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The relationship between the burden of care and fear of disease progression in mothers of children with cystic fibrosis

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***Abstract*---**Objectives: Aim of this study was determining the relationship between burden of care and fear of disease progression in mothers of children with cystic fibrosis. Methodology: 142 mothers of children with cystic fibrosis (CF) participated in this correlational study. Data were collected with sequential method. The researchers employed the self-report Zarit burden of care and fear of disease progression questionnaire in parents of children with CF. Mothers answered the questioners separately. Data were analyzed with statistical analysis of variance and independent t-test. Results: According to the results, the mean maternal burden of care was 34.12 ± 69.77, and the mean fear of disease progression was 32.12 ± 92.11.

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The burden of care had the highest regression effect on fear of disease progression in mothers of children with CF (β = 0.896). With an increase of one unit of standard deviation in the burden of care, an increase of 0.896 units occurred in fear of disease progression in parents of children with CF. Conclusion: Mothers of children with CF experience a moderate burden of care and fear of disease progression. An increase in the burden of care and psychological stress increases the fear of disease progression in these mothers.

***Keywords*---**burden of care, fear of disease progression, mother, cystic fibrosis.

Introduction

Cystic fibrosis (CF), an autosomal recessive disorder, is one of the most common and threatening diseases that newborn screening can detect. Significant progress has recently occurred in the treatment of CF patients, and their life expectancy is currently about 40 years (1). The lungs are the most important organ involved in people with CF, and more than 95% of deaths from this disease are due to lung involvement. The disease is associated with recurrent periods of respiratory infection and progressive deterioration of lung function, clinically accompanied by increased airway secretion (2). Having a child with a chronic illness imposes significant challenges on caregivers. Parents of children with CF take the role of a caregiver and provide disease-related care for the child, in addition to their parental duties. Once a child is diagnosed with the disease, many responsibilities are simultaneously assigned to their parents. Medication use, treatment management, and monitoring a child's physical condition are among the tasks they must perform, in addition to routine parental responsibilities (3). Challenges for caregivers of children with CF include uncertainty in the progression of the disease, financial problems due to direct and indirect treatment costs, adherence to a complex treatment schedule, frequent visits to healthcare centers for periodical visits, disruption in the family life because of frequent hospitalizations of the child, and the dependence of the family situation on the change in the child's health status. On the other hand, due to the autosomal recessive transmission of the disease, the parents of these children feel guilty, which affects their decisions to have another child (4, 5)

Early childhood is a significant time to optimize growth in patients with CF. For example, nutritional interventions at age four increase their survival at age 18. Adhering to nutritional guidelines has been challenging for parents of toddlers and preschoolers with CF. They find it challenging to achieve nutritional goals in these children, because certain eating behaviors prevent high-calorie absorption and energy increase at this age (6). Many studies have identified the preschool-year infection as a critical period of the onset of lung structural change (7). The long-term burden of care of a child with a chronic disease, especially a life-threatening or progressive one, imposes a range of psychological, emotional, social, physical, and financial problems upon the family, especially the primary caregiver. Studies have shown that mothers of children with CF suffer degrees of anxiety and depression. They experience a lower quality of life and higher stress compared to the fathers (3, 5).

First, the researchers discussed the fear of disease progression in parents of children with cancer. Evidence shows that fear of disease progression in these mothers is significant, and about 40% of these mothers have fear-induced clinical manifestations. However, Clever, Schepper, et al. (2018) believe that only a few care team members have paid attention to this issue and made interventions to assess and treat it. Fear of disease progression is certainly not limited to life-threatening diseases (8). According to Fidika, Herle, et al. (2015), this issue has received less attention, although caregivers of children with chronic diseases, especially life-threatening ones, also experience it during the disease process (9). In addition, Besier, et al. (2011) found that parents of children with CF are greatly concerned about their children’s future and have a fear of disease progression, as well (10). Schepper, Abel, et al. (2015) assert that fear of disease progression differs from anxiety because it occurs in the disease and treatment process (11).

Various studies have investigated the fear of disease progression in adults with cancer and other chronic diseases and their spouses (12, 13). However, there is insufficient information regarding this fear in the caregivers of children with chronic progressive diseases, especially CF (9). This disease seriously affects the lifestyle of mothers of these children, along with their physical and mental health, compared to those with other respiratory problems (such as childhood asthma). On the other hand, depression, anxiety, and family dysfunction may also reduce their adherence to treatment in the long run and endanger the health of these children (14, 15). Few researchers have worked on this issue; hence, we decided to conduct this study to determine the relationship between fear of disease progression and the burden of care in mothers of children with CF.

Methods

The participants of this correlational study included 142 mothers of children with CF. They were members of the Cystic Fibrosis Foundation and referred to the pulmonary ward and cystic fibrosis clinic of the Children's Medical Center. The researcher used a continuous sampling method and invited eligible people to participate based on the inclusion criteria. Inclusion criteria encompassed a mother whose child was diagnosed with CF and treated at least six months ago, who was the primary caregiver, who had the minimum literacy, who didn’t take care of another family member with a chronic physical or mental illness, and who didn’t suffer from a mental illness based on self-report.

Sample size

The sample size was estimated at 142, considering the variables of fear of disease progression (Manafi & Dehshiri, 2017) and maternal burden of care (Valizadeh, Joonbakhsh, et al., 2014) at a 95% confidence interval with an accuracy of 1 after quantification in the sample size formula. The standard deviation of the burden of care based on the mentioned article was 6.

$$N = \frac{z^2 \times S^2}{D^2} = 142$$

Instrument

To collect data, the researcher employed a questionnaire consisting of three sections. The first part included questions on the demographic information of mother and child (child's age, sex, duration of illness, frequency of hospitalizations, mother's age, job, the current condition of her occupation, and education). The second part included the Zarit burden interview with 22 questions to assess mothers' burden of care (Zarit et al., 1980). The caregiver completes it, and the answer to each item is scored as never (0), rarely (1), sometimes (2), quite frequently (3), and nearly always (4). The sum of the scores earned by each caregiver determines one's burden of care. Scores below 20 show little or no burden, 21 to 40 present mild to moderate burden, and 41 to 88 exhibit severe burdens. The score of each person ranges from zero to 88. According to Zarit et al. (1980), higher scores indicate a higher burden of care. The three domains of this questionnaire include psychological stress, role-playing stress, and competence and expectations (Zarit, Reever, et al. 1980; Mahmoudian, Shamsalinia, et al., 2021)

The fear of disease progression questionnaire for patients is a self-report questionnaire originally developed by Herschbach .They assessed its psychometric characteristics to measure fear in chronic diseases, e.g., diabetes, rheumatoid arthritis, and cancer (16). Fidika et al. (2015) assessed the psychometric properties of the fear of disease progression for parents of a child with CF and approved its ability to measure the fear of disease progression in the parents of these children. This questionnaire consists of 16 questions on a 5-point Likert scale (never, rarely, sometimes, often, always). The scores were calculated considering never = 0, rarely = 1, sometimes = 2, often = 3, and always = 4. In every question, never means not having fear and always means having the highest level of fear. The researchers calculated the frequency of answers to each question in the Likert scale (never, rarely, sometimes, most of the time, always) and reported the mean and standard deviation. In addition, they calculated and reported the total score of this instrument with mean (SD)(9).

According to Fidika et al. (2015), the fear of disease progression questionnaire for parents has high internal consistency (Cronbach's alpha = 0.95), and also the reliability index through test-retest after over one week was high (r = 0.94). The internal consistency coefficient of the burden of care ranges from 0.094 to 0.85(17). According to Hébert et al. (2000) and Higginson et al. (2008), Cronbach's alpha of Zarit burden of care questioner was 0.85 in the caregivers of patients with cancer (18). The present study measured the instrument's reliability using the internal consistency coefficient after 10 mothers of children with CF completed the questionnaire. The internal consistency coefficient of burden of care and fear of disease progression were α = 0.872 and α = 0.881, consecutively. Researcher referred to the Cystic Fibrosis Foundation and performed the sampling after obtaining permission. She went to the hospital's Cystic Fibrosis Clinic every Thursday from 8 to 13 to collect information. She also intermittently went to the hospital's Pulmonary Ward and the Cystic Fibrosis Foundation during the week. Sampling was performed continuously between November 28, 2019 and February 27, 2020.

After obtaining informed written consent from the participants, the researcher gave them the questionnaire to complete in a private environment. She was present during the questionnaire completion to provide them with further information on their demand. After each participant completed the questionnaire, she skimmed through it, and if it was incomplete, she asked them to complete it so that no question remained unanswered. The researcher performed the process of sampling and completing the questionnaires individually to prevent bias and the mothers' exchange of views. The frequency, mean, standard deviation, Pearson correlation test, and linear regression test, Multiple regression test (Step wise) were used for analyzing the data with the significance level of 0.05.

Results

Demographic characteristics of mothers and children with cystic fibrosis showed in table 1.

Table 1
Frequency of demographic characteristics of parents of mothers and children with cystic fibrosis

Variable			N (%)
Mother	Age (year)	<25	10 (7)
		25-35	86 (60.6)
		< 35	46 (32.4)
	Mean ± SD	33.31± 6.54 years	
	Job	Employee	19 (13.4)
		Self-employed	11 (7.7)
		Housewife	112 (78.9)
	Education level	High school dropout	44 (31)
		Diploma	67 (47.2)
		University degree	31 (21.8)
Children	Sex	Boy	72 (50.7)
		Girl	70 (49.3)
	Age (year)	1-2	51 (35.9)
		3-4	91 (64.1)
	Mean ± SD	2.83 ± 1.06 years	
	Diagnosis time (Month)	6-8	98 (69)
		9-12	22 (15.5)
		13-24	22 (15.5)
	Having siblings	No	56 (39.4)
		Yes	86 (60/6)
	FVC	normal	48(33.8)
		mild	40(28.2)

		moderate	38(26.8)
		severe	11(7.7)
		very severe	5(3.5)
	Mean ± SD	73.21± 10.71	

The most general burden of care on parents is related to their concerns about the child's future (3.52), their concern about the inability to take care of the child (3.40), and the costs and expenses imposed on the family due to the disease (3.11). Regarding the fear of disease progression, the greatest fear related to items including if I can stop my child's disease progression by doing these treatments (3.2), when I think my child's disease is progressing, I become anxious (3.16), and I am afraid of my child suffering from pain (3.15). The least reported issue in response to questions about mothers' fear of progress was fear of being gradually pushed away by my family and friends (0.5). Frequency, mean, and standard deviation of burden of care and fear of disease progression in mothers showed in table 2.

Table 2
Frequency, mean, and standard deviation of burden of care and fear of disease progression in mothers of children with cystic fibrosis

The burden of care Level		N (%)	Mean± SD
Role playing stress	Low (0-13)	54 (38)	16.7±66.57
	Moderate (14-27)	73 (51.4)	
	High (28-40)	15 (10.6)	
Psychological stress	Low (0-8)	22 (15.5)	5.99±4.97
	Moderate (9-17)	112 (78.9)	
	High (18-28)	8 (5.6)	
Competences and expectations	Low (0-6)	5 (3.5)	12.02±2.67
	Moderate (7-13)	98 (69)	
	High (14-20)	39 (27.5)	
Total burden of care	Low (0-20)	13 (9.2)	34.12± 69.77
	Moderate (21-40)	95 (66.9)	
	High (42-88)	34 (23.9)	
Fear of disease progression	32.92± 12.11		

According to the results illustrated in Table 3, there was no significant relationship between the burden of care and fear of disease progression with the demographic characteristics of mother and child.

Table 3
Mean and standard deviation of burden of care and fear of disease progression in terms of demographic variables of mothers and children with cystic fibrosis (n = 142)

Fear of disease progression and burden of care Demographic variables			Fear of disease progression	Statistical Test	Burden of care	Statistical Test
			Mean± SD		Mean± SD	
Mothers	Age	> 25	37±13.20	F=0.617 P=0.541	34.80± 11.74	F = 0.777 P = 0.642
		25-35	32.59 ±11.90		33.67±11.98	
		> 35	32.82±12.37		36.58± 14.38	
	Job	Employee	36.47± 16.02	F=1.500 P =0.27	39.42± 13.37	F = 1.645 P = 0.197
		Self-employed	28.72± 4.98		32.09±6.17	
		Housewife	32.72±11.77		34.15±13.04	
	Education level	high school dropout	30.04± 12.96	F=2.607 P =0.077	35.68±12.79	F = 0.396 P = 0.674
		Diploma	33.19± 11.26		33.68±11.61	
		University degree	33.28±11.87		34.29± 11.6	
Children	Age (Year)	1-2	36.41± 12.01	T =0.256 P = 0.799	35.48±15.21	T =0.256 P = 0.779
		3-4	37.75± 12.30		34.92± 13.64	
	Sex	Girl	33.08± 10.51	T =0.160 P= 0.837	35.25± 12.59	T =0.522 P= 0.603
		Boy	32.75± 13.63		34.12± 13.02	
	Disease duration (month)	6-8	31.62± 11/10	F=1.851 P =0.161	34.52± 11.59	F = 1.743 P = 0.179
		8-12	35.59± 14.03		31.54± 13.18	
		13-24	36.04±13.87		38.62± 16.56	
	FVC	Normal	31.06± 12.28	F=3.037 P =0.036	32.08± 13.13	F=3.543 P =0.024
		Mild	33.12± 11.92		34.45± 8.82	
		Moderate	34.39± 13.81		34.20± 6.41	
		Sever	36.45± 6.94		37.07± 10.38	
		very sever	36.80± 6.83		38.68± 5.76	

F = Analysis of Variances
T = Independent t-test
P = 0.05

Pearson correlation test showed a positive and strong relationship between burden of care and its domains with fear of disease progression in parents of children with CF (*P* <0.01). A stepwise multiple regression test was performed to investigate the relationship between burden of care and its domains with fear of disease progression. Burden of care entered in four models. In the first model, it explained 53% of the changes in fear of disease progression. Psychological stress was also included in models 2 to 4, respectively, and finally, it explained 71% of the changes in fear of disease progression in parents of children with CF (Table 4).

Table 4
The final regression model (the fourth model) of the effect of demographic and care burden variables on the fear of disease progression

Variable	Beta coefficient (β)		Std. error	T	P value	Confidence interval 95%	
	Non standard	standard				Lower	Upper
Constant	-1.759	-	7.057	-0.249	0.804	-15.853	12.335

Burden of care	1.288	0.896	0.165	7.786	<0.001	0.624	1.284
Psychological stress	1.551	0.534	0.465	3.333	0.001	0.622	2.481
Mothers age	-0.360	-0.142	0.172	-2.091	0.040	-0.704	-0.016
Summary of the 4th model	F = 39.751 P< 0.001		R-square = 0.710		adjusted- R-square = 0.692		
Dependent variable: fear of disease progression In Dependent variable: Demographics criteria							

The results indicate that the burden of care of psychological stress had a significant predictive ability for fear of disease progression in parents of children with CF. The burden of care had the highest regression effect on fear of disease progression in these parents (β = 0.896). This means that by increasing one unit of SD in the burden of care, 0.896 units' increase occurs in fear of disease progression in these parents. According to the results, the psychological stress and age of mothers affected the fear of disease progression in parents of children with CF (β = 0.534, β = 0.142). In other words, one-unit increase in SD in psychological stress, results in 0.534 units increase in fear of disease progression in these parents.

Discussion

This correlational study aimed to determine the relationship between the burden of care and fear of disease progression in mothers of children with CF. It showed that they experience a moderate burden of care and fear of disease progression. The findings are consistent with the available evidence; that is, most studies have shown that mothers of children with chronic diseases, including mothers of children with CF, diabetes, sickle-cell anemia, experience a moderate burden of care when they are taking care of their children(14, 19-23). Consistent with the results of this study, others have reported the fear of disease progression in patients, parents, and survivors of chronic diseases (9, 24-29)

Tolerating a moderate burden of care in chronic illness can endanger the health of the caregiver and the child in the long run. Moreover, it reduces the mother's quality of life and affects her physical and mental health. According to the available evidence, the survival rate for people with CF has increased, and the average life expectancy of these children has reached over 35 years. However, the lung condition of the affected person worsens, advanced complications including endocrine involvement appear, their abilities constantly reduce, and the disease conditions become more complicated (2, 30-32). Consistent with the results of this study, several studies have reported moderate to severe fear of disease progression in patients, parents, and survivors of people with chronic diseases (25, 26, 28, 29). This is one of the paramount stresses in patients with cancer and other chronic progressive diseases such as CF and their caregivers. Parents of children with the progressive disease have to cope with a continuous threat in their lives that their children's disease is progressing despite adherence to treatment (9) .According to the results of this study, the greatest fear of these mothers was about not being able to stop the disease progression despite adhering to routine treatment. Although they hope for a better future, they live in a world of uncertainty and fear for the future(33). Fear of disease progression is associated with negative consequences, such as decreased family function, reduced quality of life, parental avoidance behaviors (lack of communication and insufficient coping), and the child's poor behavioral, social, and emotional coping (8).

As the results have revealed, the mother's fear of disease progression increased with an increase in the burden of care. Among the burden of care domains, there is a significant association between psychological stress and fear of disease progression in parents of children with CF in the regression model. In other words, an increase in psychological stress led to a rise in fear of disease progression. An increase in the burden of care and psychological stress can predict the severity of fear of disease progression in these mothers(26, 34). Studies in line with the results of this study have shown that fear of disease progression has a significant positive relationship with stress, anxiety, and depression (26, 28, 29, 35)

A study has shown that the burden of care level affects the child's health condition; on the other hand, the mother's concerns about the progression of the disease can surge the burden of care (36). Tolerating the psychological stress caused by the disease progression, change in living conditions, and gradual increase in the burden of care among these mothers due to the ongoing deterioration of their children's lung condition intensifies their fear of disease progression. In the long run, this disrupts the family system, especially the mother as the primary caregiver. Concerns about a child's disease progression or health status along with new stressors lead to loss of control over events, inefficient coping with the stressors, and difficulty regulating emotions(37) . The poor prognosis of this disease leads to increased burden of care, depression, and psychological stress, followed by increased fear of disease progression; this can lead to decreased adherence to treatment by the family and child (7, 38).

The burden of care and fear of disease progression cause anxiety, depression, lower life satisfaction, less adherence to treatment, and poor clinical outcomes for the child. Parents who experience greater fear of disease progression do not perform well in their caring roles. Early identification of parents who are under the pressure of fear of disease progression and prevention of events related to fear of disease progressions, such as a decrease in the burden of care and their psychological stress, can facilitate goal-oriented psychological and social care and make efficient use of limited resources (8). It seems that appropriate care interventions by health care providers to reduce psychological stress and the burden of care of these mothers can lessen their fear of disease progression.

Consequently, the findings suggest that a similar study be conducted on the mothers of children with CF to assess the fear of disease progression and the burden of care during the COVID-19 crisis, which can have a profound effect on the life of these children. Besides, other studies can study and identify other agents affecting the fear of disease progression. The mothers' dispersion in referring to Cystic Fibrosis Center and their absence in the Cystic Fibrosis Center or clinic of the medical center affected data collection. The sampling procedure lengthened, although the officials did their best to facilitate contact with the mothers.

Conclusion

Mothers of children with CF tolerate the burden of care and long-term fear of disease progression. An increase in the burden of care and psychological stress increases the fear of disease progression in these mothers. CF is a chronic illness with to long-term process, Caregivers of this children life is under a lot of stress and fears. Consider mental health of these mothers is one of important responsibility of Nurses and other health care providers.

Ethics approval and consent to participate

The Research Ethics Committee of Iran University of Medical Sciences approved the study with the ethics code 1398.531IR.IUMS.REC. Informed consent was obtained from all participants before fulfill the questionnaire.

Competing interests

The authors declared no conflict of interest.

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Authors' contributions

Conceptualization, methodology: Mahnaz Shoghi , Mohammadreza Modaresi, Somayeh Moazami Goudarzi; Data collection: Somayeh Mohamadi, Somayeh Moazami Goudarzi ; Writing – review & editing and funding acquisition and resources: Mahnaz Shoghi, Somayeh Mohamadi,; Data analysis and writing – original draft: Mahnaz Shoghi, Somayeh Mohamadi, Mohammadreza Modaresi ; Approval of final manuscript: Mahnaz Shoghi.

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