

Original Research Article

Depression and coping strategies used among adolescents with cystic fibrosis

Surya Kant Tiwari^{1*}, Rimple Sharma², Poonam Joshi², Sushil Kumar Kabra³

¹Yatharth Nursing College and Paramedical Institute, Chandauli, Uttar Pradesh, India

²College of Nursing, AIIMS, New Delhi, India

³Department of Pediatrics, AIIMS, New Delhi, India

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*Correspondence:

Mr. Surya Kant Tiwari,

E-mail: surya.tiwari468@gmail.com

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ABSTRACT

Background: Cystic fibrosis (CF), an autosomal recessive monogenic chronic disorder affects the lungs, pancreas, and other exocrine glands, and manifests as recurrent respiratory infections, malabsorption, and a myriad of complications pertaining to other systems like hepatobiliary, endocrine and reproductive systems. Objectives were to assess the level of depression among adolescents with CF, to assess the coping strategies used by adolescents with CF and to find an association between selected sociodemographic and clinical variables with depression.

Methods: In a cross-sectional survey, 30 adolescents with CF in the age group of 12-18 years, attending the specialty clinic of a selected tertiary care facility were enrolled using a purposive sampling technique. Tools consisting of sociodemographic and clinical profile, patient health questionnaire (PHQ)-9, and ways of coping with CF were used for data collection.

Results: Most of the adolescents with CF (66.7%) had depression of varying severity with 36.7% having moderate-severe to severe depression. The frequently used coping strategies by the adolescents with CF were hopefulness (76.66±11.29), followed by optimistic acceptance (70.23±13.04). The individual coping strategy with the highest mean score was “having confidence on doctor and treatment” (3.83±0.37), while ‘I cry, eat, drink or take drugs’ had the lowest score (1.6±1.00).

Conclusion: Depression is a common problem among adolescents with CF requiring regular screening and referral to experts for enhancing their coping strategy of optimistic acceptance.

Keywords: CF, Adolescents, Depression, Coping strategies

INTRODUCTION

Cystic fibrosis (CF), is an inherited life-limiting, an autosomal recessive monogenic disorder affecting all ethnic groups world over. The disease mainly affects the respiratory, gastrointestinal, and reproductive tract leading to abnormal exocrine gland secretions in an individual. The primary cause of morbidity and mortality in CF is progressive lung disease.¹

Adolescence is a turbulent phase in the life of an individual, especially in the presence of chronic diseases

like CF. It can affect their biological, mental, and psychosocial domains. An adolescent living with CF can have significant emotional burden resulting in depression and anxiety.² Depression is an important global public health issue affecting adolescents with CF.³ Several systematic reviews, meta-analyses, and original studies indicate higher prevalence of depression among adolescents CF patients.⁴⁻¹⁰ Ranging from 3.3% to 29%, with an associated increased risk of non-adherence to treatment regimen due to depression.⁶ Causes of depression in adolescents with CF can be attributed to the lifelong complex treatment regimen, frequent and multiple

diagnostic procedures, and frequent prolonged hospitalization.⁴ The disease further worsens the nutritional status of the adolescent and invites CF-related complications such as malnutrition, diabetes mellitus (DM), pancreatitis, biliary cirrhosis, liver failure, and infertility.^{2,11,12} Traditionally, disease burden was measured using morbidity and mortality rates, but now the focus is shifted towards psychological aspects of the illness as well.¹³ This hereditary disease, has a negative impact on the mental development of adolescents with CF that distorts their social situations and self-image due to poor nutrition, increased absenteeism in school, and decreased quality of life.¹⁴

Coping is an adjustment process between an individual and the situation arising as a result of CF, which serves to prevent and control depression among them. On a continuum, it can be passive and avoiding type at one end while on the other end optimistic. Depression resulting from CF can be handled appropriately by using optimistic coping, which in turn could lead to better survival and outcome.¹⁵ Adolescents with CF having depression are likely to make use of maladaptive coping strategies as compared to healthier individuals.¹¹ Therefore identification of coping strategies used by adolescents with CF is required for future interventions. Currently, there is scarcity of research evidence in the area of depression and coping strategies used by adolescents CF patients.^{15,16} Most of the available research evidence in CF is related to the prevalence of depression in the adult population, pathophysiology, and treatment plans.¹⁷ Therefore, the present study was planned to assess depression and coping strategies used by the adolescent with CF and to find an association between selected sociodemographic and clinical variables with depression.

METHODS

Study design

This cross-sectional study was undertaken in a pediatrics chest clinic of a tertiary care facility in North India from June 2019 to February 2020. Ethical approval was obtained from the institutional ethical committee of all India institute of medical sciences, New Delhi (IECPG/129/19). Written informed assent and consent were obtained from adolescents with CF and their caregivers respectively. They were assured about the confidentiality and anonymity of the obtained information. Permission to use standardized tools was obtained from respective copyright authors. The tools were translated into Hindi and back-translated to English to ensure the adequacy of the tools. Pilot study was done and the study was found to be feasible.

Subjects and procedure

A total of 30 adolescents with a documented diagnosis of CF were enrolled in the study using the purposive sampling technique. Adolescents with CF having age

between 12-18 years, able to read and write in Hindi/English were included in the study, while adolescents with CF having co-morbid conditions like cancer, epilepsy, cerebral palsy, etc. were excluded. Considering the prevalence of depression as 10% in adolescents with CF at 95% confidence interval with 10% precision, the sample size was calculated to be 35.⁷ The study was concluded with a sample size of 30 due to the unprecedented COVID-19 pandemic outbreak and the beginning of teleconsultation in place of specialty clinic.

Sociodemographic and clinical profile of adolescents with CF was collected. Depression and coping strategies were assessed using (PHQ)-9, ways of coping with CF.^{18,19} All the tools were completed by patients immediately before they consulted with the physician.

Data collection

Sociodemographic and clinical profile

Information related to sociodemographic and clinical profiles was obtained from the subjects. The information included age, gender, educational status, socio-economic status, religion, and area of residence. Information related to clinical profile included the age at onset of symptoms and at diagnosis, number of relapses and number of hospitalizations in last one year, and clinical parameters such as height (cm), weight (kg), BMI, and PFT reports, etc. The validity and reliability of the tools were established prior to their administration.

PHQ-9

PHQ-9 was selected based on the recommendations of the international committee on mental health in CF (ICMH-CF) 2016.²⁰ PHQ-9, a self-report questionnaire consists of 9 items, which corresponds to 9 symptoms of major depressive disorder criteria of the diagnostic and statistical manual of mental disorders in which adolescents with CF reported about 'how often they had been bothered by problems' over past 2 weeks.¹⁸ The items were answered on 4-point Likert scale (0=not at all, 3=nearly every day). The total depression score ranged between 0-27. The severity of depressive symptoms was categorized as none (0-4), mild (5-9), moderate (10-14), and severe (20-27).²¹

Ways of coping with CF

Ways of coping with CF is a CF-specific questionnaire, having 20 items. Subjects responded to the stated coping strategies on a 4-point Likert scale (1-4). There were 7 statements for 'optimistic acceptance', 6 for 'hopefulness', 5 for 'distraction', and 2 statements for 'avoidance' in the questionnaire. The scores were adjusted to a scale of 0-100 for each of the four given coping strategies. Higher scores indicated more frequent use of the coping strategy and vice versa. Similarly

higher mean score for individual coping strategy represented more frequent use of individual coping style.

Statistical analysis

Each patient was given an identification number and recorded on the data collection forms. The collected data were coded and summarized in master data sheet using Excel spreadsheet. Data analysis was done by statistical program SPSS 20.0 ver. using descriptive and inferential statistics. Frequency, percentage, mean, standard deviation, and range were calculated in descriptive statistics. Chi-square test was used to explore the association of selected clinical variables on depression. The level of significance was considered as $p < 0.05$.

RESULTS

Study population

Majority of 20 (66.7%) adolescents were boys with the mean age of 14.90 ± 2.09 years. More than half of the subjects, 18 (60%) adolescents had studied up to secondary level, and 16 (53.3%) belonged to nuclear families. About 15 (50%) adolescents with CF belonged to upper-middle class and above categories, 26 (86.7%) following Hindu religion, and 28 (93.3%) resided in urban areas. Most of the patients, 26 (86.7%) had no history of CF in siblings. Majority of the adolescents, 24 (80%) had early onset of symptoms at the age less than 3 months. Majority of patients 22 (73.3%) did not experience any relapse in last 1 year. A total of 6 (20%) were hospitalized at least once in last 1 year. Twenty (66.6%) of subjects had mild to severe depression. Significant number of adolescents were severely affected in terms of being underweight (53.3%), stunted (46.7%), and wasted (40%) (Table 1 and Figure 1).

Table 1: Sociodemographic and clinical profile of adolescents with CF, (n=30).

Variables	Frequency (%)
Age (years)	
Mean (SD)	14.90 (2.09)
Gender	
Male	20 (66.7)
Female	10 (33.3)
Type of family	
Nuclear	16 (53.3)
Joint	14 (46.7)
Socioeconomic status (Kuppuswamy, 2019)	
Upper	3 (10.0)
Upper middle	12 (40.0)
Lower middle	11 (36.7)
Upper lower	4 (13.3)
Lower	0 (0)
Religion	
Hindu	26 (86.7)
Muslim	4 (13.3)
Area of residence	
Rural	2 (6.7)
Urban	28 (93.3)
Age at time of diagnosis (years)	
<1	7 (23.3)
1-3	6 (20.0)
>3	17 (56.7)
Age at onset of symptoms (months)	
≤3	24 (80.0)
>3	6 (20.0)
Disease severity	
Normal (FEV ₁ >100% predicted)*	2 (6.7)
Mild (FEV ₁ 70-100% predicted)	7 (23.3)
Moderate (FEV ₁ 40-69% predicted)	11 (36.7)
Severe (FEV ₁ <40% predicted)	10 (33.3)

* FEV₁ (predicted value).

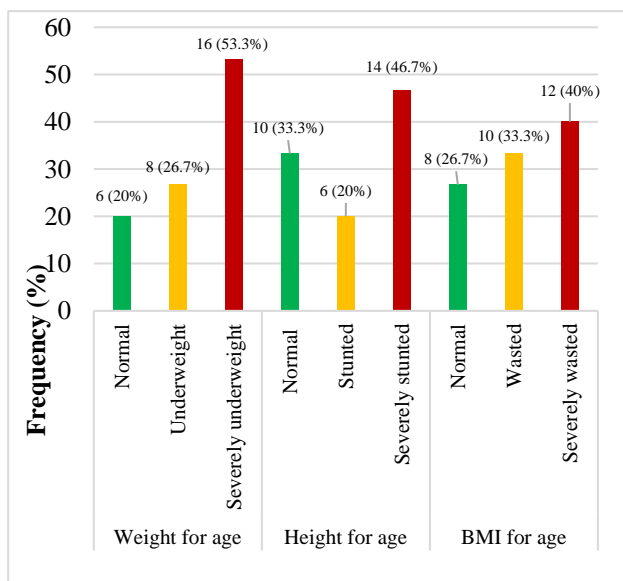


Figure 1: Nutritional status of adolescents with CF, (n=30).

Prevalence of depression

The mean depression score of CF patients was 7.73 ± 5.83 (0-21). About seventy percent of subjects had depression varying from mild to severe. There was statistically significant difference between depression among boys and girls ($p = 0.005$). Boys had more depression of mild to moderate type while girls had moderate-severe to severe depression (Table 2).

Coping strategies among patients with CF

More frequently used coping strategies by adolescents was hopefulness (76.66 ± 11.29), followed by optimistic acceptance (70.23 ± 13.04) and avoidance (62.08 ± 22.85), while relatively less frequently used was distraction (54.78 ± 15.47). More frequently used coping strategies by girls as compared to boys were ‘hopefulness’ (82.49 ± 9.78 vs. 73.74 ± 11.07 , $p = 0.04$) ‘optimistic acceptance’ (73.20 ± 12.29 vs. 68.74 ± 13.45) while less frequently used

coping strategy in both boys and girls was ‘distraction’. (Table 3).

Table 2: Estimated prevalence of depression among patients with CF, (n=30).

Level of depression (PHQ-9 score)	Frequency (%)			P value
	All	Boys	Girls	
No, (0-4)	10 (33.3)	5 (25)	5 (50)	0.005*
Mild, (5-9)	9 (30.0)	9 (45)	0	
Moderate, (10-14)	7 (23.3)	6 (30)	1 (10)	
Moderate severe, (15-19)	2 (6.70)	0	2 (20)	
Severe, (20-27)	2 (6.70)	0	2 (20)	
Mean	7.73	6.6	10.0	
SD	5.83	3.5	8.5	
Range	21	12	21	

*Chi-square test, p<0.05

Table 3: Coping strategies used by patients with CF, (n=30).

Coping strategy	Mean scores (SD)			P value
	All	Boys	Girls	
Optimistic acceptance	70.23 (13.04)	68.74 (13.45)	73.20 (12.29)	0.38
Hopefulness	76.66 (11.29)	73.74 (11.07)	82.49 (9.78)	0.04*
Distraction	54.78 (15.47)	51.92 (14.57)	60.50 (16.40)	0.15
Avoidance	62.08 (22.85)	62.50 (21.45)	61.25 (26.64)	0.89

Independent sample t-test, p<0.05

The more frequently used individual coping strategy was ‘I have confidence in the doctors and treatment’ (3.83±0.37), followed by ‘I’m looking forward to a time in the future when it will be better’ (3.77±0.56), while less frequently used individual coping strategy was ‘I cry, eat, drink or take drugs’ (1.60±1.00) (Figure 2).



Figure 2: Mean coping strategies as used by CF patients, (n=30).

Table 4: Association between selected sociodemographic and clinical variables with depression.

Variables	Depression (%)	Chi-square value	P value
Gender			
Male	15 (75)	1.875	0.171
Female	5 (25)		
Type of family			
Nuclear	9 (45)	1.674	0.196
Joint	11 (55)		
Kuppuswamy SES (2019)			
Upper	2 (10)	4.261	0.235
Upper middle	8 (40)		
Lower middle	9 (45)		
Upper lower	1 (5)		
Religion			
Hindu	17 (85)	0.144	0.704
Muslim	3 (15)		
Residence			
Rural	2 (10)	1.071	0.301
Urban	18 (90)		
Age at time of diagnosis (years)			
<1	6 (30)	1.613	0.446
1-3	4 (20)		
>3	10 (50)		
Age at onset of symptoms (months)			
<3	15 (75)	0.938	0.333
≥3	5 (25)		
Disease severity			
Normal	1 (5)	6.758	0.80
Mild	2 (10)		
Moderate	9 (45)		
Severe	8 (40)		
Height for age			
Normal	5 (25)	4.286	0.117
Stunted	3 (15)		
Severely stunted	12 (60)		
Weight for age			
Normal	3 (15)	6.938	0.03*
Underweight	3 (15)		
Severely underweight	14 (70)		
BMI for age			
Normal	4 (20)	2.700	0.259
Wasted	6 (30)		
Severely wasted	10 (50)		

*p<0.05

Association between selected sociodemographic and clinical variables with depression

None of the selected sociodemographic and clinical variables showed significant association with depression except weight for age (p<0.05) (Table 4).

DISCUSSION

Major findings of the study suggest that depression is a common problem affecting adolescents with CF in varying intensity. Boys had milder to moderate type of

depression, while girls had moderate-severe to severe type. More frequently used coping strategies were hopefulness followed by optimistic acceptance by adolescents in general and specifically by girls.

The prevalence of depression in adolescents with chronic diseases is reported to be high and associated with significant morbidity and mortality.^{4,7,10,22,23} In adolescent phase of life, children begin to understand the chronic nature of the disease and the involved financial implications. In the present study, about two-thirds of adolescents with CF had depression of varying intensity

among boys and girls; most affected with moderate-severe to severe type. Additionally, due to the lack of support from health care facilities for all chronic illnesses, there is significant economic burden and emotional stress on the family and the child. Information on the prevalence of depression in children with CF from countries like India where CF is an emerging illness is scarce. Studies reported from other parts of the world report depression from 3.3% to 29%. Smith et al in their study on American CF patients aged between 7-17 years reported depressive symptoms in 28% enrolled subjects.⁵ Catastini et al had found the prevalence of depression to be 6.1% in Italian adolescent CF patients.⁴ Modi et al in their study on 59 adolescents/young adults with CF (Mean age 15.8 years) registered at Cincinnati children's hospital observed that 3% of adolescents/young adults had clinically elevated depressive symptoms but 32% exhibited clinically elevated anxiety symptoms.⁸ Duff et al in their study on UK adolescents and adults with CF reported low levels of depression scores but higher levels of anxiety scores.⁹ Ploessl et al in their retrospective study on 190 (mean age 14.5 years those with depression and 11.6 years in those without depression) participants registered in Riley hospital for children at Indiana university health reported 9% depression in enrolled subjects.⁹

Early detection and management of depression are essential for improving treatment adherence and health outcomes among adolescents with CF.²³ The international committee on mental health in CF (ICMH-CF) recommends regular screening of adolescents with CF for depression and early referral for its management. In the present study, the researcher used PHQ-9 as a screening tool for depression and referred affected children with moderate-severe to severe depression to experts.

In the present study, hopefulness as a coping strategy was used more in comparison to optimistic acceptance, while distraction and avoidance were less used. Having confidence in doctors and treatment was the individual coping strategy reported by the adolescents with CF as well. Use of a coping strategy such as hopefulness, may be a good option for adolescent CF in short run, but in the long run optimistic acceptance of the disease helps patients in better adjustment, hence should be ideally promoted. In contrast to the present study findings, a study done by Askew et al in young adult CF patients, reported that the majority of patients had made use of optimistic acceptance.²⁴ Adolescents with CF should bank upon positive coping strategies such as optimistic Acceptance, which would enhance their self-esteem, increase their productivity and quality of life. Having confidence in treating physicians and treatment is a delightful coping strategy, which needs to be reinforced as that would improve their treatment adherence. Further, it would help them in better psychological adjustments and dealing with depression. At the same time use of avoidance as a coping strategy should be discouraged as this would lead them to a world away from reality.²⁴

In this comprehensive study, we have used standardized CF-specific self-report questionnaire, which may give some insight to the health care team about the psychosocial problems faced by adolescents with CF. We are aware that small sample size and single-center study limits the generalizability of the study. Risk of selection bias because of purposive sampling and self-report bias cannot be ignored. In future studies, patients from different CF centers with large sample size is warranted to explore the coping strategies used by these adolescents.

CONCLUSION

Depression is a common problem among adolescents with CF that requires regular screening and referral to experts for enhancing their coping strategy of optimistic acceptance.

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Conflict of interest: None declared

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