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Quality of Life in Jordanian Children with Cystic Fibrosis as Perceived by Children Themselves and their Parents

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Abstract

Background: Children with cystic fibrosis facing health challenges and negatively effects on their health-related quality of life. The management of cystic fibrosis should be carried out on a daily basis, which require parental monitoring.

Objective: This study assessed the quality of life of Jordanian children with cystic fibrosis as perceived by themselves and their parents.

Methods: A cross-sectional design was conducted on 200 children with cystic fibrosis aged 6 to 13 years and their parents. The Arabic Cystic Fibrosis Questionnaire Revised (Cystic Fibrosis Questionnaire-Child version (CFQ-Child) and Cystic Fibrosis Questionnaire-Parent version (CFQ-Parent) was used to collect the data from participants who attended a pediatric hospital in northern Jordan between December 2012 and March 2013. Multivariate analysis and Pearson's correlation coefficient were performed to assess children's quality of life.

Results: The total domains mean of the CFQ-Child and CFQ-Parent were 58.1 (SD = 16.3) and 50.6 (SD = 19.0) respectively. Males and children aged 6-11 years had better quality of life digest ($p = 0.011$), emotional ($p= 0.005$), social ($p = 0.007$), body image ($p = 0.005$) domains. Parents with higher educational level and employed were more likely to perceive that their children had better quality of life. CFQ-Child domains and CFQ-Parent domains were not significantly correlated.

Conclusions: Quality of life of children with cystic fibrosis was poor as perceived by themselves and as perceived by their parents. CFQ-Child domains CFQ and parent domains were not significantly correlated.

Keywords: Children; Cystic Fibrosis; Parents; Quality of Life

Introduction

Cystic Fibrosis (CF) is a life-threatening genetic disease that is caused by a mutation of the cystic fibrosis transmembrane conductance regulator gene that regulates the movement of salt in and out of cells [1,2]. It results in a multisystem disease, affecting the lungs [2], gastrointestinal system, salivary glands, pancreas, liver [3,4], sweat ducts [1], and reproductive tract [5]. The

occurrence of cystic fibrosis varies across the world. Cystic fibrosis is most common in white populations [6]. In the European Union 1 in 2000-3000 new borns is found to be affected by CF. In the United States of America, the incidence of CF is reported to be 1 in every 3500 births [6,7]. In developing countries, CF have remained largely unrecognized [7,8]. The few published studies about cystic fibrosis in Arab countries highlighted an elevated incidence rate of CF/ particularly in observation of the high consanguinity rate of 25-60% [7,8]. Little is known about Cystic fibrosis in Jordan [9,10]. Nazer [1] reported an incidence rate of 1:2650 in Jordan is per new births. Rawashdeh & Manal [9] reported 202 cases (114 boys and 88 girls) diagnosed in Jordan over a period of 9 years.

Children with cystic fibrosis tolerate further health challenges such as cystic fibrosis related diabetes [11], look thinner and shorter than others [12], and delay in puberty and growth [5] which in turn significantly restrict patients' daily activity and causing school absenteeism and negatively effect on their quality of life [13]. Moreover, parents of children with cystic fibrosis try to maximize quality of life of their children [14]. The management of cystic fibrosis in a childhood period requires adherence to multiple health-related behaviors that should be carried out on a daily basis, which require parental monitoring [15]. Parents are responsible to manage the disease necessities such as improve the symptoms of poor nutritional status, airway obstruction, and inflammation [16] and to deal with additional developmental requirements [17], which accordingly affect their children's quality of life [18]. The parents provide emotional support, arrange appointments in the clinic for treatment and follow up, and assist to cope with unpleasant treatment regimen, handle the financial difficulties; they furthermore have to keep their own employment even with the disturbance of personal family routine [19].

In the last few decades, measurement of quality of life has become a significant area of interest in cystic fibrosis [20]. Accordingly, an understanding the burden of this diseases on quality of life needs to be known to adjust health care in order to meet the needs for those patients and their families. The primary objective of this study is to assess the quality of life and the associated factors among Jordanian children with cystic fibrosis as perceived by children themselves and their parents.

Methods

Research Design

A cross-sectional design was conducted among children with cystic fibrosis and their parents who attended the governmental affiliated teaching pediatric hospital in northern Jordan during the period from December 2012 through March 2013. This hospital is a referral hospital that provides medical and surgical services for children from birth to 13 years old. A total of 200 children with cystic fibrosis aged 6 to 13 years who attended outpatient clinics in the selected hospital and their parents were included in this study.

Instrument

The Arabic Cystic Fibrosis Questionnaire Revised [21] was used in the current study. The instrument is a self-rating questionnaire composed of two versions: Cystic Fibrosis Questionnaire-Child version (CFQ-Child) and Cystic Fibrosis Questionnaire-Parent version (CFQ-Parent). The CFQ-Child is a disease-specific quality of life measure for children with CF aged 6 to 13 years old. It has two versions: The first one is an interviewer-administered version for children 6 -11 years and children choose the answers from a special answering card. The second one is a self-report version for 12 -13-year-old. The CFQ-Child consisting of 35-items that includes three generic domains of quality of life, including Physical Symptoms (6 items), Emotional Functioning (8 items), and Social Functioning (7 items). The CFQ-Child also assesses five disease-specific dimensions which include Body Image (3 items), Eating Disturbances (3 items), Treatment Burden (3 items), Respiratory Symptoms (4 items), and Digestive Symptoms (1 item). Children are answered nineteen items on a four-point Likert scale on a true-false rating ranging from "Not at all true" to "Very true", and sixteen items on a frequency response ranging from "Never" to "always".

The CFQ-Parent is a measure of the parent's report of their child's quality of life for children aged 6 to13. The parent version is a proxy-rating questionnaire with eleven domains and 44 items that assesses four generic domains Physical Symptoms (9 items), Emotional Functioning (5 items), Vitality (5 items), and School Functioning (3 items), and seven disease-specific domains Eating Disturbances (2 items), Body Image (3 items), Treatment Burden (3 items), Respiratory Symptoms (7 items), Digestive Symptoms (3 items), Weight Problems (1 item), and overall Health Perception scale (3 items). In the parent version, similar four-point Likert scales are used supplemented by five items with 4 eligible standard phrases for answer selection. The values for each question range from 1 to 4. Some of the questions are phrased in a positive direction like (Q2: Walking as fast as others? 1. A lot of difficulty, 2. Some difficulty, 3. A little difficulty, and 4. No difficulty). Other questions are phrased in negative direction. So, these questions were reversed and transformed to the positive frame. In parent version some items were recorded (emot6, vital10, vital12, phys15, treat31, health22, health24, health32, school28, and resp37) as following: (1=4), (2=3), (3=2), and (4=1). Also, in children version some items were recorded (phys1, phys2, phys3, phys4, phys5, emot14, treat18, eat19, social20, social22, social24, and social26) as following: (1=4), (2=3), (3=2), and (4=1). The mean score for quality of life for each domain was calculated according to the specific formulae. The mean score of each domain ranged between 0 and 100. Zero (0) indicated that a bad quality of life and 100 indicated a higher quality of life. Any missing item was given the mean score of the completed items for that domain; if more than half of the answers for that specific domain were available.

Otherwise they were left blank and recorded as missing. Results were categorized into each domain according to the cystic fibrosis version. All items in the questionnaire referred to a time frame of the past two weeks before completing the questionnaire. The CFQ-Child version was administered by the research coordinator to all children

Data Collection

Ethical approvals were obtained from the Ethical Research Committee at Jordan University of Science and Technology and Jordan Ministry of Health. Informed consents were obtained from the participants themselves or from their representatives. Children with cystic fibrosis and their parents were met in assigned room at the outpatient clinic in the selected hospital while waiting for health care or after they received the care. The study purposes, data collection procedure, and instrument instructions were explained to children and their parents. Confidentiality and anonymity were maintained.

Data Analysis

Descriptive statistics including percentages, frequencies, means, and standard deviations for each study variable were used. Multivariate analysis was performed to test the association of socio-demographic characteristics with quality of life. Pearson's correlation coefficient was calculated to assess the correlation between quality of life in children with cystic fibrosis as perceived by children and as perceived by their parents. P-value of less than 0.05 was considered statistically significant.

Results

Socio-Demographic Characteristics of Children with Cystic Fibrosis and Their Parents

A total 200 children with cystic fibrosis (64 (32%) males and 136 (68%) females) and their parents were included in this study. Two thirds of children (65.0%) aged 6-11 years and 35.0% aged 12-13 years old**.** Of the 200 parents, 168 (84%) were mothers, and 32 (16%) were fathers. The mean age of parents was 39.50 years (SD = 6.3), with a range of 28-59 years. The majority of parents (81.5%) had education less than high school level, and 19% of parents were employed. Socio-demographic characteristics of parents of children with cystic fibrosis are shown in (Table 1).

Variables	N (%)
Child relationship:	
Father	32 (16.0)
Mother	168 (84.0)
Age:	
28-39 years old	109 (54.5)
> 40 years old	91 (45.5)
Marital Status:	
Single	23 (11.5)
Married	177 (88.5)
Educational Level:	
≤ high school	163 (81.5)
> high school	37 (18.5)
Career:	
Unemployed	162 (81.0)
Employee	38 (19.0)

Table 1: Socio-demographic characteristics of parents of children with cystic fibrosis (n = 200).

Descriptive Data for Participants' Scores on the CFQ-Child and CFQ-Parent (N = 200)

In the current study, the mean scores for the 9 domains and 3 symptoms scales of CFQ-Child and CFQ-Parent are described in (Table 2). Scores for each domain are expressed on a scale 0 - 100; where the higher mean scores indicate more positive health and better quality of life. The total domains mean of the CFQ-Child and CFQ-Parent were 58.1 (SD = 16.3) and 50.6 (SD = 19.0) respectively. Social functioning domain score was the highest in CFQ-Child version (73.9, SD = 8.9) and physical domain score was the lowest (mean = 34.5, SD = 18.9). On the other hand, treatment burden domain was the highest in CF-Parent version (mean = 78.8 SD = 13.1) and school performance domain score was the lowest (37.1, SD = 15.6).

Domains	CFQ-Parent **(N= 200)**			CFQ-Child **(N= 200)**		
	No. of items	Mean (SD)	Mean range score	No. of items	Mean (SD)	Mean range score
Physical Functioning	9	37.5 (11.9)	14.8 -74.0	6	34.5 (18.9)	9.9 -77.8
Emotional Functioning	5	54.3 (14.4)	20.0- 80.0	8	58.6 (16.5)	20.8 - 91.7
Vitality	5	42.8 (10.7)	20.0 - 66.7	Not applicable		
Subjective Health Perception	3	49.1 (15.6)	11.1- 88.9	Not applicable		
Respiratory Symptoms	7	60.7 (20.9)	5.6 -100	4	56.8 (13.1)	16.7- 83.3
Treatment Burden	3	78.8 (13.1)	44.4 -100.0	3	66.9 (15.9)	22.2 - 100.0
School Functioning	3	37.1 (15.6)	8.3 - 88.9	Not applicable		
Social Functioning	Not applicable				73.9 (8.9)	47.6 - 90.5
Body Image	3	38.5 (15.2)	6.5 - 88.8	3	53.2 (14.6)	11.1- 88.9

Eat Disturbance	2	56.1 (22.4)	16.7-100	3	60.8 (16.8)	11.1-100
Weight Problems	1	47.3 (22.8)	6.8 -100	Not applicable		
Digestive Symptoms	3	58.0 (23.4)	11.1-100	1	60.5 (26.3)	26.6- 100
Total	44	50.6 (19.0)	15.3 -100	35	58.1 (16.3)	30.2 - 100

Table 2: Descriptive data for participants' scores on the CFQ-Child and CFQ-Parent (N=400).

Quality of Life of Children with Cystic Fibrosis according to their Socio-Demographics Characteristics

The results of multivariate analysis using general linear model for CFQ-Child domains according to socio-demographics characteristics are shown in (Table 3). The analysis revealed that after adjusting for important variables (the variables including parents' age, educational level, employment status; and child's age, class level, and out school vacation) gender and age were the only significant variables that associated with child's quality of life. Gender was significantly associated with digest domain. Male patients had significantly increased digest domain scores (p = 0.011). Children aged 6-11 years had higher scores in emotional (p= 0.005), social (p = 0.007) and body image (p = 0.005) domains scores.

Domains	Physical functioning Mean(SD)	Emotional functioning Mean(SD)	Eat Disturbance Mean (SD)	Treatment burden Mean (SD)	Social functioning Mean (SD)	Body image Mean (SD)	Respiratory symptoms Mean (SD)	Digest Symptoms Mean (SD)
Variables								
Child gender								
Males	33.9(1.7)	58.2(1.5)	60. 5(1.4)	67.4(1.3)	73.9(0.8)	53.8(1.2)	55.7(1.2)	63.7(2.2)
Females	35.8(2.2)	59.4(1.8)	61.5(2.1)	66.0(2.1)	73.8 (1.2)	51.7 (1.9)	56.1 (1.5)	53.6 (3.2)
P-Value	0.5	0.64	0.69	0.55	0.95	0.342	0.833	0.011
Child age (years)								
06-Nov	22.8(0.9)	67.6(1.0)	62.5(1.6)	66.5(1.5)	75.1(0.8)	56.8(1.3)	53.1(1.1)	57.7(2.1)
Dec-13	56.1 (1.3)	41.8(1.2)	57.6 (1.5)	67. 8(1.6)	71. 6(1.1)	46.3 (1.5)	60.8 (1.5)	65.7 (3.5)
P-Value	0.005	0.005	0.05	0.588	0.007	0.0005	0.0005	0.04

Table 3: Quality of life of children with cystic fibrosis according to socio-demographics characteristics (N = 200).

Quality of life of children with cystic fibrosis as perceived by their parents according to their socio-demographics characteristics

Parents with higher educational level and employed parents were more likely to perceive that their children had better quality of life. Parents with higher educational level were more likely to perceive that their children had better quality of life for treatment burden (p = 0.025), body image (p = 0.006), school performance (p = 0.046) domains. Employed parents perceived their children had significantly higher average scores for treatment burden (p = 0.0005) and respiratory symptoms (p = 0.005) than unemployed parents. Our current findings found there was no significant correlation between CFQ-Child domains with any domain of CFQ-Parent domains.

Discussion

The findings indicated that CFQ-Child domains and CFQ-Parent domains were not significantly correlated; there was a disagreement between children's and their parents' perceptions toward their quality of life. Parents rated the emotional functioning, body image, eat disturbance, and digestive symptoms lower in comparison with their children's reports. In contrast, children reported lower quality of life on the physical functioning, respiratory symptoms and treatment burden in comparison with parents. The explanation for these findings could be that parents have unresolved anger to have a child have been diagnosed with CF. Parents have obscurity expressing their emotions directly to their children. Parents were aware of the health consequences of these conditions including reduced overall quality of life of their children. While children had lack of adequate awareness of the serious impact that CF can have on their health. However, this finding is not consistent with the findings of previous research [22] who found higher patient/proxy concordance for observable domains, such as physical functioning, and lower agreement between children and their parents on emotional. Hegarty et al. [22] reported that there was a significant interaction between child/parent report for emotional state and eating disturbances [23,24]. Verrips et al. [25] found there was a lower agreement between children and their parents on emotional state. Modi and Quittner [26] found that children reported lower quality of life on the emotion scale in comparison with parents.

The highest mean score reported by children was in social functioning domain, while the highest mean score reported by parents was in treatment burden domain. The treatment burden domain represents perception of parents of the children with cystic fibrosis regarding to their commitment with treatment regimen. Jordanian parents perceived that their children had moderate difficulty in managing their health regimen. Parents had higher score of treatment burden than their children. This finding could be explained by that parents are rejecting and denying to their children's condition. These children may experience the treatment is boring, children found themselves they were responsible and committed to their health regimens. In Jordan, cystic fibrosis patients have health insurance coverage including medications, admissions to the hospital, free regular vaccination, which may decrease the parents' perception of treatment burden on their children. Our findings are consistent with those of Hegarty et al. [22] who found that children aged between 6 to 13 years clearly perceived less treatment burden than did their parents. However, our finding is not consistent with Modi and Quittner [26] who found there was a disagreement between parents and children with cystic fibrosis perceptions to treatment burden. The social functioning domain represents the children perception of their need to enhance social interaction and support from their friends and families, and the ability to establish relationships to meet normal roles [24]. In the current study, children had the highest mean score in social functioning domain and this finding could be explained by that children had good access to health services and often invited friends and teachers to their houses, and feel comfortable discussing their illness and concerns.

The lowest mean score reported by children was in physical domain while, the lowest score reported by parents was in school performance domain. Physical domain is concerned with the children's perception that their illness or treatments limited their ability to perform vigorous activities, walk or climb stairs as fast as others, carry or lift heavy objects, go for school, participate in other sports or activities, and to recover easily after physical effort. However, the results of current study were lower than that reported in the study of Hegarty et al. [22]. School performance is concerned with the parents' perception that children' disease limited their ability to concentrate in the class, and keep up with school work and summer activities. The current study showed that 90 % of children out of their school, and had vacations related to health status. This finding is in contrary with other study results of Grieve et al. [23] who indicated that cognitive abilities and academic achievement were normal and within an acceptable range. Recurrent absences from school related to children hospitalization and illness showed that there is an urgent need for school support; to promote their sense of self-value. Those patients also should be compensated with the lost time related to their recurrent absences. Parents with higher educational level and employed parents were more likely to perceive that their children had better quality of life. Well educated parents have improved their abilities in managing and taking care of children with cystic fibrosis. This finding is disagreed with the findings of previous work [27]; because they verified that parents with lower educational level had better quality of life explained that the there was an association between hope and other health symptoms. Warfield et al. [28] reported that employed parents had better quality of life than unemployed parents; because employment decreases parents' stress and their emotional suffering.

Males reported significantly higher score on the digest quality of life domain than females. Modi and Quittner [26] found that boys scored lower in eating disturbances domain than girls. The authors clarified their results by the nature of girls and their interests in television programs, and fashion magazines. So, girls feel less forced into eating. The results of the current study found that age of the children was significantly associated with CFQ-Child domains. Children aged 6-11 years scored better quality of life for emotional, social, and body image domains than those aged 12-13 years, while children aged 12-13 years scored better quality of life for physical, respiratory symptoms, and digest than those aged 6-11 years. This finding is congruent with the finding of Hegarty et al. [22] who found that young people aged 6-13 years had better quality of life than those older for emotional state, body image and treatment burden domains. A Possibly explanation for this finding is that younger children have insufficient understanding for the future vision, such as the sequences of cystic fibrosis.

In light of the finding of the current study that there was no significant correlation between the children's own perception of QOL, as compared to their parent's view of how things were going. However, the scores of CFQ-Child domains (M = 58.1, SD = 16.3) and CFQ-Parent domains (M = 50.6, SD = 19.0) were low, indicating that the quality of life in children with cystic fibrosis as perceived by children and parents was poor. Our findings are lower than the findings of previous research [22-23] who found that cognitive abilities and academic achievement were normal and within an acceptable range. However, in general, children reported had better quality of life than did their parents. This finding is consistent with previous studies [20,24]. Havermans et al. [20] found that children with cystic fibrosis were more satisfied than their parents. Britto et al. [24] reported adolescents had better quality of life than their parents where adolescents had less susceptible to illness and less worried about their health than their parents.

Conclusion

The findings of this study showed the quality of life in children with cystic fibrosis as perceived by children themselves and their parents was poor. CFQ-Child domains and CFQ-parent domains were not significantly associated. Social functioning and treatment burden domains were the highest mean scores reported by children and parents respectively. physical functioning and school performance were the lowest mean score reported by children and

parents. Males reported significantly higher score on the digest quality of life than females. Parents with higher educational level and employed parents were more likely to have better quality of life.

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