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ORIGINAL ARTICLE

Prevalence of Depression among Caregivers of Indian Children with Cystic Fibrosis

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Abstract

Objective To study the prevalence of depression among caregivers of children with cystic fibrosis and its impact on the health and well being of these children.

Methods This cross-sectional study was conducted in a tertiary care hospital from September 2015 through August 2016. Forty one parents of children receiving treatment at the Cystic fibrosis (CF) clinic were approached to be part of the study. Six families declined the request resulting in 85% recruitment rate. The Centre for Epidemiological Studies Depression Scale (CES-D) was used to assess depression score among caregivers. The CES-D provides clinical cut-off scores of ≥16 that help in identifying persons at risk for depression. CES-D was completed by the parent closely associated with care of the affected child. Main outcome measure was to find the number of caregivers of patients who has score of ≥16 on CES-D scale, and its effect on growth and respiratory exacerbations of the affected child.

Results A total of 23 fathers and 12 mothers participated in the study. The mean age of male and female caregivers was 30.9 ± 5.4 and 27.8 ± 4.7 y respectively. Eighteen (51.4%) caregivers scored above the clinical cut-off on the CES-D in the index study with mean score of 22.0 ± 4.0. The mean CES-D score among non-depressive caregivers was 7.76 ± 4.2. Significant negative association was found between parental depression and child's health. Children with high parental CES-D score suffered significantly more respiratory exacerbations (3.83 ± 1.2 episodes) in last six months than parents with low CES-D score (2.18 ± 1.28 episodes) (p value = 0.00). Similarly, stunting was more commonly seen in patients with high caregiver CES-D score (15 *vs*. 7; P value = 0.01).

Conclusions A very high prevalence of caregiver depression was found in cystic fibrosis, which negatively impacted care and well being of the affected patients. Depression was more common in families with poor economic and education level.

Keywords Cystic fibrosis · Caregiver depression · CES-D scale

Introduction

Cystic fibrosis (CF) is an autosomal recessive multisystem disease and is the most common fatal genetic disorder among Caucasian populations. It is relatively less common among Africans and Asians [1]. The incidence of Cystic fibrosis in our country is not known due to lack of proper registration system; however, it is not uncommon in this part of the world. The study conducted by Kabra et al. [2] reported a 3.5% incidence of cystic fibrosis among total children attending Pediatric Chest Clinic. Although better understanding of disease pathophysiology in recent times has led to increases in lifespan, Cystic fibrosis continues to be one of the most difficult chronic conditions to manage, with very high mortality in untreated patients [3]. Caring for a child with a chronic, life consuming disease can be profoundly distressing to the parents. Numerous studies have demonstrated that parents of children with chronic diseases are at an increased risk for depression [4–6]. Furthermore, poor family income, less years of education makes them even more susceptible to this condition. This can seriously compromise the optimal management of these patients due to a multitude of reasons like change in interpersonal relations, increased conflict rate and decreased caregiver

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availability to the child. Individuals with cystic fibrosis and caregiver depression have a greater risk of exacerbation with more frequent hospitalizations and growth faltering. A recent study by Barker et al. [7] observed that depression in caregivers of children with cystic fibrosis negatively impacted treatment adherence in these children, which in turn, compromised their growth velocity. Similarly Smith et al. [8] in their study found that child depressive symptoms had a significant negative association with their adherence to airway clearance. Kashmir is the northern most area of the Indian subcontinent and cystic fibrosis is a common disease here [2] due to high prevalence of consanguinity. The patients are managed in a dedicated cystic fibrosis clinic. Poor drug compliance is commonly seen in these patients. The present study was conducted to assess prevalence of depressive symptoms among caregivers of children between 2 mo to 12 y of age with cystic fibrosis. The secondary objective was to study the association of caregiver depressive symptoms on growth and respiratory exacerbations in affected children.

Material and Methods

This was an outpatient department based cross sectional study, conducted from September 2015 through August 2016 in the Department of Pediatrics, Sher-i-Kashmir Institute of Medical Sciences, Srinagar. Eligibility criteria included (1) diagnosed cases of cystic fibrosis (2) Patients on regular follow-up in cystic fibrosis clinic (3) Age between 2 mo and 12 y (4) Caregiver willingness to participate in the study. Caregivers with established mental illness before the diagnosis of CF in their child was made were excluded from the study.

Sample size calculation was done by using the G-Power 3.0.10 sample size calculating software. It is based on using Sample size formula for qualitative variable with presumed prevalence of depression in high risk group of 10% and power of 80% and alfa error of 0.05. Based on above assumption, sample size of 34 was calculated.

Forty one caregivers of children receiving treatment at the CF clinic were approached for the study. Six families declined the request resulting in 85% recruitment rate. Informed consent was obtained from all the caregivers. Majority of times only one caregiver accompanied the patients. Only in eight patients both parents were present; in such a case, caregiver most closely associated with care of the CF child was assessed. Demographic data like socioeconomic status, monthly income and level of education was obtained at the CF clinic from all the study participants. History of the number of respiratory exacerbations in the past six months was retrieved from electronic database created for CF patients. Clinical examination, including complete anthropometry was done in all studied patients at the time of enrollment in the study. The Centre for Epidemiological Studies Depression Scale (CES-D scale), a tool that has been in the public domain since 1977 [9] was used to assess depression score among caregivers. This is a 20-item measure that asks caregivers to rate how often they had experienced over the past week, symptoms associated with depression, such as restless sleep, poor appetite, and feeling lonely. Response ranges from 0 to 3 for each item. Scores range from 0 to 60, with high scores implying greater depressive symptoms.

The CES-D also provides clinical cutoff scores of ≥16 that help in identifying persons at risk for depression, with good sensitivity and specificity and high internal consistency. CES-D was completed by the caregiver closely associated with care of the affected child.

Statistical analysis was performed using SPSS 20. Normality of the data was checked by using Shapiro-Wilk test. Parametric data are expressed as mean ± SD and non-parametric data as median (IQR). Categorical variables are presented as percentages. Binary logistic regression was done to find variables that can significantly determine the chances of depressive symptoms among caregivers.

Results

Study participants included caregivers of 35 children aged 2 mo to 12 y of age. A total of 23 fathers and 12 mothers participated in the study. Mean age of male and female caregivers was 30.9 ± 5.4 and 27.8 ± 4.7 y respectively. Descriptive data for the study population are provided in Table 1. Eighteen (51.4%) caregivers scored above the clinical cut-off on CES-D in present study with mean score of 22.0 ± 4.0. Mean CES-D score among non-depressive caregivers was 7.76 ± 4.2 (Table 2).

Table 1 Child and caregiver demographic characteristics

Child	
Age (months), Median(IQR)	32.0 (44)
Weight (Kg), Median (IQR)	12.0 (7.2)
Height (cm), Median (IQR)	85.0 (35.0)
Female, n(%)	20 (57.1)
Rural: Urban	2.1:1
Consanguinity, n(%)	21 (60)
Caregiver	
Education	
High school, n(%)	21 (60.0)
College, n(%)	10 (28.6)
University, n(%)	4 (11.4)
Median monthly income (INR)	20,000 (50000)
Mean monthly expenditure	2442 ± 811
Mean Depression Score (mean ± SD)	15 ± 8.2

A significant negative association was found between caregiver depressive symptoms and child's health. Children with high caregiver CES-D score suffered significantly more respiratory exacerbations (3.83 ± 1.2 episodes) in last six mo than caregivers with low CES-D score (2.18 ± 1.28 episodes) (p value = 0.00). The sputum culture/pharyngeal culture during respiratory exacerbations was done in 71% of total exacerbations. In 50.6% (38) of exacerbations, no organism was found on sputum/pharyngeal culture. In thirty seven episodes of respiratory exacerbation specific organism was isolated which included *Pseudomonas aeruginosa* (33.3%), *Staphylococcus aureus* (10.7%), *E-coli* (2.7%), *Klebsiella pneumoniae* (1.3%) and *Burkholderia capcea* (1.3%). Though the Pseudomonas colonization was more frequent in patients with high caregiver depressive symproms, the difference was statistically insignificant. Total hospitalization rate was more among patients with high caregiver depressive symptoms (12 *vs*. 6), however the difference was not statistically significant (P = 0.508, OR = 0.688). Stunting was significantly more common in patients with high caregiver CES-D score (15 *vs*. 7; P value = 0.01).

Binary logistic regression was performed to ascertain the effects of monthly family income, caregiver education level and residence (rural/urban) on the likelihood of depressive symptoms among caregivers. The logistic regression model was statistically significant ($\chi 2 = 15.6$, p 0.004). The model explained 48.1% (Nagelkerke R2) of the variance in caretaker depressive symptoms and correctly classified 82.9% of cases. An increase in monthly income was seen to be associated with a decrease in the likelihood of caretaker depressive symptoms.

Discussion

This study indicates that depressive symptoms are highly prevalent among caregivers of children with Cystic fibrosis. The depression rate in the general adult population is approximately 13.2% [10]. The authors found that about 51.4% of caregivers in present study scored above the clinical cut-off on the CES-D scale which is significantly higher than the general population. In a recent multi-country study (TIDES study), about one-third of caregivers of CF patients scored in clinically depressed range [5].

The Center for Epidemiologic Studies Depression Scale (CES-D), a self-report depression scale was used for screening for depressive symptoms in present study because of its ease of administration and because it is less time consuming. It has been widely used in population surveys across the world and has a satisfactory level of reliability and validity in numerous cultures [9, 11]. In the present study, a universal cut-off point of 16 was employed, since it most effectively detects and covers "probable" depression symptoms [12].

The authors found a significant association between caregiver depressive symptoms and number of respiratory exacerbations and frequency of stunting in affected children. Children with higher caregiver CES-D score were more frequently stunted and had a higher frequency of respiratory exacerbations in last six months. This is a significant observation, as the optimal outcome of Cystic fibrosis is mainly dependent on active involvement by caregivers. The results of this study are consistent with previous studies where caregiver depressive symptoms were associated with decreased adherence to enzyme regimens [7] as well as airway clearance [8]. The elevated rates of caregiver depressive symptoms highlights the significance of routine screening for depressive symptoms in caregivers. An association of caregiver depressive symptoms with poor health outcomes of affected CF patients strongly suggests that the mitigation of depressive symptoms will also bring an improvement in the management of CF patients.

The authors performed a binary logistic regression model to determine variables which can predict likelihood of depressive symptoms among caregivers. They found monthly income and education level as two important determinants of caregiver depressive symptoms. People with lower income were having significantly higher CES-D score. Similarly, CES-D score was higher in caregivers with lower education levels.

Conclusions

A very high prevalence of depressive symptoms was found in caregivers of children with Cystic fibrosis and this affected the optimal disease management. Depressive symptoms were more common in families with poor economic and educational level. Given the high prevalence of depressive symptoms and its negative effects, authors propose a routine annual screening of caregivers for symptoms of depression. When caregivers screen positive for depressive symptoms, effective treatments should be offered either at the CF clinic, for milder symptoms, or via referral to a psychiatrist for more severe or

Table 2 Outcome of patients in relation to caregiver depression

	Caregiver depression present (18)	Caregiver depression absent (17)	P value
Respiratory exacerbations (mean ± SD)	3.83 ± 1.2 episodes	2.18 ± 1.28 episodes	0.000
Stunting n(%)	15(51.4)	7(41.1)	0.01

chronic depression. Effective communication between the specialty clinic and the psychiatrist is important to ensure an optimal management of these patients.

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Author Contributions JIB: Conducted the study; AAA: Analyzed the data; BAC: Drafted the manuscript; WAW: Collected the data; SWA: Made critical analysis and will act as gurarntor for this paper; QIA: Reviewed the manuscript.

Compliance with Ethical Standards

Conflict of Interest None.

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