

Health Related Quality of Life among Jordanian Children with Renal Diseases

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ABSTRACT

Background: Quality of life (QOL) is a widespread evaluation of person's wellbeing. QOL encompasses various areas including physical, emotional functions, social interactions, school performance and environmental values. Measuring Health-related Quality of Life (HRQOL) of healthy children, as well as sick children suffering from diseases such as cancer, asthma, and renal disorders, is considered a valuable indicator of child's well-being and functioning. It could be used to evaluate the impact of the disease as well as the effects of the treatment strategies.

Aims: This study aimed at measuring the health-related quality of life among children with renal disease and to determine factors affecting their QOL.

Methods: a cross sectional design was used. A convenient sample of 121 children accompanied by their care givers was interviewed during years 2017-2018. These children were diagnosed with renal diseases and treated in the pediatric nephrology clinic at Prince Hamza Hospital/ Hashemite Kingdom of Jordan. Two instruments were used for data collection: Questionnaire for patients with renal diseases including socio demographic data, parents' characteristics and Peds QL4.0 Generic Core Scale was used to measure HRQOL.

Results: Children's age ranged from 2-13 years old with 43.8% of them between 6-10 years. 80.2% of the them came from low Socio-economic class. The majority of parents' education levels were secondary education or less (fathers 81.0%, mothers 82.6%). Children's mean total HRQOL score was 71.85 ± 14.80 . Mean of social, physical, psychosocial QOL items were above 70, while emotional and school functioning were less than 70. Low socioeconomic class children showed low score in all HRQOL aspects, while children with highly educated parents had high HRQOL scores.

Conclusions and recommendations: Renal diseases have substantial consequences in numerous areas of children's life. This study recommends an integrated program between home, school and health care facilities to educate, support and improve children's HRQOL. In addition to use the HRQOL scale as a part of the clinical assessment in all health care institution.

Key Words: Health-related quality of life, Children, renal diseases

1. INTRODUCTION

Renal diseases in children are a common health problem. They have substantial consequences in numerous areas of child's life. It can lead to dreadful complications such as; chronic kidney disease (CKD) (1,2).

CKD increases in prevalence globally with an annual incidence rate of 8%. It is a gradual loss of renal function that ultimately leads to end-stage renal disease (ESRD). Worldwide the morbidity and mortality due to renal failure are high with an estimated 5–10 million people death annually. Renal diseases can also present as acute renal failure increasing the risk for heart diseases, failure of growth and development leading to alteration of quality of life (QOL) (3-5).

Advanced medical technology and medical care have resulted in numerous changes in physical outcomes and increased survival rates. Merely surviving a long-term disease is not enough; the quality of survival is an essential focus of healthcare, which make the conventional measurement such as mortality, morbidity, and life expectancy for the of public health insufficient to assess state of health and well-being (6-8).

Assessment of children's quality of life (QOL) and health-related quality of life (HRQOL) began during the 1980's, nowadays it is widely used in medical practice (9,10). Quality of life (QOL) is a substantial subjective evaluation of person's wellbeing. QOL encompasses various areas including physical (9,11,12), emotional functions (13,14), social interactions (15,16), school performance (17-20) and environmental values (21).

Measuring Health-related Quality of Life (HRQOL) of healthy children, as well as sick children suffering from diseases such as cancer, asthma, cystic fibrosis, arthritis and renal disorders, is considered as a valuable indicator of child's well-being and functioning. It can be used to evaluate the impact of the disease as well as the effects of treatment strategies. HRQOL can identify health inequalities, prioritize health problems, allocate resources and identify factors affecting QOL (22-24).

Based on the World Health Organization (WHO) statement, "quality of life(QOL) includes individuals' perceptions from their life situation with regard to their culture, value system, goals, expectations, standards, and concerns" (25)

Quality of life of children with renal diseases is influenced beside the disease itself, by the family environment. Numerous studies have identified the effect of such factors as parent's level of education and family social status on QOL. These factors affect the pre-diagnosis period, they could also influence the patient outcomes. Early detection, management of renal diseases and its related consequences will enhance children's QOL, facilitate their growth, development and successful transition into adulthood (26-30).

While, HRQOL of children with renal disease studies in literature is well established (31-33), few studies have been conducted on group of chronic disease in Jordan (34), to the best of researchers' knowledge this is the first study to demonstrate HRQOL on Jordanian children with renal diseases solo.

2. METHODS:

2.1 Research design and subjects:

A quantitative descriptive cross-sectional design was utilized. A convenient sample of 121 children accompanied by their care givers was interviewed during years 2017-2018. These children were diagnosed with renal diseases and treated in out patients' nephrology clinic at Prince Hamza Hospital. It is a tertiary, referral, and teaching hospital located in the Jordanian capital Amman. It is affiliated to the Jordanian Ministry of Health (JMOH), and the Hashemite University.

2.2 Research Instrument:

Two instruments were used for data collection, in order to achieve the purpose of this study. The first instrument was Kidney Disease Patient Questionnaire. It consists of the following items: socio demographic data include children's characteristics (age, sex) and parents' characteristics (level of education, socio-economic class), and type of renal diseases. The questionnaire was tested for reliability by using the Cronbach's Alpha test, it was reliable and the coefficient value was 0.86.

The second instrument was Core Pediatric Quality of Life (QoL), Version 4 (PedsQL) (35) (Arabic version) used to measure Health-related quality of life (HRQOL). PedsQL is an instrument designed to measure health-related quality of life (HRQOL) in children and adolescents ages 2-18 years. It was validated with Cronbach's alpha 0.90. It included 23 items cover the following dimensions: Physical functioning (8 items); emotional functioning (5 items); social functioning (5 items); and school functioning (5 items). A 5-point Likert response scale was used. Scoring for QoL items were reversed and linearly transformed to a 0-100 scale as follow 0 (Never) =100, 1(Almost never) =75, 2 (sometimes) = 50, 3 (often) = 25, 4 (Almost always) = 0. The higher scores indicated better health related quality of life. The total score was the sum of all the items over the number of items answered on all scale.

2.3 Ethical consideration:

Prior to the study an official permission and agreement from the hospital ethic committee was obtained. A consent form was attained from the children's care givers after explaining the aim of the study. The participation was voluntary and they have the opportunity to refuse or to withdraw at any time. In addition, the anonymity, confidentiality, and privacy were assured through using code numbers.

2.4 Data Analysis:

The Statistical Package for Social Studies (SPSS) version 24.0 was used. Data were coded and summarized using means values, standard deviation and percentage to characterize the sample.

1. RESULTS

Socio-Demographic Data

A convenient sample of 121 Jordanian children diagnosed with renal diseases accompanied by their care givers was interviewed. Children's age ranged from 2-13 years old with 43.8% between 6-10 years. More than half of studied children were males 61.1%. The majority of the children came from low Socio-economic class (80.2%). Moreover, the majority of parents' education levels were secondary education or less (fathers 81.0%, mothers 82.6%). (Table1)

Table (1): Socio-demographic characteristics of studied cases (n=121)

Variable	No.	%
Age		
2-5 years	39	32.2
6-10 years	53	43.8
10-13years	29	23.9
Gender		
Male	74	61.1
Female	47	38.8
Education of the mother		

Illiterate/ primary/ elementary	38	31.4
Secondary	62	51.2
University	21	17.4
Education of the father		
Illiterate/ primary/ elementary	48	39.7
Secondary	50	41.3
University	23	19.0
Socio-economic class		
Low (100-400) JD	97	80.2
Middle/ High (400 +) JD	24	19.8
Min. – Max.	35.0– 2000.0	
Mean ± SD.	390.74 ± 267.30	

Type of Renal Disease

Congenital, genetic renal disorder and Urinary tract infection were the most frequent diagnosis in this research, appearing in 43% and 38% of studied children respectively. The chronic Renal failure was seen in 11.5% while; other diseases represented 7.4 % of diagnostic categories. (Table 2)

Table (2): Distribution of the studied cases according to renal diagnosis (n=121)

Disease	No.	%
Congenital/ Genetic renal disorder	52	43
UTI	46	38.0
Chronic Renal failure	14	11.5
Miscellaneous	9	7.4

Quality of life subscales

The mean of social, physical, psychosocial QOL items was above 70, while the emotional and school functioning was less than 70. The mean total QOL score was 71.85± 14.80 (Table3).

Table (3): Quality of life items among Jordanian children with renal diseases (n=121) low

Quality of life subscales	Mean	SD.
Social Functioning	76.86	18.04
Physical Functioning	72.26	18.09
Psychosocial Health	71.62	15.20
School Functioning	69.12	18.07
Emotional Functioning	68.85	18.73
Overall quality of life	71.85	14.80

Quality of life items according to personal characteristics of children

The QOL aspects showed no statistically significant difference regarding age and gender, except the emotional functioning as females showed significantly higher score than males (68.6 ± 17.9 versus 64.9 ± 17.2 respectively p = .03). (table4)

Table4: Quality of life items according to personal characteristics of children with renal diseases (n=121)

Variables	No.	Items of Quality of life					
		Social	Physical	Psychosocial	School	Emotional	Overall QoL
Age (years)							
2-5	39	67.8 ± 18.7	70.9 ± 15.7	70.9 ± 15.7	65.8 ± 17.8	80.8 ± 18.4	70.9 ± 12.7
6-10	53	65.0 ± 18.2	70.3 ± 15.1	70.3 ± 15.1	68.5 ± 18.0	79.1 ± 20.5	71.5 ± 13.7
10-13	29	62.3 ± 19.4	69.9 ± 13.7	69.9 ± 13.7	66.6 ± 17.3	76.9 ± 17.6	70.7 ± 014.0
t-test		2.2	0.1	0.1	0.6	1.4	0.1
p		.1	.9	.9	.6	.3	.9
Gender							
Male	74	65.9 ± 18.2	79.3 ± 17.1	69.6 ± 14.9	69.6 ± 14.9	64.9 ± 17.2	70.3 ± 13.8
Female	47	67.4 ± 17.1	77.8 ± 19.8	70.8 ± 14.2	70.8 ± 14.2	68.6 ± 17.9	71.9 ± 12.4
t-test		0.8	0.8	0.8	0.8	2.2	1.3
p		.4	.4	.4	.4	.03	.2

Quality of life items according to family characteristics of children

The physical, psychosocial, school and total QOL scores were significantly higher among children with educated mothers (secondary, university and higher) than the less educated mothers (Illiterate, primary and elementary education). Moreover; children whose fathers have university education showed significantly higher scores for emotional functioning than those whose fathers had lower educational levels. The middle and high social class Children showed significantly high emotional functioning scores and total QOL, whereas; low socioeconomic class children had significantly low school function scores.

Table 5: Quality of life items according to family characteristics of children with renal diseases (n=121)

Variables	No.	Items of Quality of life					
		Social	Physical	Psychosocial	School	Emotional	Overall QoL
Education of the mother							
Illiterate/Primary/elementary	38	69.0 ± 13.9	76.5 ± 18.6	63.8 ± 18.4	64.0 ± 18.9	69.3 ± 14.7	68.8 ± 12.4
Secondary	62	69.2 ± 15.2	80.1 ± 20.0	65.7 ± 16.9	65.4 ± 19.3	72.1 ± 15.2	71.1 ± 13.6
University	21	74.8 ± 14.9	84.5 ± 17.2	72.9 ± 17.2	69.9 ± 19.6	72.7 ± 14.1	76.1 ± 13.4
f-test		2.7	4.5	4.0	2.9	1.4	4.8
p		.05	.004	.008	.04	.3	.003

Education of the father							
Illiterate /Primary/ elementary	48	76.5 ± 18.7	69.3 ± 14.7	66.3 ± 17.8	69.2 ± 15.2	62.3 ± 18.2	68.9 ± 14.0
Secondary	50	78.1 ± 17.8	72.1 ± 15.2	65.9 ± 16.9	70.2 ± 13.8	64.7 ± 18.4	70.2 ± 14.5
University	23	82.2 ± 21.1	72.7 ± 14.1	71.1 ± 16.1	74.8 ± 14.9	68.8 ± 18.8	72.5 ± 14.5
<i>f</i> -test		1.4	1.4	1.1	2.7	2.9	2.7
<i>p</i>		.2	.3	.3	.05	.03	.07
Socio-economic class							
Low	97	68.0 ± 15.7	71.5 ± 13.4	70.8 ± 13.5	59.2 ± 20.2	77.5 ± 19.1	70.1 ± 14.7
Middle/ High	24	66.5 ± 17.9	70.8 ± 13.3	70.1 ± 14.7	65.4 ± 18.4	83.6 ± 15.6	70.8 ± 13.5
<i>t</i> -test		0.6	0.3	0.3	2.2	2.6	0.3
<i>p</i>		.5	.7	.7	.03	.01	.7

2. DISCUSSION

The current study had two aims, the first one is to assess the association between renal diseases and HRQOL in children, and the second is to identify demographic and socio-economic variables linked to impairment in physical, emotional, social functioning and school performance.

The study findings revealed that the participant suffer from chronic renal diseases mostly related to congenital, genetic and chronic renal failure, which is consistent with several research studies results (2,7,12,15). Furthermore, the results revealed that HRQOL of Jordanian children with renal disease compared to those of other studies conducted in different countries on pediatric patients with renal diseases was not severely impaired. (14, 17, 32,33). In facts it was higher than studies in the developing and regional countries (1,11-13,15, 21, 31). However, special consideration should be given to the variation in study design (scales utilized, age varieties, type and stage of disease).

The overall HRQOL as well as physical, social, emotional, school functioning was low. Yet, the greatest alterations were in school and emotional functioning. Impaired academic achievement may be attributable to frequent hospital admissions which interfere with school attendance. Besides, the disease itself restrict their learning capabilities and cognitive functioning. They have difficulty in perception, attention, accomplishment, time managements and remembering steps of a task that has been given to them. (13,14,17-20)

The negative impact on HRQOL scores in the emotional and social functions may be due to delay in physical growth and developments, alteration in the body image (9,11,12). The isolation, anxiety and depression due to the recurrent hospitalization and restrictions enforced by the disease (13,15,20). The social struggling, especially at school due to physical weakness make them unable to share in peer-related activities. As a result, they usually feel solitude, rejected, and socially isolated. The current study results were consistent with numerous published studies documenting that children with CKD report worse physical psychosocial health and school performance despite the different studies using different questionnaires (12,13-16)

The family environment was another vital factor when assessing HRQOL in children with renal diseases. More specifically, parents' education level and socio-economic status. Advanced parents' education was associated with higher HRQOL scores, which is consistent with previous studies on the positive association between parents' education and HRQOL. Parents' educational level, is greatly associated with their children's quality of life (26,27,30).

Before the diagnosis, low educational level of the parents is associated with the delay in seeking medical care. Parents may not recognize their children needs to medical support, or they overlook its importance. Early detection and management before the deterioration in renal function or the appearance of complications is important, failure to seek help may cause worsening of the child's health. After diagnosis, level of education affects child's response to the disease and health progress over time. Low educational level parents may exhibit difficulty in supporting child emotional psychosocial needs, caring of the child especially if advanced machines needed at home (26-30).

Furthermore, the current study finding demonstrate that family with poor economic status show poor assessment of HRQOL. Renal diseases require expensive treatments, procedures and hospitalization, family financial problems may impeded access to health care (28,30).

3. CONCLUSION

This study concluded that children with different types of renal disease suffer HRQOL disturbances. School and emotional functioning problems are the most prominent. Additionally, the family environment has a huge effect on HRQOL especially parent's education and socio-economic status.

While, previously published studies have described impaired quality of life in children with renal disease, this is the first study to describe Jordanian children quality of life impairments. More studies are needed on national level since this study is conducted on one hospital.

4. RECOMMENDATION

This study recommends an Integrated program between child's home, school and health care facilities to educate, support and improve children's HRQOL. Also, to add the HQOL scale as a part of the clinical assessment of these children.

5. LIMITATION

There are a few issues that limit the generalizability. First, this study conducted in one hospital, it is important for findings to be replicated nationally. Secondly, does not have compassion healthy children group. This limitation, however, should not change the internal validity of the study in examining factors that are associated with poor health related quality of life in children with renal diseases.

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