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Parenting Stress And Coping Strategies For The Parent Of Children With Cystic Fibrosis

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ABSTRACT

Background: Cystic fibrosis (CF) is an inherited autosomal recessive chronic disease affecting the body's mucus glands. Also, it mainly affects the respiratory and digestive systems and reproductive systems. Having a child with Cystic fibrosis (CF) is stressful for parents, as it requires the family to change their life to adopt an alternative lifestyle For their Child. To overcome the cons of Cystic fibrosis (CF) effectively, parents must have accurate and adequate information about the disease, treatment, and appropriate management.

Purposes: the study aims at exploring parenting stress and coping for the parents of Cystic fibrosis

children.

Material and methodology: the cross-sectional design was used between January and July 2019; a sample included 200 parents (106 mothers and 94 fathers aged 19 years or older) who have Cystic fibrosis (CF) Child and met the requirements of the inclusion criteria and agreed to take part, who attend health facilities. The following measures used were: the parenting stress index short form (PSI), the child coping health inventory for parents (CHIP), and the cystic fibrosis questionnaire-revised (CFQ-R).

Results: there is a significant association between parenting stress, coping strategies

(especially coping pattern II), and health-related quality of life for children with Cystic fibrosis (**CF)**.

Recommendations: Further research is needed regarding parenting stress and coping

strategies for parents of children with Cystic fibrosis and improving the quality of life for **cystic fibrosis** patients to provide more evidence-based findings.

Keywords: Cystic Fibrosis, parenting, parenting stress, coping

Introduction:

Cystic fibrosis is a fatal inherited autosomal recessive chronic progressive disease that affects the body's mucus glands. The average lifespan of individuals with CF has improved over the years. It used to be approximately six months, and it increased to 30 years (Davis, 2006), and recently, nowadays, it reached 50 years in some countries (Gonska & Ratjen, 2015).

Parents of a child with chronic illness are more exposed to parental stress than parents with healthy children—making them at a higher risk of illness-related parenting stress (Cousino & Hazen, 2013). Parents of children with a

chronic illness will inevitably experience high levels of parenting stress as they face additional challenges, more than typical caregivers, such as having more financial burdens and work roles, as well as having increased health care tasks for their child, including illness management, communications with a health care team, or counteracting the child's non-compliant behavior. In addition, there were sometimes parental guilt feelings with hereditary illness conditions. All the previous factors lead to maladaptive parenting (Pinquart, 2017).

Cystic fibrosis is a chronic disease, and No doubt that parenting a child with cystic fibrosis (CF) is a very stressful condition for parents, as it requires the family to change their life to adopt an alternative lifestyle to handle the child.

The role of parents in the management of CF is burdensome because of the daily demands required of them. The Parent's position involves an array of activities related to the nutritional needs of the child (high-fat and calorie diet, daily pancreatic enzyme replacement tablets (capsule), multi-vitamins and regular antibiotics, and ensuring airway clearance, as well as going through monthly hospital clinic appointments) (Sheehan, Hiscock, Massie, Jaffe, & Hay, 2014). The current study aimed to identify the relationship between parenting stress and coping strategies for parents of children with CF.

Materials & Methods

The cross-sectional descriptive study design was conducted between January 2019 and July 2019. The target population was all parents of children diagnosed with cystic fibrosis in Jordan. The study sample comprises parents aged 19 years or older with a child diagnosed with cystic fibrosis between 4 and 14 years. The parents attended the designated CF clinics. Parents were included in the study provided that: they have a child diagnosed with cystic fibrosis, the child's age is between 4 and 14 years old, the child does not have other chronic diseases, and finally, the child lives within a stable family (i.e., parents are not separated).

Sampling

According to Hair et al. (Multivariate Data Analysis, 7th Edition, 2010), the general rule is to have a minimum of 5 observations per variable (5:1), and an acceptable sample size would have ten observations per variable (10:1). For the current study, which has 12 variables, (15:1) was adopted. Therefore, 15 subjects * 12 variables, the needed sample is 180 subjects, 10% attrition rate (20 observations) was added (Hair et al.,2015); the total sample for the current study was 200 participants.

Because most parents prefer secrecy and avoid revealing family-related issues, and because of the stigma of inherited diseases in Jordanian culture, it was tough to recruit study participants. Convenience sampling was used in this study. The sample size was 200 parents (106 mothers, 94 fathers). One Parent (the mother or father) was enough for the interview.

Then the first step was to reach the target population in this study, and the second was to collect the required data. Participants were contacted during the duration of their child's admission to pediatric wards in the hospitals above or during their visit to outpatient clinics in the same hospitals.

Ethical considerations

Ethical approvals were obtained from the Committee on Ethics of Scientific Research and the Committee on Human Research Ethics at Jordan University of Science and Technology and the Jordanian Ministry of Health.

Before starting data collection, permissions from the administrators of the selected hospitals were also obtained. Parents were informed about the purpose of the study and were assured that their participation would be voluntary and that if they decided not to complete the questionnaire, they could withdraw from the study.

The participants were informed that the information collected would be anonymous and that no participant would be identified by their data. Only the principal investigator and the supervisors had access to the data.

Authors of the instruments (Questionnaires) were asked for their permission to use their work, and some tools were bought for this study.

Measures

1- **Demographic characteristics:** The demographic characteristics were of two parts: 1- the Parent's socio-demographic variables included; gender, age (years), educational level, family number, annual family income, the number of children with cystic fibrosis, and the number

Children are affected by other diseases. 2- The

socio-demographic variables for cystic fibrosis children were; the age and gender of the affected child, number of years of child treatment, the number of their admissions to the hospital (years), and the number of follow-up visits to outpatient clinics per month.

2- **The parenting stress index short form (PSI) (Abidin, 2012).** The 4th Edition of parenting stress index-short form by Richard R. Abidin (2012) is a 36-item measure of the source and magnitude of stress in the parent-child relationship. It is a self-report questionnaire that covers three domains deemed theoretically crucial in the experience of stress in parenting, and these domains are: Parental Distress (PD), Parent-Child Dysfunctional Interaction ((P-CDI), and Difficult Child (DC), all of these domains are combined to evaluate Total Stress. The interaction between the three domains influences parenting behaviors that will influence the child's outcomes, either positively or negatively, based on these behaviors (Abidin, 2012). Cronbach's alpha for the three domains respectively, are: (0.90), (0.89), (0.88), and for total stress (0.95) (Abidin, 2012). See appendix (1) for more information.

3- The child coping health inventory for parents (CHIP) (McCubbin et al., 1983). Child coping health inventory for parents was developed by Hamilton McCubbin, Marilyn McCubbin, Robert Nevin, and Elizabeth cable in 1981. It was developed to assess parents' appraisal of their coping responses to managing family life when they have a child member who is seriously or chronically ill. It is a self-report instrument consisting of a checklist of 45 specific behaviors. Each item is rated on a scale of zero to three, and it consists of three subscales:

1- Coping pattern I (family integration, cooperation, and an optimistic definition of the situation), 2-Coping pattern II (maintaining social support, self-esteem, and psychological stability), and 3- Coping pattern III (understanding the health care situation through the communication with other parents and consultation with the health care team) (McCubbin et al., 1983).

Cronbach's alpha for the three subscales of this instrument listed is 0.79, 0.79, and 0.71. It is widely used in children's chronic illness and disability studies (McCubbin et al., 1983). See appendix (1) for more information.

3- **The cystic fibrosis questionnaire-revised (CFQ-R)** Cystic fibrosis questionnaire-revised was created by B Henry, P Aussage, C Grosskopf, JM Goehrs, R Launois, and the French CFQOL Study Group in 2002. It is a reliable, well-validated measurement considered a disease-specific instrument used to measure the impact of cystic fibrosis on overall health, daily life, perceived well-being, and symptoms. Three versions of the instrument have been developed; one for adults and adolescents 14 years of age and older (48 items); two for assessing children's ages 6-13 years, one to be completed by the child (35 items) and one to be completed by the Parent (44 items) (Quittner et al., 2012; Vandeleur et al., 2018).

The CFQ-R contains 9 Quality of life domains (physical well-being, body image, eating, vitality, emotion, role, school functioning, social, treatment burden, and health perceptions) and three symptom scales; weight, respiratory, and digestion. Cronbach's alpha for most dimensions was 0.70 strong internal consistency for most scales (Quittner et al., 2012; Vandeleur et al., 2018).

Data analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 23 to compute all descriptive statistics for all variables. Chi-square was used to examine the relationship between social-demographic variables and parenting stress, socio-demographic variables and coping patterns, socio-demographic variables and child health outcomes, and the relationship between parenting stress coping strategies and child health outcomes.

Results

Two hundred parents of children with CF were recruited from different hospitals and clinics from the various clinics in the country. All participants completed the pre-prepared questionnaire via personal interview or a phone call.

Parents' ages ranged between 19 and 64 years old, with a mean of 19.34 years (SD=18.985) for the mother and 20.17 years (SD=22.040) for the fathers. The majority are between 35 and 44 years old for the fathers (24%) and 35 to 44 years for the mothers (26%). 94

(47%) The total sample was male parents, and 106 (53%) were female (N=200). Table 1 represents the socio-demographic characteristics of the participants.

Parenting Stress

The three subscales total of parenting stress index-short form showed that most parents (68.0%) experienced medium total stress. In contrast, the other parents were divided between high parental distress (15%) and low parental distress (17%).

Subscale one (parental distress subscale) presented (65%) of the parents with medium parental distress, and other parents were divided between high parental distress (16.5%) and low parental distress (18.5%) with a mean of 22.95. The minimum score was six, and the maximum was (45).

Subscale two (Parent-child dysfunctional interaction); most parents (75.5%) reported medium parent-child dysfunctional interaction stress, followed by low stress (12.5%) and high stress (12%) on the same scale, with a mean of 13.49 and a minimum of 2 and a maximum score of 37.

The third subscale measured how severe a child with CF is. Also, on this scale, most of the parents (60.5%) reported medium stress scoring for the difficult child scale, followed by low stress (24%) and high stress (15.5%) on the same scale, with a mean of 22.5 and a minimum of 12 and a maximum score of 41.

Coping Strategies

In the current study, parents were spread between having high coping strategies (46.5%) and having a low coping strategy (53.5%), with a mean of 93.18 (SD=11.51). According to the coping health inventory for parents, results in (Table 2) revealed that parents used all coping strategies, but there is a disparity in using them by parents in different percentages (Table 3) shows the coping strategy which parents of children with cystic fibrosis mainly used to decrease the The stress was the coping pattern II (maintaining social support, self-esteem, and psychological stability) (39.5%) for low Coping strategies and (60.5%) for high Coping strategies with a mean of 35.91 (SD=6.87).

Nevertheless, coping pattern I (maintaining family integration, cooperation, and optimistic definition of the situation) was significantly higher in high coping strategies (59.5%) with a mean of 42.69 (SD=4.28). In contrast, coping pattern III (understanding the health care situation through communication with other parents and consultation with the health care team) was also significantly higher in high coping strategies (52.5%) with a mean of 14.58 (SD=6.40).

Discussion

The current study indicated that most of the parents (68.0%) showed medium total stress, while the remaining parents indicated low parental distress (17%) and high parental distress (15%), respectively. This is a promising result based on previous studies since the late 1960s, and now, CF has high levels of psychological distress and increased risk of depressive symptoms in parents (Besier et al., 2011). However, the level of parental stress is somewhat similar to that mentioned in the study of Pinquart as CF parents show slight to moderate elevations of total parenting stress, especially in stress related to the parent-child relationship (Pinquart, 2017)

most of the parenting stress sources came from multiple responsibilities they have to handle, which is more than their expectations, as parents, to meet their children's needs (healthy & unhealthy children), as well as the additional demands of their children who have CF. Parents of children with chronic illnesses carry a double burden of responsibility compared to other parents. Parents have no choice except to cope with the progression of the disease, disruptions in plans, and everyday life challenges, including regular out-clinic visits, hospitalizations, a Child's Adherence to complex treatment regimens and financial stress due to the costs of treatments (Besier et al., 2011).

Considering the significant association between the total parental stress and income level, it is evident that annual income plays the leading role in increasing the parents' stress levels. Nowadays, the burden and the difficult economic situation in the whole region are pressuring parents who receive low annual income. As a result, most of these parents indicated a level of suffering between medium and high-stress groups. This result corresponds to a study by Fitzgerald and his colleagues (2018) and a study by Pinquart (2017); both studies considered that the financial burden of medical care and ivory for their children is regarded as one of the great sources of parental stress (Fitzgerald et al., 2018; Pinquart, 2017).
Moreover, there is a significant association

between parental stress and the number of hospital admissions per year for children (P=0.012). High and medium parental stress levels were visible, especially among the parents of children admitted to the hospital more than twice a year.

Finally, it can be summarized that the sources of parental stress among parents of children with CF in Jordan are; the multiple parental responsibilities being more than expected, the economic burden to cover the treatment cost, the commitment to follow-up of medical treatment, and the behavioral problems of the affected child.

Coping Strategies

Coping with chronic disease, especially during childhood, is the responsibility of all family members, particularly the parents. This study investigated the coping strategies of parents of children with CF; the parents coping indicators were divided into two main categories; parents who showed high coping levels (58.0 %) and parents who showed low coping levels (42.0%). In This calls for further research to determine the reasons for increased coping and reduced parental stress.

The parents coping strategies are separated into three levels. In this study, most parents adopted significantly coping pattern II (maintaining social support, self-esteem, and psychological stability) and revealed a high coping level (60.5%). In the Arab region, most families adopt a socially extended family style. Traditionally, in the Islamic and Arabic cultures, most people support each other, particularly relatives, neighbors, and close family friends who support parents during their child's disease. Results are contrary to a study by Besier et al. (2011). They pointed out that parents caring for a child with CF showed less time as a couple to engage in social and recreational activities (Besier et al., 2011). Nevertheless, it is in line with the study of Fitzgerald and colleagues, which reported that many parents of CF children show excellent social support, especially in the care tasks when needed (Fitzgerald et al., 2018).

The second coping strategy used by the Parent in this study was the coping pattern I (maintain family integration, cooperation, and optimism). Results indicated a significantly high coping level, almost (56.5%) of the whole sample. The result is congruent with the study by Venters (1981), which discussed that the first coping strategy at that time, was used by the parents of a CF child was sharing demands and burdens of the disease among the family members and with individuals outside of the family environment (Venters, 1981). Also, McCubbin and his colleagues pointed out, in their study conducted in 1983, that the mothers coping patterns were directed towards maintaining social support, family bonds and interactions, optimism, self-esteem, emotional stabilization, and cooperation among family members. While the fathers coping patterns tend to maintain psychological stabilization with their well-being and self-esteem as well as social support (McCubbin et al., 1983).

Moreover, the results of this study were somewhat similar to the survey conducted (2016), which was about the parents of children with mitochondrial disease (a rare genetic life-limiting disease). The researchers reported significant correlations between parenting stress and coping strategies such as family integration, social support, and understanding of health care (Senger, Ward, Barbosa-Leiker, & Bindler, 2016). The results are also consistent with a study (2018) where it was explained that one of the most used coping strategies by the mothers of CF children is religion and seeking instrumental support (Zubrzycka, 2018). Instrumental support is one of the major types of social support that "refers to the various types of tangible help that others may provide as help with childcare or housekeeping, provision of transportation or money" (Seeman, 2008). Moreover, Picci et al. (2015) mentioned that parents of a child with chronic disease prefer to use active coping, construing it in favorable terms (positive reinterpretation), and seeking instrumental social support as seeking assistance, advice, or information about it (Picci et al., 2015).

The parents' responses to the CHIP questionnaire indicated that the faith in God helped most of them (99%), it helped to cope with their child's health conditions, which led to a positive impact on their firm belief that the child's health status will be improved. This result corresponds to the study of Szczesniak et al. (2015), which indicated that parents of children with CF reported significantly higher levels of emotional support from the members of their religious congregation (Szczesniak et al., 2015). Moreover, the current study results correspond to Grossoehme. Et al. (2009) study where most parents of CF children showed that they felt supported by God and assumed God was benevolent. Besides, they found hope in this belief, and the study showed that all religious beliefs were clinically significant and relevant to their motivations to adhere to their child's treatment plan (Grossoehme et al., 2009).

It can be summarized that the most common coping strategy for parents of children with cystic fibrosis cf children in Jordan besides religious coping was coping pattern II, which includes maintaining social support, self-esteem, and psychological stability.

According to the purposes of this study, the results illustrated that the parents of children with CF have a moderate level of parenting stress, while the most coping strategies which parents of children with CF used were maintaining social support, then strengthening family integration and cooperation, and lastly understanding the medical conditions by communication with medical staff and consultation. The results also showed that most children with CF in Jordan had a moderate quality of life.

Moreover, the study results indicated a significant association between total parenting stress with annual family income (P=0.005). Therefore, the financial situation of families with a child with CF must be improved, and financial support from the government should not be limited to some treatment expenses. Moreover, there was a significant association between total parenting stress and hospital admissions per year (P=0.012);, Signaling the need for improving the quality of health services in health institutions (especially in primary care centers) to reduce the number of hospital admissions and to raise the level of health services during the entry of the child to the hospital to reduce the level of parental stress at that time. Moreover, there was a significant association between the number of clinic visits per month and child quality of life (P=0.008). Signaling calls for confirming the importance of periodic monthly visits to patients for outpatient clinics to follow up on their health situations by competent medical staff.

Finally, we emphasize that parents' proper mental and psychosocial health leads to children's optimal psychological and physical health.

Implications

The current study provided new information on the stress levels of parents of children with Cystic Fibrosis and their coping strategies, as well as the association between those variables and their children's health-related quality of life. The implications of the study findings are helpful to nursing research, nursing practice, nursing education, and nursing administration. In addition, the findings of this study provide precious information for the medical field's future.

Limitations

- The sample size was relatively small, with only 200 participants. A larger sample would probably enhance the reliability of future research.
- Lack of specialized medical centers for this disease in Jordan as it is in most developing countries.
- Lack of cooperation from medical staff, especially specialist doctors who did not cooperate with us in facilitating our access to their patients.
- The length of the three instruments discouraged some parents from participating in this study.
- In some cases, parents refused to participate in our research due to the stigma of the inherited diseases in our country.

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Table 1: Socio-demographic variables for parents

Item	Categories		N (%)[1]
Group	Father		94 (47%)
	Mother		106 (53%)
Parent age	Father	19 TO 24	1 (.5%)
		25 TO 34	7 (3.5%)
		35 TO 44	48 (24%)
		45 TO 54	32 (16%)
		55 TO 64	6 (3%)
	Mother	19 TO 24	7 (3.5%)
		25 TO 34	34 (17%)
		35 TO 44	52 (26%)
		45 TO 54	13 (6.5%)
Mother education	Primary		32 (16%)
	Secondary		57 (28.5%)
	Higher		17 (8.5%)
Father education	Primary		35 (17.5%)
	Secondary		42 (21%)
	Higher		17 (8.5%)
Hospitals	Irbid Governorate hospitals		81 (40.5%)
	Amman Governorate hospitals		56 (28%)
	Royal Medical Services hospitals		63 (31.5%)
Total family number	3		2 (1%)
	4		32 (16%)
	5		32 (16%)
	6		59 (29.5%)
	7		37 (18.5%)
	8		19 (9.5%)
	9		10 (5%)
	10		4 (2%)
	11		5 (2.5%)
Annual income	Lower-income (less than 703 JD yearly)		18 (9%)
	Lower middle income (704- 2760 JD yearly)		33 (16.5%)
	Upper middle income (2769-8564 JD yearly)		132 (66%)
	High income (more than 8565 JD yearly)		17 (8.5%)
Number of cystic fibrosis patients per family	1		138 (69%)
	2		50 (25%)
	3		7 (3.5%)
	4		2 (1%)
	6		1 (.5%)
	7		2 (1%)

Number of patients with other chronic diseases	0	168 (84%)
	2	32 (16%)

Table 2: Socio-demographic variables for CF children

Item	Categories	N (%)
Child gender	Male	**112 (56%)**
	Female	**88 (44%)**
Child age group	Preschooler (less than six years)	**32 (16%)**
	School-age (6-11 years)	**88 (44%)**
	Adolescents (12 to 14 years)	**80 (40%)**
Treatment years	<4 Years	**49 (24.5%)**
	5-9 Years	**61 (30.5%)**
	>10 Years	**90 (45%)**
Hospital admission number	Never	**104 (52%)**
	Once	**39 (19.5%)**
	Twice	**20 (10%)**
	More than two	**37 (18.5%)**
Monthly clinic visit	Unknown	**22 (11%)**
	Once monthly	**108 (54%)**
	Twice monthly	**5 (2.5%)**
	More than twice monthly	**3 (1.5%)**
	Once in 3 months	**32 (16%)**
	Twice in 3 months	**30 (15%)**

Table 3: Coping pattern subscale:

Coping scales		Frequency	Percent
Coping pattern I (Family integration, cooperation, and optimism)	Low coping	87	43.5 %
	High coping	113	56.5 %
Coping pattern II (Social support, self-esteem, and psychological stability)	Low coping	79	39.5%
	High coping	121	60.5%
Coping pattern III (Medical communication and consultation)	Low coping	95	47.5%
	High coping	105	52.5%

Coping pattern I: mean 50.32, SD= 5.207
Coping pattern II: mean 35.91, SD= 6.87
Coping pattern III: mean 14.85, SD= 6.40

Table 4: Total parenting stress and parent group

	Total parenting stress			
Parent group	Low stress	Medium stress	High stress	Total
Father %*	23 (24.5%)	68 (72.3%)	3(3.2%)	94 (100.0%)
Mother %*	7 (6.6%)	68 (64.2%)	31 (29.2%)	106 (100.0%)
Total %*	30 (15.0%)	136 (68.0%)	34 (17.0%)	200 (100.0%)

X^2=30.984, df=2, P=0.000)
%*: % within Parent group

Table 5: total stress with total coping strategies

	Total stress			
Total Coping level	Low stress	Medium stress	High stress	Total
Low coping *%	5 (6.0%)	56 (66.7%)	23 (27.4%)	84 (100.0%)
High coping *%	25 (21.6%)	80 (69.0%)	11 (9.5%)	116 (100.0%)
Total	30 (15.0%)	136 (68.0%)	34 (17.0%)	200 (100.0%)

Total (X^2=17.122, df=2, P=0.000)
*%: % within total coping level

Table 6: Total parenting stress and Coping pattern II

Coping pattern II (maintaining social support)	Total parenting stress			
	Low Stress	Medium stress	High stress	Total
Low coping %*	2 (2.5%)	46 (58.2%)	31 (39.2%)	79 (100.0%)
High coping %*	28 (23.1%)	90 (74.4%)	3 (2.5%)	121 (100.0%)
Total %*	30 (15.0%)	136 (68.0%)	34 (17.0%)	200 (100.0%)

Father (X^2=3.007, df=2, P=0.222)
Mother (X^2=25.943, df=2, P=0.000)
Total (X^2=53.361, df=2, P=0.000)
%*: % within coping II