about perceived capability to manage the medical regimen in the face of anxiety when things go wrong. The child version (≤ 14 years) includes six items.

For each item, participants rated the strength of their beliefs in their capability to execute the designated activities, using a 5-point response format ranging from perceived incapability to complete self-assurance in one's capability.

The multidimensional scale of perceived social support (MSPSS)^[10] includes 12 items. Respondents rate their perceived social support obtained from family, friends, and a beloved person on a scale from 1 (totally false) to 7 (totally true). We used the Italian version.^[11]

The questionnaire was administered to patients ≥ 14 years old (70 patients).

The severity of CF was evaluated with the Shwachman score.^[12]

STATA software was used (version 8.0).

T score was calculated as follows: $T = (\text{observed score} - \text{minimum of possible score} / \text{maximum possible score} - \text{minimum}) * 100$. Cronbach's alpha was adopted to evaluate internal consistency of questionnaires. Continuous variables were reported as medians (and interquartile ranges [IQR]) and as means (and standard deviations), and inferences

were tested with parametric or non-parametric tests accordingly to their distribution.

Written informed consent was obtained from the patient or from a parent for patients < 18 years; ethical and scientific approval was granted by the hospital board for clinical research.

RESULTS

Patient characteristics

Of 120 patients, 116 accepted to participate (response rate 96.7%).

Patients were aged between 7 and 39 years (median 16.0, IQR - 11.0–20.5). The analysis was carried out on 46 children 7–14 years old, 27 patients > 14 –17 years old, and 43 patients 18 years old or more. 69 patients were female (50.9%).

Median FEV1 was 85.0 (IQR 70.0–98.0), with the majority of patients in the normal range ($> 80\%$, Table 1). The older patients show a more advanced disease, i.e. a lower FEV1, more chronic infections [Table 1], as expected in a chronic, progressive disease, and diagnosis were done later.

Self-efficacy

The scales disclosed good internal consistency [Table 2].

Older patients scored higher than children and early adolescents, and self-efficacy scores were similar in this last group without ventilatory impairment and in the older patients group with severe impairment [Table 2]. A trend toward lower self-efficacy with lower FEV1 was consistent through both groups, but no significant difference was shown in Table 2.

No significant difference was evident by sex of patients, by education of parents, and chronic infection or complications, while in patients 7–14 years self-efficacy was significantly lower in patients with a BMI $< 10^{\text{th}}$ centile (37.0 vs. 61.5, $P = 0.03$).

No correlation was found between self-efficacy and severity (Shwachman score), age, number of exacerbations, and time from diagnosis, while there was a significant, positive correlation with age at diagnosis among patients > 14 years old (0.26, $P = 0.03$).

Social support

A high Cronbach's alpha was found for both groups of patients [Table 3].

The SS of patients was higher from family and the beloved person than from friends [Table 3] and was not significantly but consistently lower in patients with ventilatory insufficiency [Table 3], No significant difference was found

Table 1: Clinical characteristics of CF patients by age group

Variable	n (%)		P value
	7–14 years	>14 years	
Sex			
Males	22 (47.8)	35 (50.0)	0.73*
Females	24 (52.2)	35 (50.0)	
Fathers' education			
≤8 years	19 (41.3)	31 (44.3)	0.67*
>8 years	27 (58.7)	39 (55.7)	
Mothers' education			
≤8 years	19 (41.3)	35 (50.7)	0.32*
>8 years	27 (58.7)	34 (49.3)	
FEV1			
Median (IQR)	92 (80–100)	80 (62–96)	0.004**
Severity (Shwachman score) median (IQR)	96 (91–98)	89 (81–95)	<0.001**
Age at diagnosis	0 (0–1)	3.5 (0–9)	<0.001**
Exacerbations in past 12 months	0 (0–1)	1 (0–2)	0.06**
Ventilatory impairment			
None (FEV1>79%)	35 (76.1)	35 (50.0)	0.008*
Mild (FEV1 65–79%)	8 (17.4)	16 (22.9)	
Severe (FEV1<65%)	3 (6.5)	19 (27.1)	
Chronic lung infections			
Yes	18 (39.1)	54 (77.1)	<0.001*
No	28 (60.9)	16 (22.9)	
Comorbidity/complication			
Yes	13 (28.3)	30 (42.9)	0.10*
No	33 (71.7)	40 (57.1)	
BMI			
<10 th cent.	3 (6.4)	14 (20.0)	0.04*
≥ 10 th cent.	44 (93.6)	56 (80.0)	
Tot.	47 (100.0)	70 (100.0)	

*Chi-square test. **Kruskal–Wallis test. IQR: Interquartile range. FEV1: Forced expiratory volume 1 second. BMI: Body mass index

Table 2: Self-efficacy (SCFS) by age group and ventilatory function (T scores)

Ventilatory impairment	Median	IQR ^o	Mean	SD	P value	Alpha
None	66.7	50.0–72.2	61.7	18.9	0.23 [^]	
Mild-severe	50.0	44.4–66.7	54.0	17.6		
Tot. 7–14 years	61.1	50.0–72.2	59.9	18.7		0.70
None	75.6	60.0–88.9	74.7	17.2		
Mild	72.2	60.0–92.2	75.1	19.3	0.43*	
Severe	66.7	53.3–84.4	68.8	19.0		
Tot. >14 years	71.1	60.0–88.9	73.2	18.1		0.92

^oIQR: Interquartile range. *Kruskal–Wallis test. [^]Student's *t*-test

by sex, infection, BMI, or complication, nor between patients 14 and 18 years old and >18 years old.

There was an inverse, significant correlation with the time elapsed from diagnosis (-0.30 , $P = 0.01$), and, among

Table 3: Social support (MSPSS) perceived by patients >14 years old, by subscales and ventilatory function ($n=70$ - T score)

Ventilatory impairment	Median	IQR ^o	P value*	Alpha
None	91.7	83.3–100		
Mild	95.8	85.4–100	0.45	
Severe	91.7	79.2–100		
Tot. family	91.7	83.3–100		0.89
None	91.7	66.7–100		
Mild	89.6	70.8–100	0.99	
Severe	83.3	66.7–100		
Tot. beloved person	89.6	66.7–100		0.88
None	75.0	66.7–87.5		
Mild	85.4	58.3–95.8	0.50	
Severe	66.7	54.2–87.5		
Tot. friends	75.0	62.5–87.5		0.92
None	84.7	69.4–94.4		
Mild	84.7	75.7–95.1	0.61	
Severe	79.2	69.4–88.9		
Tot.	84.7	72.2–94.4		0.89

^oIQR: Interquartile range. *Kruskal–Wallis test

subscales, with the subscale of SS from friends (-0.27 , $P = 0.02$), while no correlation was found with other subscales, severity, age, exacerbations, and age at diagnosis.

Self-efficacy was significantly correlated with SS among patients >14 years old (0.40 , $P < 0.001$) and for every subscale: With support from a beloved person (0.30 , $P = 0.01$), from family (0.42 , $P < 0.01$), and from friends (0.32 , $P = 0.008$).

DISCUSSION

Younger patients show a less advanced disease but show a limited self-efficacy, as one can expect from children and early adolescents with limited autonomy, and this is particularly true for patients with nutritional problems. Among late adolescents and young adults, the later the patient was diagnosed, the higher was his/her self-efficacy, probably connected with the achieving a higher level of autonomy, whatever the ventilatory function. These patients perceive a high SS, especially from family, and it is higher as the shorter is the time from diagnosis, possibly because the management compromises the accessibility to socialization outside the family.

The period of the life when the diagnosis of CF is made seems to influence both the aspects of coping we explored directly (for self-efficacy) or through time elapsed from diagnosis (for SS), but we cannot exclude a bias from selection of older

patients who survived, or differential loss from the follow-up of patients more prone to self-management.

Therefore, we cannot firmly conclude that coping improves with age due to the cross-sectional design of the study. Some room is anyway available to improve self-efficacy, possibly through psychological support.

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