Perceived Stress and Quality of Life for Children with Chronic Kidney Disease Undergoing Hemodialysis

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Abstract: Background: Chronic kidney disease (CKD) presents a progressive and challenging condition in children, often leading to significant impairment in their quality of life (QoL) and psychological well-being. Aim : To assess perceived stress and quality of life for children with chronic kidney disease undergoing hemodialysis. A descriptive cross-sectional research design was used. Subjects and method were (60) children on hemodialysis from 6 to 18 years' old, enrolled at pediatric hemodialysis units in Assiut University Children's Hospital. Three tools were used to, which included structured interview questionnaire for personal and medical data, pediatric quality of life inventory (PedsQL™ 4.0Generic core scale) and perceived stress level scale. Results: It was found that the all domain of QoL was affected in CKD children and the children physical function is more dominated one (119.16667) while social function is less affected (215.41667). The majority (71.67%) of studied children had high stress level compared to only (6.67%) of children had low stress level. Conclusion: children with CKD undergoing hemodialysis had poor QoL and high perceived stress. Recommendation: The study recommended that provide cooperation of parents, pediatric nephrologists, nurses and psychologist to improve the QoL and psychological condition of children under hemodialysis.

Keywords: Children, Chronic Kidney Disease, Hemodialysis, Quality of Life, Stress.

1. Introduction

Chronic kidney disease (CKD) is considered one of the significant public health problems worldwide. In developed countries, the mortality rate due to CKD is alarmingly high [1**].** Chronic kidney disease (CKD) is characterized by a reduced glomerular filtration rate (less than 60 mL/min/1.73 m2) persisting for at least 3 months or the presence of kidney damage, regardless of the filtration rate (even if it is above 60 mL/min/1.73 m2). Determining the global prevalence of CKD is challenging due to late diagnoses, particularly in low-resource areas, where children are frequently affected. The reported prevalence of CKD in children ranges from 15 to 74.7 cases per one million. However, since CKD often lacks symptoms in its early stages, it is likely underreported or undiagnosed, indicating a potentially higher prevalence among children. In some cases, CKD can progress to end-stage renal disease (ESRD) [2].

CKD is a debilitating condition that significantly impacts the physical and psychosocial well-being of children, leading to a poor (QoL). Children with CKD face various lifestyle restrictions, including dietary and fluid limitations, to manage their condition. These restrictions have a profound effect on their social functioning, as they must carefully balance their nutritional needs, such as maintaining adequate vitamin, iron, and protein levels. Such restrictions can disrupt patients' beliefs about their illness and their sense of personal control, resulting in stress, anxiety, and depression, which hinder their ability to cope and adjust to the challenges of CKD [3].

Advancements in medical treatments like dialysis and kidney transplantation have improved the survival rates of children and young people with CKD. However, despite increased survival, their overall QoL remains compromised and often persists into adulthood [4**].** The long-term need for medication, frequent interactions with healthcare professionals, and disruptions in schooling and daily activities can contribute to psychological difficulties in affected

children [5**].** All these symptoms can influence how individuals perceive stress related to their disease and their perceived health-related QoL. Perceived stress arises when individuals perceive their relationship with the environment as threatening or overwhelming, which can negatively impact their well-being [6**].**

The primary focus of nursing care for pediatric patients with CKD revolves around primary prevention, early detection, and proactive management. Pediatric nurses play vital roles in stress reduction among children undergoing hemodialysis. Through their provision of physical comfort, emotional support, education, and facilitation of coping strategies, nurses contribute to enhancing the overall well-being and QoL of these children. Multidisciplinary collaboration and ongoing professional development in pediatric nephrology are essential to ensure optimal care for children on hemodialysis [7**].**

1.1. Significant of the Study

Assessing (QoL) and stress levels is as crucial indicators for appraising healthcare interventions and treatments. These measures play a vital role in comprehending the impact of diseases, discerning disparities in health, allocating healthcare resources effectively, and facilitating epidemiological studies and health surveys.Understanding the relationship between perceived stress and QoL in children undergoing hemodialysis is crucial for developing effective interventions and support strategies to improve their well-being.

1.2. The aim of the Study: was to assess perceived stress and quality of life for children with chronic kidney disease undergoing hemodialysis

1.3. Research Questions

1. What is the prevalence of perceived stress among children with CKD undergoing hemodialysis?
2. What is the QoL among children with CKD undergoing hemodialysis?
3. How does perceived stress affect the physical, emotional, school and social aspects of QoL in children with CKD undergoing hemodialysis?
4. Are there any demographic or clinical factors that influence the relationship between perceived stress and QoL in this children?

2. MATERIALS AND METHODS

2.1. Research Design

A descriptive cross sectional research design was utilized in this research.

Setting:

The study was conducted at pediatric hemodialysis units in Assuit University Children's Hospital.

Subjects:

Purposive sampling of 60 children undergoing hemodialysis enrolled from previous mentioned setting.

Inclusion criteria include:-

- Children between the ages of 6 and 18 years.
- Children diagnosed with CKD who have been undergoing hemodialysis for a minimum of 6 months.

- Patients who have maintained stable dialysis modalities for the past 30 days.
- Patients who have not been hospitalized within the previous 14 days
- . Within the preceding 30-day period, the child has not encountered any stressful life event unrelated to their kidney ailment, such as the death of a family member or loss of a relative.

Outcome measures:

Tool (1): Structure Questionnaire Sheet, it included two parts:-

Part one: Personal data such as (Age, gender, birth order, residence and educational level).

Part two: Medical data such as (Duration of illness, duration of HD treatment**,** number of session per week, age at disease diagnosis and associated diseases).

Tool (2): Pediatric quality of life inventory (PedsQL™ 4.0Generic core scale) which was used to assess the children's QoL. The HRQOL questionnaire consisted of 23 items that were categorized into four domains: physical (8 items), emotions (5 items), social functioning (5 items), and school performance (5 items). Each item was scored on a scale of 0-4.

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.

- Poor QoL if child score was less than 50%
- Fair QoL if child score was between 50% and less than 75%.
- Good QoL if child score was between 75% and 100%.

Tool (3): Perceived Stress Scale

The Perceived Stress Scale (PSS) [8]is a classic stress assessment instrument. This tool, helping to understand how different situations affect feelings and child perceived stress. The questions in this scale asked about child feelings and thoughts. In each case, the child was asked to indicate how often felt or thought a certain way. This scale consisted of 10 questions; each question was earn score from (0-4).

Scoring system:.

- From 0 :13 was low stress.
- From 14 : 26 was moderate stress.
- From 27 : 40 was high perceived stress.

2.2. Method of Data Collection

- Official authorization was obtained from the director of pediatric hemodialysis units at Assuit University Children's Hospital to collect the required data for this study.

- A pilot study was conducted on 10% (6) of the children to assess the clarity and applicability of the research tools and estimate the time needed to complete each questionnaire.

- Written informed consent was obtained from the parents of each participating child, ensuring the confidentiality and exclusive use of data for research purposes.

- The HRQOL measure used in this study was assessed for reliability and validity, showing good internal consistency (α = .98).
- The perceived stress scale used in this study demonstrated good internal consistency with a reliability of α = .86.

- The research was conducted over a four-month period, starting from July 2022 and ending in November 2022. Data collection took place three days per week from 8:00 am to 8:00 pm. Each child was interviewed individually, with the researcher introducing herself and explaining the purpose of the study to the selected child. The questionnaires were read, explained, and the choices were recorded by the researcher. The average time taken for each child to complete each questionnaire was 30 minutes.

2.3. Ethical Consideration

A research proposal was approved by the local Ethical Committee in the Faculty of Nursing at Assiut University.

Each parent of a child who participated in the study provided written informed consent, and it was ensured that the information would be kept private and used only for research purposes.

2.4. Statistical Analysis

Analyze the collected data using appropriate statistical methods such as correlation analysis, t-tests, chi-square tests, and regression analysis to explore the relationship between perceived stress and quality of life, while considering the influence of demographic and clinical factors. A P-value of 0.05 was stated statistically significant.

3. Results

Table (1) Distribution of studied children relating to personal data n=60.

Children's personal data	(n=60)	
	N	%
Child age		
6 <10 years	11	18.3
10<14 years	20	33.3
14:18 years	29	48.3
Gender:		
Male	39	65.0
Female	21	35.0
Birth order:		
1st	15	25.0
2nd	23	38.3
3rd	12	20.0
4th and more	10	16.7
Level of education:		
Illiterate	6	10.0
Primary education	25	41.7
Preparatory education	15	25.0
Secondary education	14	23.3
Residence		
Urban	18	30.0
Rural	42	70.0
Consanguinity of parent:		
Positive consanguinity	39	65.0
Negative consanguinity	21	35.0

Table (2): Allocation of examined children pertaining to their clinical data n=60.

Clinical data	**(n=60)**	
	N	%
Cause of kidney failure:		
Unknown cause	18	30.0
Congenital anomalies	23	38.3
Glomerulonephritis	10	16.7
Nephrotic syndrome	7	11.7
Lupus nephritis	2	3.3
History of other family member affection with renal failure		
Yes	13	21.7
No	47	78.3
Associated diseases:		
Yes	25	41.7
No	35	58.3

Table (3): Allocation of examined children pertaining to their hemodialysis therapy n=60.

Hemodialysis therapy	**(n=60)**	
	N	%
Duration of hemodialysis therapy/ years:		
<one year	12	20.0
1<5 years	32	53.3
5<10 years	14	23.3
10 years	2	3.3
Number of session per week:		
Two sessions	18	30.0
Three sessions	42	70.0
Duration of each session/ hour:		
3 hours	3	5.0
4 hours	56	93.3
5 hours	1	1.7
Dialysis access:		
Arterial venous shunt	17	28.3
Arterial venous fistula	43	71.7
Complications during dialysis session:		
Yes	41	68.3
No	19	31.7
If yes		

✓	Nausea and vomiting	4	6.7
✓	Dizziness, confusion and headaches	3	5.0
✓	Shortness of breath and chest pain	3	5.0
✓	Muscle cramps	4	6.7
✓	Hypotension	12	20.0
✓	Hypertension	15	25.0

Table (4) Allocation of examined children pertaining to QoL aspects' scores n=60.

QoLaspects	Test Value = 0					
	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
Physical functioning	5.546	59	.000	119.16667	76.1736	162.1597
Emotional functioning	8.092	59	.000	132.50000	99.7353	165.2647
Social functioning	12.478	59	.000	215.41667	180.8709	249.9624
School functioning	11.243	59	.000	172.50000	141.7981	203.2019
Total score	9.884	59	.000	639.58333	510.0955	769.0711

One-Sample Test

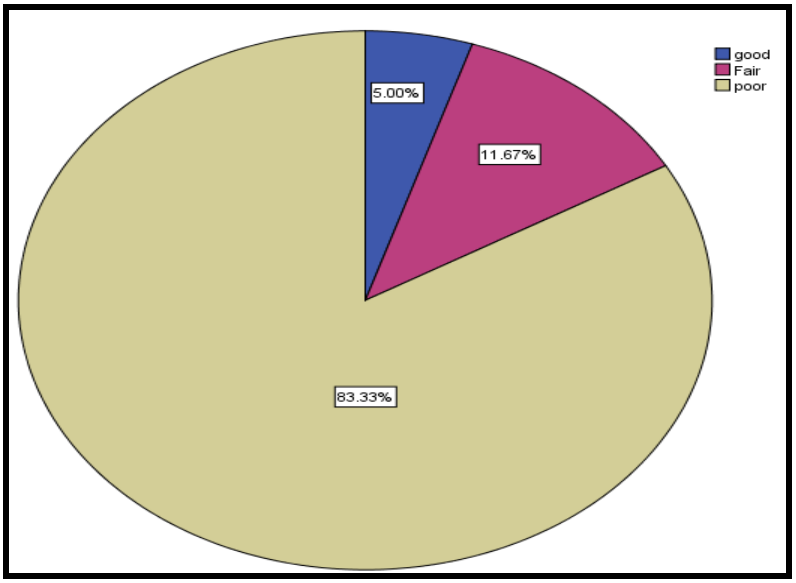

Figure (1): Allocation of examined children pertaining to total QoL level n=60.

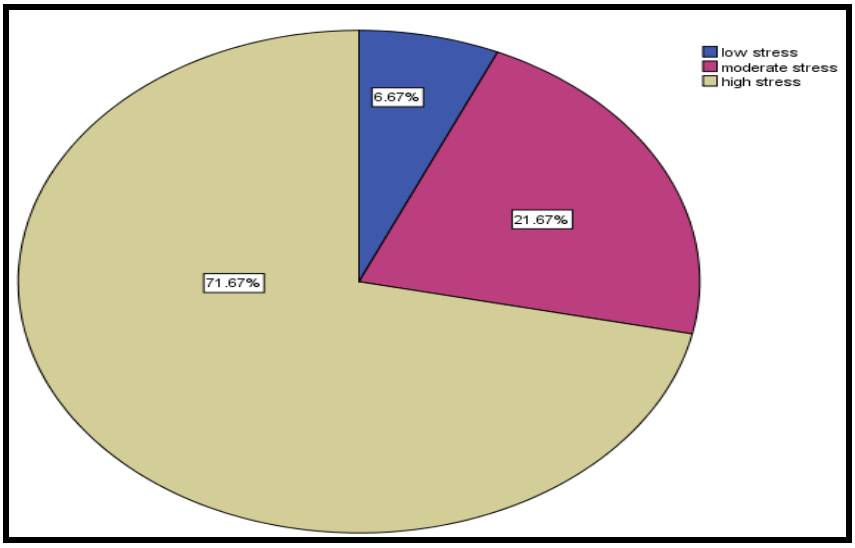

Figure (2): Allocation of examined children pertaining to total perceived stress level n=60.

Table (5) Correlation between examined children perceived stress score and their total QoL with their personal and clinical data n=60.

		Total Quality of Life	Perceived Stress Score	Age	Residence	Gender	Duration of hemodialysis therapy	Associated diseases
Total Quality of Life								
Perceived Stress Score	r-value	**.665-****						
	p-value	**.000****						
Age	r-value	.165	.084					
	p-value	.208	.523					
Residence	r-value	.077	.042	.202				
	p-value	.559	.748	.232				
Gender	r-value	.104	.020	-.106-	-.130-			
	p-value	.428	.877	.421	.324			
Duration of hemodialysis therapy	r-value	**.486****	**.487****	**.300***	-.010-	.042		
	p-value	**.000****	**.000****	**.020***	.941	.749		
Associated diseases	r-value	**-.287-***	-.211-	.067	-.037-	.124	-.159-	
	p-value	**.026***	.106	.612	.780	.345	.226	

**Correlation is high significant at the 0.01 level (2-tailed.)
*Correlation is significant at the 0.05 level (2-tailed).

Table (1) shows the distribution of studied children regarding their personal data. It was noted that near to half (48.3%) of children were in the age group 14–18 years old. Regarding child gender and level of education, more than half (65%) of children were male and less than half (41.7) were in primary school. Also, (70%) of children were from rural areas. It was also observed that (65%) of the studied children's parents had positive consanguinity.

Table (2) represents allocation of examined children pertaining to their clinical data. It was observed that (38.3%) of the studied children the mean cause of renal failure was due to congenital anomalies in the urinary system. Regarding history of other family member affection with renal failure more than three quarter (78.3%) had positive family history of renal failure. It was also shown that (58.3%) of the studied children didn't have any disease associated with renal failure.

Table (3) presents the allocation of examined children pertaining to their hemodialysis therapy. It was found that (53.3%) of the studied children, the duration of hemodialysis was from 1 to 5 years. In relation to the number of sessions per week, most (70%) of the studied children had three sessions per week. Also, this table enumerated that the vast majority (93.3%) of studied children, the duration of each session was 4 hours, and dialysis access was done by using an arterial venous system (71.7%).Finally (68.35%) of children had complication during hemodialysis and the hypertension is the most common complication.

Table (4) displays the QoLof studied children. It was found that the all domain of QoL was affected in CKD children and the children physical function is more dominated one (119.16667) while social function is less affected (215.41667).

Fig (1) illustrates that the majority (83.33%) of studied children had poor QoL level compared to only (5%) of children had good QoL level.

Fig (2) illustrates that the majority (71.67%) of studied children had high stress level compared to only (6.67%) of children had low stress level.

Table (5) represents that there was highly statistically significant negative correlation (P.Value =0.000) between children PedsQLTM score and perceived stress score. Also highly statistically significant correlation between duration of hemodialysis therapy with PedsQLTM score, perceived stress score and child age (.000**, .000**, .020*) respectively. Finally there was a significant association between PedsQLTM score and associated diseases (P.Value =0.026*).

3. DISCUSSION

CKD is a serious health issue for children worldwide, often requiring renal dialysis or kidney transplantation for survival. CKD affects various aspects of a child's life, influencing their (QoL) and relationships with peers and family. It can lead to severe limitations in daily living activities and psychological problems[9**] .**

Based on the current study's findings, it was observed that nearly half of the children fell within the age range of 14-18 years **(Tab1)**. This observation leads to the hypothesis that the adoption of an unhealthy lifestyle and the delayed treatment of pre-existing comorbidities have had detrimental effects on the renal system's integrity in children. These findings are consistent with a previous study conducted by **(H. Salama et al.)** [10**]** where the mean age of children in the study and control groups was reported as 11.28 ± 2.84 and 12.04 ± 3.29 years, respectively. Additionally, **(Gheissari et al.**) [11**]** also found similar results in their study on CKD in children, with children undergoing hemodialysis having an average age of 11.01 ± 0.39 years.

As shown in the present study regarding the gender distribution of the participants, it was observed that more than half of the children were male **(Tab1)**. This observation supports the notion that males generally possess larger kidneys compared to females, which may render them more susceptible to certain kidney-related conditions. Furthermore, the hormonal profiles of males may differ, potentially influencing kidney function. These findings are in line with previous studies conducted by**(Sadeghinejad et al.**) [12] **, (Mahmoud Farrag et al.)** [13**] ,** also with **(Güzel et al.)** [14] they explored the effect of gender on acute kidney injury in the intensive care unit and found a higher prevalence of acute kidney injury among males compared to females.

The current results also revealed that more than two third of studied children were from rural areas **(Tab1)** and this may be indicated that CKD is more prevalent in rural areas than urban. This can be explain in the light of many factor as rural areas often have limited access to healthcare facilities, poor sanitation and hygiene, certain environmental factors prevalent in rural areas, such as exposure to toxins, pollutants, and agricultural chemicals, may increase the risk of kidney damage. These results is congruent with**(Abd El-Hamid Hassan et al.**) [7]who found that more than two third of children were from rural area.

Regarding the QoL in children with CKD undergoing hemodialysis **(Tab 4, Fig 1)**, the current study denoted that the all domain of QoL was affected with CKD and the children physical function is more dominated one while social function is less one and the majority of studied children had poor QoL level compared to only five percent of studied children had good QoL level. This is explained by the researcher as CKD can cause various physical symptoms such as fatigue, weakness, poor appetite, nausea, vomiting, and difficulty sleeping. These symptoms can directly impact a child's daily activities, energy levels, and overall well-being, leading to a decreased QoL. Living with a chronic illness like CKD can take an emotional toll on children. They may experience feelings of sadness, anxiety, frustration, or isolation due to their health condition and the lifestyle adjustments they need to make. Children with CKD may face challenges in attending school regularly due to medical appointments, hospitalizations, or the need for homebound education. They may also experience difficulties in participating in physical activities or social events due to their health limitations. This result go on line with**(Pardede et al.)** [15**]** and**(Aier et al.)** [2**].**

It was found that the majority of the studied children had a high stress level **(Fig2)**. This might be explained as the child's experience with dialysis may entail various physical and psychological strains, exacerbated by the unpredictability of the body's response to treatment, painful fistula cannulation, the need for lifelong medication, social limitations, and the uncertainty of how the body will react to unforeseen stressors, this creates apprehension and stress **(Marthoenis et al.)** [16**].** These results were in accordance with**(Nurdina et al.**) [17] who observed that the average distress thermometer score for pre-test stress was high , which decreased in the post-test.

The current study also indicated that, there was highly statistically significant negative correlation (P.Value =0.000) **(Tab5)** between children PedsQLTM score and perceived stress score. Also highly statistically significant positive correlation between duration of hemodialysis therapy with PedsQLTM score, perceived stress score and child age. Also there was a significant association between PedsQLTM score and presence of associated diseases with CKD (P.Value =0.026*).It can be explained by the research as the fact that comorbidities are common in children with CKD and can have a significant impact on their overall health and well-being. The presence of this associated disease can impact a child's psychological wellbeing in a number of ways, such as increasing symptoms, limiting activities, and increasing the burden of treatment which ultimately increases stress in children. This finding was in line with a study conducted by **(Baek et al.)** [18**]** who cited that the child's self-reported total health score was significantly affected by the presence of comorbid chronic diseases.

Finally there was no statistically significant differences were found between child QoL and child age, gender and residence**(Tab5)**. These results are in line with**(Darwish et al.**) [4**]** they revealed that there was no statistically significant difference in children's sex, residence, and QoL between cases and controls. Our results contradict**(Mbeje & Mtshali)** [19**]** and **(Abu-El-Goud et al.)** [20**]** who noted that female sex was associated with lower HRQOL total health scores than male sex.

Conclusion

The findings of this study clearly demonstrate the negative impact of CKD on various dimensions of children's QoL, including physical, social, emotional, and school functioning. Physical function was found to be the most affected, while social function was relatively less impacted. Additionally, a significant majority of the children examined exhibited high levels of stress, and a strong negative correlation was observed between their (QoL) and stress levels (p-value 0.000).

Recommendations

- In the management of pediatric CKD, it is crucial to incorporate the assessment and management of QoL.
- Distinct school tutorial programs should be developed specifically for children with CKD to enhance their academic performance.
- Educating children and their families about the nature of the disease, treatment plans, and the importance of medication adherence is essential.
- Encourage children to engage in spiritual activities to enhance self-satisfaction.
- Dialysis centers should be prepared to cater to the amusement and entertainment needs of children, aligning with their age group. This will improve their psychological state and make dialysis sessions more enjoyable and comfortable.
- Collaboration between pediatric nephrologists, social specialists, psychotherapy specialists, and nurses is crucial in conducting child rehabilitation sessions. These sessions aid in the reintegration of children into society, enhance self-acceptance, and boost their confidence.
- Further studies should be conducted to devise specialized programs aimed at improving quality of life.

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