

Original Article

Assessment of quality of life in children with chronic kidney disease on dialysis and their mothers.

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ABSTRACT

Introduction: Chronic kidney disease in children (CKiD) represents a major global health issue that is becoming more and more common. It burdens the child and his family. Their quality of life (QoL) is impacted.

Aim of the study: to assess the quality of life (QOL) of children with end-stage renal disease (ESRD) and their mothers.

Methods: This study was carried out in Pediatric Nephrology Unit at Assuit university Hospital on 35 child with ESRD on regular hemodialysis and their mothers. Using WHOQOL-BREF, Peds QL-ESRD and Parental Stress Scale .in a period from May 2022 to May 2023.

Results: According to Peds QL-ESRD, there is low quality of life in all of its domains, with children ≥ 12 years have higher quality of life than younger children in the worry domain with significant p- value ($=0.049$). As regard duration of dialysis, children on dialysis more than one year had higher quality of life than those less than one year. Mothers of children with ESRD show low quality of life according to WHOQOL-BREF. There is a significant difference according to their age in the psychological domain (p value $=0.049$) and social domain (p- vale < 0.010). Parental Stress Scale shows elevated level of stress with significant p-value < 0.001 .

Conclusion: Quality of life of children on regular hemodialysis and their mothers is low in most aspects. Older children and older mothers had better quality of life than younger ones suggesting that older experienced mothers can cope better with their diseased children. Mothers of ESRD children have elevated level of stress in general but they are satisfied.

Keywords: Quality of life, chronic kidney disease, dialysis

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geget: The Journal of the Egyptian Society of Pediatric Nephrology and Transplantation (ESPNT)

geget <https://geget.journals.ekb.eg/>

Published by ESPNT <http://espnt.net/>

Cohosted by Egyptian Knowledge Bank <https://www.ekb.eg>

INTRODUCTION

Chronic kidney disease (CKD) in children is a serious health problem with an increasing incidence nowadays [1]. CKD children and their families have high physical and psychological burden. Families are usually disappointed, exhausted, with continuous emotional uncertainty about the permanent nature of the disease. Such heavy burden can lead to a negative effect on the child's health outcomes, and their psychological development. In addition, it can be disabling for parents themselves as well [2]. Health-related quality of life (HRQoL) is a subdomain of quality of life (QoL) which points to subjective perception of how health-related issues can affect the individual well-being and personal satisfaction with life [3]. Children with chronic kidney disease (CKD) require sophisticated, ongoing, and comprehensive care from their parents to improve their HQoL. [4] Actually, neglection of such comprehensive care can result in deterioration of social, cultural, and health-related functions [5].

Regular dialysis is considered as a disease of the whole family. Giving medications, making frequent hospital visits, maintaining personal hygiene, offering patients physical, emotional, and social support, and following certain guidelines during hemodialysis are exhausting for all family members. Parents usually give superiority to the patient's needs compared to their own needs, and this can adversely affect their own QoL. [6]. This study aimed to assess the quality of life of children with ESRD on regular HD and their mothers.

METHODS

The study was performed on 35 ESRD child and their mothers as caregiver. They represent whole number of patients who fulfill inclusion criteria in our pediatric nephrology unit at our hospital. The present work was carried out from May 2022 to May 2023.

Type of study: cross sectional study.
Inclusion criteria: children with (ESRD) on regular hemodialysis, aged from 5 years to 18 years old of both sex were included . Caregiver of child is his/her mother. **Exclusion criteria:** children aged less than 5 years and if the caregiver is not the mother were excluded from the study.

Outcome measures

1- Structured questionnaire sheet that was utilized to evaluate the personal and medical data of the participating children. The personal data included (age, sex, birth order, educational level, parents' education, and occupation), However, the medical information included (the duration of illness, duration of hemodialysis, No of sessions/week, the age at time of diagnosis, and related co- morbidities).

2-The World Health Organization Quality of Life-Brief (WHOQOL-BREF)(Arabic version): A 26-item adaptation of the WHOQOL-100 evaluation, the WHOQOL-BREF Instrument is designed to quickly assess health-related functions across four domains of health. Cross-cultural applicability has been encouraged by its proven reliability and extensive use in a variety of cultural groups, including the Arab general population.

Four domains comprise the WHOQOL-BREF instrument: environment (8 items), social relationships (3 items), psychological health (6 items), and physical health (7 items). The final two

items deal with the overall assessment of quality of life (Q1) and Q2). Every question has a score ranging from 1 to 5, with higher scores denoting a higher quality of life. The total HRQOL is measured using a 5-point Likert scale that goes from 1 = (strongly agree) to 5 = (strongly disagree). The mean scores of the responses to each subscale were used to calculate the score. The four domains' raw scores were converted to a 4–20 score, which was then linearly converted to a 0–100 scale, with 100 being the highest QOL and 0 representing the lowest. A higher score denotes a greater standard of living.

3-Pediatric Quality of Life (PedsQL™) scale version 3.0 and it translate into Arabic and to check its locally validated and there local normal values. The instrument is a questionnaire comprising 7 domains with a total of 34 questions/items. The domains include: general fatigue, about my kidney disease, treatment problems, family and peer interactions, worry, perceived physical appearance and communication. For responses aged 8 to 18, a five-point rating system is used ranged from zero equals never a problem, to four equals almost always a problem. For the young child self-report (ages 5–7 years), a three-point answer scale is used as an exception to make it easier for children to respond (0, 2, 4). The scoring system for each item was 0 =100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0.

The total scoring system was used to categorize the QoL of the children. If a child's score was less than 50%, their QoL was deemed poor. If their score was between 50% and less than 75%, their QoL was considered fair. Finally, if their score was between 75% and 100%, their QoL was regarded as good.

4-Parental Stress Scale (PSS):

It is an 18-item self-report measure in which parents respond to statements about their typical relationship with their child. It is a 5-point -type scale. The range is from 18 (low stress) to 90 (high stress), Higher scores reflect more parental stress. It is used to assess degree of maternal stress and worry about her child disease. It also can assess degree of maternal satisfaction about her child condition.

Ethical considerations: This study was carried out after being accepted by the local Ethical Committee of Assuit Faculty of Medicine; We take consent from parents of children after explaining aim of the work to them. Privacy of collected data was assured.

STATISTICAL ANALYSIS

Using SPSS 22.0 for Windows (SPSS Inc., Chicago, IL, USA), all data were gathered, tabulated, and statistically examined. We used the Shapiro Walk test to see if the data were normally distributed or not. The frequencies and relative percentages were used to describe the qualitative data. To compute the difference between the qualitative variables, the chi square test (χ^2) and Fisher exact were employed. Mean \pm SD (standard deviation) and range were used to express quantitative data. To compute the difference between quantitative variables for parametric and non-parametric variables, respectively, the Independent T test and the Mann Whitney test were employed. More than two dependent groups of normally distributed variables were compared using the one-way ANOVA test. For non-normally distributed variables, however, Kruskal-Walli's test was employed. Every statistical

comparison had two tails. P-values at or below 0.05 are considered significant, $p < 0.001$ denotes a highly significant difference, while $P > 0.05$ denotes a non-significant difference.

RESULTS

This work included 35 children with ESRD and their mothers with mean age of children of 12.4 ± 3.37 years. (60%) of patients was more than 12 years old. Meanwhile, 65.7% of patients were males. 57.1% of the patients were on regular dialysis for more than one year. The mean mother age was 38.23 ± 7.23 years, with 62.9% more than 35 years old. According to mother education 57.1% of the patients had no education yet, 28.6% had moderate education, and 14.3% had high education **Table 1.**

Table 2 shows that mean physical domain of the studied mothers was 16.54 ± 2.47 (31%), mean psychological domain was 17.37 ± 2.21 (44%), mean social relation was 9.86 ± 1.14 (50%) and mean environmental domain was 25.57 ± 3.5 (56%). It also shows that older mothers have higher quality of life more than

younger mothers in all domains with significant difference between 2 age groups only in psychological domain and social domain. There was no significant difference in all domains according to maternal educational level.

There is low quality of life according to child peds-QL in all of its domains which did not exceed 50% except communications domain which was higher than 50%. In addition, there is a significant difference between children who were older than 12 years and those who were younger as regard worry domain only. Children on dialysis more than one year showed significantly higher means in 3 domains of quality of life than those with dialysis duration less than one year, but lower mean in treatment problems

Table 3.

Table 4 shows that mean total parent stress scale was 49.83 ± 3.39 and ranged between (44 – 56), which means elevated level of stress and p -value < 0.001 . The mean of parent stress subscale was 35.03 ± 2.97 and mean of lack of parent satisfaction 14.8 ± 2.37 with p -value < 0.001 .

Table1 : Demographic characteristics of the studied children and their caregivers:

Mothers (n=35)		Child	
Age (years) Mean \pm SD	38.23 ± 7.23	Age (years) Mean \pm SD	12.4 ± 3.37
< 35 years	13 (37.1%)	< 12 years	14 (40%)
\geq 35 years	22 (62.9%)	\geq 12 years	21 (60%)
Consanguinity		Gender	
Yes	22 (62.9%)	Male	23 (65.7%)
No	13(37.1%)	Female	12 (34.3%)
Mother education		Duration of dialysis	
High education (university education)	5 (14.3%)	Less than a year	15 (42.9%)
Moderate (diplomat can read and write)	10 (28.6%)	A year or more	20 (57.1%)
No education (can't read or write)	20 (57.1%)		

Table 2: WHOQOL-BREF domains distribution among the studied mothers according to their age

	Total (n=35)	Mother age < 35 yr (n=13)	Mother age ≥ 35 yr (n=22)	P
Domain 1: Physical				
Mean ±SD	16.54 ± 2.47 (31%)	15.62 ± 1.71(31%)	17.09 ± 2.71(38%)	0.087
Range	13 – 22	13 – 18	13 – 22	
Domain 2: Psychological				
Mean ±SD	17.37 ± 2.21 (44%)	15.31 ± 2.59(38%)	18.87 ± 2.02(50%)	0.049
Range	13 – 23	13 – 22	13 – 23	
Domain 3: Social				
Mean ±SD	9.86 ± 1.14 (50%)	9.23 ± 0.832(50%)	10.23 ± 1.15(56%)	0.010
Range	8 – 12	8 – 10	8 – 12	
Domain 4: Environmental				
Mean ±SD	25.57 ± 3.5 (56%)	25.69 ± 3.88(56%)	25.7 ± 3.35(56%)	0.878
Range	20 – 34	22 – 34	20 – 31	

Table 3: Peds QL-ESRD domains distribution among the studied children according to age and disease duration:

	Age < 12 years n=14	Age ≥ 12 years n=21	P	Duration of dialysis < a year n=15	Duration of dialysis ≥ a year n =20	P
Domain 1: General fatigue						
Mean ±SD	24.16±8.9	29.46±14.8	.28 2	25.83±9.1	40.75± 15.49	.01
Range	50 – 150	50 – 250		50 – 150	50 – 250	
Domain 2: about my kidney disease						
Mean ±SD	36.78± 14.88	41.43±14.7	.37 0	38± 14.85	50.03±14.98	.050
Range	75 – 300	125 – 325		50 – 300	50 – 325	
Domain 3: Treatment problems						
Mean ±SD	41.5±17.44	42.56±15.0	.85 2	49.91±19.05	35.06±13.64	.049
Range	25 – 250	50 – 275		25 – 275	50 – 250	
Domain 4: Family and peer interaction						
Mean ±SD	47.03 ±10.6	45.23±13.3	.67 8	47.22±25.41	45±13.89	.601
Range	100 - 200	100 – 225		100 – 200	75 – 225	
Domain 5: Worry						
Mean ±SD	24.28± 7.93	30.4±9.27	.04 9	27± 8.24	39.75± 9.95	.045
Range	100 – 400	150 – 450		100 – 400	150 – 450	
Domain 6: Perceived physical appearance						
Mean ±SD	41.46± 9.80	45.6± 14.8	.43 4	45± 10.82	42.91± 14.63	.646
Range	75 – 175	50 – 225		75 – 175	50 – 225	
Domain 7: Communications						
Mean ±SD	73.57± 5.91	78.35± 9.74	.12 2	77.33± 6.23	75.77±10.63	.616
Range	325 – 450	250 – 450		350 – 450	250 – 450	

Table 4: Parental stress scale among the studied patients.

Studied patients. (n=35)	
Total scale	
Mean ±SD	49.83 ± 3.39
Range	44 – 56
1-Parent stress	
Mean ±SD	35.03 ± 2.97
Range	30 – 40
2-Lack of parent satisfaction	
Mean ±SD	14.8 ± 2.37
Range	11 – 22
P-value	<0.001

DISCUSSION

A serious illness such as CKD affects children and their families in many aspects of life and can have a significant impact on their quality of life (QoL) [7]. Dialysis is suspected to raise the patient's standards of life. However, because this treatment alters social, familial, and personal dynamics, patients and their families may find it difficult to deal with this lifelong modality of therapy. Every day, children and their families must cope with a variety of medical treatments [8].

Sixty percent of the patients in our current study were older than twelve, with the mean age was 12.4 ± 3.37 years. Male patients made up 65.7% of the study population. Regarding the mother's age, it varied from 28 to 60 years old, with a mean of 38.23 ± 7.23 .

Wiedebusch et al.'s [9] investigated the psychosocial stressors, coping mechanisms, and health-related quality of life in parents of children with chronic renal failure. Their study reported similar range of parental age between 22 and 65 years, with 65.1% of their patients were boys. Higher occurrence of congenital abnormalities of the kidneys and urinary tract (CAKUT) in boys can explain higher male incidence of CKD in both studies. The physical, psychological, and social

domains had low mean scores (less than 50) when we examined the WHOQOL-BREF domain scores to characterize quality of life. The environmental domain revealed a moderate score of quality of life.

Dembowska et al.'s study [10] tried to compare the quality of life of patients on HD to that of normal participants. The physical domain had the lowest value of all the assessed domains. The second-lowest value was the psychological domain. However, the domain with the highest mean value was the environmental one. There was a difference in the quality of life based on the maternal age; older mothers had better quality of life than younger mothers in all domains, with the psychological and social domains showing the only significant differences. This may indicate that mothers learn how to care for their children better as they age, enabling them to cope with their illness and enjoy a higher quality of life. Accordingly, the introduction of social and educational initiatives aimed toward younger mothers may contribute to the enhancement of the quality of life of both children and their mothers.

To get more homogeneous data for this work, we exclude children whose caregivers are not their mothers. According to a study by Mahmoud et al. [11], women made up 90.0% of the

caregivers in their work. This can be explained by the fact that women are more likely than men to be emotionally invested in their children disease and to be concerned about their children well-being. It can also be attributed to socio-cultural norms that always place the onus of caregiving on women.

In the present work, no significant difference in all the studied domains according to their maternal educational level. However, El Nagar et al. [12] found that there was a positive relationship between level of maternal knowledge, and their care and support of CKD children. Regarding Peds QL-ESRD domains among the studied patients, there was a low quality of life in all domains not exceeding 50%, except communication domain. This indicates that such children experience a low quality of life in most aspects. This should attract attention to the importance of physical, social, and psychological rehabilitation programs for such weak sad small population. The detrimental impact of CKD on physical function could be attributed to pubertal delay and growth impairment. Both of which are associated with childhood onset of CKD. Physical characteristics that emerge throughout puberty, such short height and bone abnormalities, are crucial components of self-acceptance and self-esteem [13].

Patients above the age of twelve have a better quality of life than those under the age of twelve, only in the worry domain. Our findings were consistent with those of Park et al. [14], who discovered that there were no age-related variations in the PedsQL ESRD domains except in the worry domain. According to duration of dialysis there was significant difference between 2 groups as children on dialysis

for \geq one year was higher quality of life in domains: general fatigue, about my kidney disease and worry, but lower than children on dialysis for less than one year in treatment problems domain. This is likely due to that in the first year of illness, mothers feels huge fear and responsibility for their kids giving medications so less treatment problems. In addition, higher scores of children with longer duration of dialysis may reflect some adaptation from this young population to their illness.

Our study agreed with Darwish et al. [15] who aimed to compare QoL in CKD and healthy children and to find out variables associated with lower quality of life. They reported that children with longer disease duration had higher scores of quality of life than children with shorter duration. They also found that children on conservative treatment achieved higher scores in all domains of PedsQL than those on dialysis.

Concerning parental stress scale among the studied mothers, the mean total parental stress scale was 49.83 ± 3.39 with significant p-value <0.001 which means moderate to high level of stress. The mean parent stress subscale was 35.03 ± 2.97 and mean lack of parent satisfaction 14.8 ± 2.37 with p-value <0.001 , parent stress scale was higher than lack of parent satisfaction which means that mothers are stressed but satisfied and this was reflected from their answers. To our knowledge this is the 1st study which uses Parental Stress Scale in ESRD caregivers.

Bawalsah [16] conducted a study to understand the stress levels and coping mechanisms employed by Jordanian parents of disabled children, Parental Stress Scale (Berry & Jones, 1995) translated into Arabic form was

administered to 134 parents whose children had mental, physical, or hearing impairments. The findings showed that parents of disabled children often suffer significant levels of stress; with parents of children who have physical disabilities typically experience the highest levels of stress. Having a disabled kid is a significant life event that has a negative impact on families and forces them to reassess their plans, objectives, and interpersonal dynamics considering the constraints and limitations imposed by the child's condition.

Parents who have a child with a chronic illness, however, report substantially more stress than parents of healthy children and display poorer psychological adjustment. In addition to experiencing worse health-related quality of life, children with chronic health conditions are more likely to experience emotional and behavioral problems compared with their healthy peers [17].

Parents of children on dialysis reported experiencing stress and difficulty on several levels, according to Ong et al. [18], who tried to systematically examine sources of stress experienced by parents during HD. Parents described themselves as despondent, misunderstood, and socially alienated, handling family issues on their own without enough official or informal support.

The severity of the condition and the extensive care required for these ESRD children, combined with outside stressors like social stigma, may have a negative impact on caregivers' physical and mental well-being, which may then lower the standard of care they can offer their child [19].

Clinical data showing that ESRD patients experience numerous short- and long-term

complications that change their lives, such as frequent hospitalizations, excruciating medical procedures, missed school, and activity restrictions that have a negative emotional and behavioral impact, may help to explain lower scores for ESRD patients and their caregivers [20].

CONCLUSION

In summary, quality of life of children on hemodialysis is low in most physical and social aspects. Older mothers had higher WHOQOL-BREF scores for psychological and social domain, suggesting that older experienced mother age cope better with their diseased children. Mothers of ESRD children have elevated level of stress in general but they are satisfied.

RECOMMENDATIONS

- 1- We recommended that mothers require a range of physical skills and psychological preparation to deal with routine activities and challenges, to maintain a good QOL.
- 2- Social and psychological specialist should be included in the teamwork of any Pediatric Nephrology Unit.
- 3- To improve the QOL of both ESRD patients on hemodialysis and their mothers, the government and Non-Governmental Organizations need to support these groups of people such as developing special support groups that consists of patients, caregivers as well as health staff. They can share their knowledge, experiences, ways to handle crisis, improve treatment compliance and many more.

4- We recommended that future research should include multi centric studies in Egypt. They should be conducted to help development of a special program

for quality of life improvement for Egyptian cases.

ABBREVIATIONS

CKD	Chronic kidney disease
CAKUT	congenital abnormalities of the kidney and urinary tract
ESRD	end-stage renal disease
HR-QOL	Health-related quality of life
Peds-QL	Pediatric Quality of Life
PSS	parental stress scale
QOL	Quality of Life
WHOQOL-BREF	The World Health Organization Quality of Life-Brief

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AUTHORS' CONTRIBUTION

Study conception and design: MAH, ABA

Data collection: BMH, AHI

Statistical analysis of data and interpretation of results: AHI, MAH, ABA

Discussion of results and draft manuscript preparation: ABA, BMH, AHI, MAH

All authors reviewed the results and approved the final version of the manuscript.

STATEMENTS

Ethics approval and consent to participate.

This study protocol and the consents were approved and deemed sufficient by the Ethical Committee of the Faculty of Medicine, Al-Azhar University, Assuit, Egypt. And informed written consent was obtained in every case from their legal guardians.

Consent for publication.

The contents and material of the manuscript have not been previously reported at any length or being considered for publishing elsewhere.

Availability of data and material

"Not applicable"

Conflict of interest

The authors declare no conflict of interest.

Funding

The authors declare that this research work did not revise any fund.

Acknowledgements

Authors would like to thank all patients and their family members for their valuable contributions to the study.

Submitted: 08/11/2023

Accepted: 28/12/2023

Published: 31/12/2023