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Health-related quality of life in children and adolescents with chronic kidney diseases at Sohag, Egypt: a case–control study

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Abstract

Background and objectives

Chronic kidney diseases (CKD) have multiple complications that could impair the quality of life in the affected children and their families. This study aimed to assess the health-related quality of life (HRQOL) and detect factors affecting it in children with CKD and their families at Sohag, Egypt.

Patients and methods

The study included 113 children and adolescents with CKD stages 1–5, aged 2–18 years old, attending the pediatric nephrology outpatient clinic and the pediatric dialysis unit at Sohag University Hospital. Two hundred twenty-six children were in the control-group age and sex matched to cases with urinary-system condition but with minor and transient ailments, for example, common cold, diarrhea, etc. The PedsQL version 4.0 Measurement Model was used to assess HRQOL for the study participants and their parents.

Results

Children with CKD and their parents had significantly lower mean scores for different domains of HRQOL ($P < 0.0001$). Multivariate regression analysis of factors associated with HRQOL revealed that hemoglobin concentration was the most significant variable associated with self-reported HRQOL total health scores ($B = 4.0$, confidence interval: 2.5; 5.5, $P < 0.0001$) followed by the presence of associated chronic illnesses and the female sex. The disease stage was the most significant variable ($B=-4.5$, confidence interval: −6.2; −2.8, $P < 0.0001$) associated with parent-reported HRQOL total health scores.

Conclusion

CKD impaired the HRQOL for the affected children and their families. Detection of CKD at early stages of the illness, improving hemoglobin concentration in the affected children, and preventing comorbid illnesses might improve the HRQOL for those children and their parents.

Keywords: Children and adolescents, chronic kidney diseases, health-related quality of life

Introduction

Health-related quality of life (HRQOL) can be defined as an index of a patient's perception of their own position in life made over the course of a particular disease and its treatment [1]. The study of HRQOL focuses on the assessment of the impact of the disease and therapy on a patient's life, as subjectively perceived by the patient [2]. Several instruments and questionnaires have been developed for the estimation of HRQOL in children and adolescents and are now available for use in these populations [3].

Chronic kidney disease (CKD) is defined as the presence of a structural or functional kidney abnormality for more than or equal to 3 months detected by laboratory tests, imaging, or histopathological examination [4]. A glomerular-filtration rate

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less than 60 ml/min/1.73 m^2 for more than or equal to 3 months is consistent with the presence of CKD [5]. The annual global prevalence of CKD was estimated to be about 82 cases per one million children [6].

Children with CKD need strict dietary and lifestyle modifications and frequent medical consultations. Moreover, several cardiovascular, hematological, endocrinal, and psychosocial complications might be associated with CKD. These factors could affect the quality of life for children with CKD and their families [7].

Several previous studies were conducted to assess the effect of CKD on the HRQOL of the affected children and their families. Kiliś-Pstrusińska *et al.*[8] assessed the HRQOL of 205 children with CKD (on conservative and dialysis treatment) and their 388 parents/proxies and found that the HRQOL scores for children with CKD were significantly lower compared with population norms. Gerson *et al.*[9] assessed the HRQOL in children with mild-to-moderate chronic CKD and revealed that those children had significantly lower physical, emotional, social, and school-functioning HRQOL scores in comparison with the healthy-control group.

However, only a few studies were conducted to assess the HRQOL among children with CKD and their families in Upper Egypt. There is a need to assess the impact of CKD on the HRQOL for those children and their families and to find out any community-related factors that may affect HRQOL for them.

Therefore, this study aimed to assess the HRQOL for children with CKD attending Sohag University Hospital and their families in comparison with sex-matched and age-matched healthy-control children and to find out factors that affect the HRQOL among those children and their families.

Patients and methods

Study settings

This was a case–control hospital-based study conducted over 1 year from December 2019 to November 2020 at Sohag University Hospital, Sohag, Egypt.

Inclusion and exclusion criteria

The study included children and adolescents aged 2–18 years old who were diagnosed with CKD for at least 3 months prior to their participation in the study, whether they were on conservative treatment or hemodialysis. We excluded children and adolescents who had major life events affecting the quality of life in the last 6 months (e.g., death of one of the parents). Children and adolescents who were unable to speak (mute) or listen (deaf) were also excluded.

One-hundred thirteen pediatric patients with CKD were included as cases, and 226 healthy children and adolescents' sex matched and age matched to cases with no urinary-system condition but with minor and transient ailments (common cold, gastroenteritis, etc.) were included as controls. Seventy-nine cases were recruited from the pediatric nephrology outpatient clinic, and 34 cases on hemodialysis were recruited from the pediatric dialysis unit. The control children were age matched, sex matched to the cases and were recruited from children attending the pediatric outpatient clinic with acute nonserious complaints and without evidence of any chronic diseases.

Data collection

Data were collected through personal interviews with the study participants and their parents using the following.

Medical data-collection sheet

It was developed by the investigators and was evaluated by two senior pediatric nephrologists and included the following:

(1) Sociodemographic data of the study participants: age, sex, and place of residence.
(2) Family history of the study participants: age, educational level and occupation of the parents, the monthly income of the family, the number of siblings, and the order of the child in the family.
(3) Data related to the disease (for cases only): the time of onset of the disease, the primary illness – if known –, the duration of the disease, the type of treatment, the duration of dialysis – if on dialysis –, the presence of other chronic diseases, and the most recent results of some investigations done for the cases, such as serum creatinine, hemoglobin concentration, and albumin in the urine.

The Arabic translation for Egypt of The Pediatric Inventory of Quality of Life Core Scales, version 4.0 (Mapi Research Institute, Lyon, France).

It was obtained from Mapi Research Trust (https://mapi-trust.org) following their approval. This is a 23-item generic health-status instrument that assesses five domains of health (eight items for physical functioning, five items for emotional and psychological functioning, five items for social functioning, and five items for school functioning).

For children aged 8–18 years old, self-reports, and parent proxy reports, the item scoring was done using a five-item Likert scale from 0 (never) to 4 (always). Items were reverse-scored and linearly transformed to a 0–100 scale as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0.

For young child reports (aged from 5 to 7 years old), three-item Likert scale 0 (not at all), 2 (sometimes), and 3 (always) was used and then transformed to (not at all)=100, (sometimes)=50, and (always)=0.

The parent report for toddlers (ages 2–4) was composed of 21 items comprising four dimensions (physical health, psychological health, social health, and school functioning), but the school-functioning domain was composed of three items only.

The child self-reported scores and the parent-reported scores were calculated separately. The scores for different items of each domain were added to give a total domain score. The mean score of each domain was calculated by dividing the sum of

the items in this domain by the number of items answered. The total health score is the sum of physical health-domain score, psychological health-domain score, social health-domain score, and school-functioning domain score.

Statistical analysis

Data were analyzed using IBM SPSS Statistics for Windows, version 22.0 (IBM Corp., Armonk, New York, USA). Quantitative data were expressed as mean, median, SD, and range (minimum–maximum). Qualitative data were presented as numbers and percentages. A χ^2 test was used for comparison between two or more groups of categorical variables. An independent-sample *t* test was used to compare means between two groups of normally distributed continuous variables. For comparison between two or more groups of nonparametric continuous variables, the Mann–Whitney *U* test and Kruskal–Wallis test were used, respectively.

Spearman's correlation coefficient was calculated between age, serum creatinine, hemoglobin concentration, and disease duration, and the mean scores for different domains of the parent-reported and the child's self-reported HRQOL.

Univariate regression analyses were carried out to determine independent variables associated with the parent-reported and the child's self-reported HRQOL total health scores. Age, sex, place of residence, parental consanguinity, presence of associated chronic diseases, the stage of the CKD, hemoglobin concentration, and serum creatinine were included in the analysis. Only variables that were found to be significant in univariate analysis were included in the multivariate model to find the simultaneous effect of these variables. *P* value less than 0.05 was considered to be statistically significant.

Ethical considerations

The study protocol was approved by the Sohag Faculty of Medicine Research Ethics Committee. Written informed consents were obtained from adolescents over 16 years of age and from the parents of all the study participants. Verbal consents were obtained from children and adolescents under 16 years of age whenever possible. Confidentiality of the data of the study participants was ensured.

Results

The study included 113 children and adolescents with CKD and 226 healthy age-matched and sex-matched control children. Table 1 shows the sociodemographic characteristics of the study participants. The mean age of cases with CKD was 10.2 ± 4.4 years old, and the mean age of the control children was 8.8 ± 4.2 years old. Fifty-seven (50.1%) cases were females, and 117 (51.7%) control children were males. There were no statistically significant differences between cases and controls as regards age, sex, place of residence, parental consanguinity, and the number of siblings. The educational levels of the parents of the cases were significantly lower compared to the educational level of the parents of the control children ($P < 0.0001$). There was no statistically significant difference in the paternal state of employment between both groups. However, a significantly lower percentage of the mothers of cases shared in the labor force in comparison to those of the control children ($P = 0.006$).

The clinical characteristics of children with CKD are shown in Table 2. The mean duration of CKD was 4.0 ± 3.2 years, with a range from 4 months to 17 years. Thirty-four (30.1%) cases had stage-5 CKD (stage of chronic renal failure). The primary causes for chronic kidney problems were steroid-dependent nephrotic syndrome in 31.9% of the cases and steroid-resistant nephrotic syndrome in 15.9% of the cases. The primary cause for CKD was not known in 37.2% of the cases. Seventy-nine (70%) cases were on conservative medical treatment (predialysis stages), and 34 (30%) cases were on hemodialysis. There was another associated chronic illness in 13% of the cases.

Table 3 shows the mean total health score and the mean scores for different domains of the HRQOL reported by the cases, the control children, and the parents of children of both groups. Children with CKD and their parents had significantly lower total health scores and lower mean scores for different domains of HRQOL compared with the control children and their parents ($P < 0.0001$).

Table 4 shows the correlation between sociodemographic and clinical characteristics of children with CKD and their self-reported and parent-reported mean scores for different domains of HRQOL. The age of the child with CKD had significant negative correlations with the self-reported mean scores for the social health domain and school-functioning domain, as well as the parent-reported mean score for the school-functioning domain. The serum creatinine levels of children with CKD had significant negative correlations with self-reported and parent-reported mean scores for all domains of HRQOL, except the self-reported mean score for the psychological health domain. Serum hemoglobin levels had significant positive correlations with self-reported mean scores for all domains of HRQOL, as well as the parent-reported mean scores for the physical health domain and school-functioning domain. There was no significant correlation between the duration of CKD and self-reported or parent-reported mean scores for any HRQOL domain.

Table 5 shows univariate and multivariate analysis of factors associated with the child's self-reported and the parent-reported total health scores for children with CKD. Multivariate regression analysis revealed that hemoglobin concentration was the most significant variable associated with the child's self-reported total health scores ($B = 3.4$, confidence interval: 1.7; 5.1, $P < 0.0001$) followed by the female sex, the presence of associated chronic illness, and place of residence, and after elimination, the serum hemoglobin was found to be significantly associated followed by female sex and the presence of other chronic diseases in the final regression model. However, there were no factors significantly associated with the parent-reported total health scores ($P > 0.05$), but

Table 1 Sociodemographic characteristics of the study participants

Sociodemographic characteristics	Cases (n=113) [n (%)]	Controls (n=226) [n (%)]	P
Sex			
Male	56 (49.9)	117 (51.7)	0.5[a]
Female	57 (50.1)	109 (48.3)	
Age			
Mean±SD	10.2±4.4	8.8±4.2	0.06[b]
Median (interquartile range)	9.0 (6.0)	9.0 (7.0)	
Age groups (years)			
2-4	17 (15.0)	48 (21.2)	0.6[a]
5-7	12 (10.6)	42 (18.6)	
8-12	53 (46.9)	91 (40.3)	
13-18	31 (27.5)	45 (19.9)	
Place of residence			
Rural	57 (50.1)	120 (52.4)	0.4[a]
Urban	56 (49.9)	106 (47.6)	
Parental consanguinity	48 (41.5)	98 (43.4)	0.9[a]
Number of siblings			
Median (interquartile range)	4.0 (2.0)	3.0 (1.0)	0.1[c]
Father's educational level			
Illiterate	37 (32.7)	34 (15.0)	
Read and write	19 (16.8)	14 (6.2)	
Primary and preparatory school	7 (6.2)	13 (5.8)	<0.0001[a]
Secondary schools	30 (26.6)	74 (32.7)	
Faculty or institute	20 (17.7)	88 (38.3)	
Father's employment			
Professional	19 (16.8)	47 (20.8)	
Clerical, farmer, driver, or shop owner	36 (34.5)	93 (42.5)	0.7[a]
Skilled or unskilled worker	42 (37.2)	48 (21.2)	
Working abroad	0	22 (9.7)	
Unemployed	13 (11.5)	13 (5.8)	
Mother's educational level			
Illiterate	56 (49.6)	62 (27.4)	
Just read and write	17 (15.0)	15 (6.6)	<0.0001[a]
Primary or preparatory school	5 (4.4)	29 (12.8)	
Secondary school	23 (21.3)	64 (28.3)	
Faculty or institute	11 (9.7)	56 (24.9)	
The mother is sharing in the labor force	12 (10.6)	50 (22.1)	0.006[a]

[a]χ^2 test (categorical variables). [b]Independent t test (parametric test). [c]Mann-Whitney test (nonparametric test).

after elimination of the most insignificant variables, the stage of the disease was found significant in the final regression model (B=−4.6, confidence interval: −6.2; −3.0, $P < 0.0001$).

Discussion

Children with CKD have multiple serious complications and need strict dietary and lifestyle modifications with frequent medical consultations [5]. These factors affect the HRQOL for those children and their families [10]. Early identification of factors affecting the HRQOL in children with CKD may decrease the prevalence of poor educational, occupational, and social outcomes in adults with childhood-onset kidney disease [11].

The current study demonstrated that children with CKD and their parents had significantly lower mean total health scores and lower mean scores for different domains of the HRQOL compared with the control children and their parents. The difference between patients and controls was most obvious and statistically significant in school functioning, this may be due to metabolic disorders, central nervous-system affection, reported fatigue, and poor school attendance in children with CKDs. These findings confirmed the results of previous studies that evaluated the effect of CKD on HRQOL. Lopes *et al.*[12] found that patients with CKD stages 4–5 had lower self-reported and parent-reported mean scores for physical health, social, and school-functioning domains of HRQOL compared with their healthy peers. Similarly, Goldstein *et al.*[13] reported that the mean scores for all domains of HRQOL were significantly lower in children with CKD-stage 5 than in healthy-control children.

Several studies assessed the effect of different factors on self-reported and parent-reported HRQOL scores. Pardede

Table 2 Clinical and laboratory characteristics of participants with chronic kidney diseases

Variables	
Duration of the disease (years)	
Mean±SD	4.0±3.2
Median (interquartile range)	3.0 (3.5)
Stage of the disease [*n* (%)]	
Stage 1 (eGFR ≥90)	22 (19.5)
Stage 2 (eGFR; 89-60)	33 (29.2)
Stage 3 (eGFR; 59-45)	12 (10.6)
Stage 4 (eGFR; 44-15)	12 (10.6)
Stage 5 (eGFR; ≤15)	34 (30.1)
Cause of the disease [*n* (%)]	
Steroid-dependent nephrotic syndrome	34 (30.1)
Steroid-resistant nephrotic syndrome	18 (15.9)
Glomerulonephritis	7 (6.2)
Obstructive uropathy	7 (6.2)
Polycystic kidney or other congenital anomalies	5 (4.4)
Unknown cause	42 (37.2)
Type of treatment [*n* (%)]	
Medical treatment	79 (70.0)
Hemodialysis	34 (30.0)
Positive family history of kidney diseases [*n* (%)]	36 (31.9)
Presence of other associated chronic disease [*n* (%)]	17 (13.0)
Type of associated chronic disease if present [*n* (%)]	
Diabetes mellitus	2 (11.8)
Hypertension	11 (64.7)
Chronic liver disease	1 (5.9)
Cardiac disease	3 (17.6)
Serum creatinine (mg/dl)	
Mean±SD	3.4±3.8
Median (interquartile range)	1.4 (6.3)
Hemoglobin concentration (g/dl)	
Mean±SD	10.9±1.5
Median (interquartile range)	10.9 (2.1)

eGFR, estimated glomerular-filtration rate.

et al.[6] found that CKD duration of more than 60 months and the stage of the disease were significantly associated with both the children's and the parents' HRQOL scores. Gerson *et al.*[9] also studied the association between different factors and the HRQOL for children with mild-to-moderate CKD. They found that higher maternal educational level and the disease duration were significantly associated with the self-reported and the parent-reported means scores for different domains of HRQOL. However, the current study revealed that hemoglobin concentration was the most significant factor associated with self-reported total health scores, followed by the presence of associated chronic illness and the female sex. Moreover, the present study found that the stage of the disease was the most significant factor associated with the parent-reported total health scores.

This study found that hemoglobin concentration had significantly positive correlations with self-reported mean scores for all domains of HRQOL, as well as the parent-reported mean scores for the physical health domain and school-functioning domain. Anemia is a frequent complication of CKD due to erythropoietin deficiency and dialysis-related blood loss. Anemia presents with weakness, easy fatigue, and intolerance to exercise, so it leads to impaired physical, psychological, social, and school-functioning domains [14]. In line with our findings, Imani *et al.*[15] demonstrated that anemia was significantly associated with lower overall parent-reported HRQOL scores. Moreover, Baek *et al.*[16] reported that patients with hemoglobin levels more than 11 g/dl had higher parent-reported physical health mean scores compared with those with lower hemoglobin levels.

Our results showed that the female sex was associated with lower HRQOL total health scores. This is because females are emotionally liable compared with males.

In line with this finding, Tong *et al.*[14] also found that sex was associated with HRQOL scores in children with CKD. However, Gerson *et al.*[9] revealed that the female sex – in comparison with the male sex – was associated with higher school-functioning domain mean scores in the parental reports.

The current study demonstrated that the child's self-reported total health score was significantly affected by the presence of comorbid chronic diseases. This finding agreed with that found by McKenna *et al.* [10], who reported that patients with nonrenal comorbidities had significantly lower self-reported HRQOL mean scores. Moreover, Baek *et al.*[16] reported that patients without comorbidities had better self-reported physical health mean scores compared with those with comorbidities.

In the current study, multivariate-regression analysis revealed that the stage of the disease was the most significant factor associated with the parent-reported total health scores. Similarly, Baek *et al.*[16] found that the parent-reported mean scores for different domains of HRQOL were significantly lower in children with advanced CKD stages, especially those with CKD stage 4. In line with our findings, they also did not find a significant effect for the disease stage on the child's self-reported HRQOL scores. In addition, Pardede *et al.*[6] reported that children with CKD stage 3 and above had lower self-reported and parent-reported mean scores in all domains of HRQOL. Moreover, Imani and colleagues reported that the parents of children with advanced CKD had significantly lower mean scores for physical and social-functioning domains, as well as lower overall HRQOL scores compared with the parents of children with earlier stages of the disease (15 lower HRQOL scores in advanced CKD stages could be related to the multiple complications commonly found at these stages such as nutritional deficiencies and depression with interference with social activities and school attendance) [17]. On the other hand, Kul *et al.*[18] reported that neither the stage of CKD nor the treatment modalities had any significant effects on the self-reported mean scores for any domain of HRQOL. However, the inclusion of children with mild-to-moderate CKD only in their study might explain these findings as the HRQOL is likely to be more affected in later stages of CKD.

Table 3 Comparison between cases with chronic kidney diseases and the control children in self-reported and parent-reported total health mean scores and mean scores for different domains of health-related quality of life

	Self-reported score			Parent-reported score		
	Cases	Controls	*P*[a]	Cases	Controls	*P*[a]
Total health score						
Mean±SD	60.5±13.5	80.4±7.6	<0.0001	54.6±14.1	75.4±9.0	<0.0001
Physical health-domain score						
Mean±SD	56.3±16.8	80.1±11.9	<0.0001	59.9±19.1	71.7±15.3	<0.0001
Psychological health-domain score						
Mean±SD	62.3±13.2	78.0±11.2	<0.0001	56.5±16.7	69.4±12.6	<0.0001
Social health-domain score						
Mean±SD	69.3±13.8	84.1±10.9	<0.0001	59.2±16.1	80.5±12.8	<0.0001
School-functioning domain score						
Mean±SD	59.6±17.2	79.6±12.9	<0.0001	54.8±19.3	74.4±13.7	<0.0001

[a]Mann-Whitney test.

Table 4 Correlations between sociodemographic and clinical characteristics of participants with chronic kidney diseases and their self-reported and parent-reported mean scores for different domains of health-related quality of life (Spearmann correlation test)

	Physical health correlation coefficient	*P*	Psychological health correlation coefficient	*P*	Social health correlation coefficient	*P*	School functioning correlation coefficient	*P*
Age								
Self-reported mean score	0.02	0.57	−0.060	0.86	−0.159	0.01	−0.275	<0.0001
Parent-reoported mean score	0.072	0.45	−0.031	0.74	−0.130	0.17	−0.583	<0.0001
Duration of disease								
Self-reported mean score	0.136	0.19	0.113	0.27	0.129	0.21	0.040	0.70
Parent-reported mean score	0.139	0.15	0.057	0.55	−0.081	0.40	−0.064	0.541
Hemoglobin concentration								
Self-reported mean score	0.440	<0.0001	0.251	0.01	0.469	<0.0001	0.269	0.01
Parent-reoported mean score	0.182	0.06	0.196	0.04	0.339	0.19	0.263	0.003
Serum creatinine								
Self-reported mean score	−0.232	0.03	−0.089	0.40	−0.407	<0.0001	−0.375	<0.0001
Parent-reported mean score	−0.284	0.003	−0.192	0.05	−0.272	0.01	−0.544	<0.0001

The present study demonstrated that serum creatinine levels of children with CKD had significant negative correlations with the self-reported and the parent-reported mean scores for all domains of HRQOL, except the self-reported mean score for the psychological health domain. This is because as serum creatinine increases, the stage of the disease increases with multiple complications affecting children's HRQOL. Similarly, Gerson *et al.*[9] reported that the progressive decline in kidney function was associated with lower self-reported and parent-reported mean scores for different domains of HRQOL.

Previous studies did not find significant effects of the child's age on the self-reported or the parent-reported mean scores for different domains of HRQOL [8,16,19]. However, the current study found significant negative correlations between the age of the child with CKD and both the self-reported and the parent-reported mean scores for the school-functioning domain. Our findings could be explained by decreased school-functioning mean scores for children in the 13–18-year age group due to dropping out of school of some children in this age group.

The current study found that there was no significant correlation between the duration of CKD and the self-reported or the parent-reported mean score for any HRQOL domain. This may be because there were variations: some children and their parents with longer duration of disease reported higher mean scores for different domains of HRQOL due to tolerance to the disease and more adaptation and other children with longer duration of disease and their parents reported lower mean scores as more complications of the disease appeared or progression of the disease had occurred. In line with our findings, Baek *et al.*[16] demonstrated that there was no association between the disease duration and both the child's self-reported and the parent-reported HRQOL scores. Moreover, Kiliś-Pstrusińska *et al.*[8] reported that there was no significant relationship between the child's self-reported mean scores for different domains of HRQOL and the duration

Table 5 Factors affecting the child's self-reported and the parent-reported total health scores for participants with chronic kidney diseases (multiple linear regression)

	Child's self-reported score				Parent-reported score			
	Univariate analysis		Multivariate analysis (after elimination)		Univariate analysis		Multivariate analysis (after elimination)	
	B, r^2 (95% CI)	*P*	*B* (95% CI)	*P*	*B*, r^2 (95% CI)	*P*	*B* (95% CI)	*P*
Female sex	−7.0, 0.2 (−12.3; −1.6)	0.01	−7.0 (−11.9; −2.1)	0.01	−3.0, 0.01 (−8.8; 2.8)	0.31	−3.4 (−9.2; 2.4)	0.24
Age	−2.0, 0.1 (−6.5; 2.4)	0.36	−0.2 (−1.0; 0.5)	0.55	−4.8, 0.1 (−9.4; − 0.3)	0.04	−0.4 (−1.3; 0.5)	0.40
Place of residence	−2.8, 0.01 (−8.4; 2.8)	0.32	−5.1 (−9.8; −0.3)	0.04	−0.4, 0.0001 (−6.3; 5.5)	0.90	−2.1 (−7.6; 3.5)	0.46
Parental consanguinity	2.9, 0.01 (−2.7; 8.5)	0.31	−1.5 (−6.5; 3.4)	0.54	2.3, 0.01 (−3.6; 8.3)	0.44	−1.8 (−7.5; 3.5)	0.55
Presence of associated chronic illness	8.5, 0.1 (1.1; 15.9)	0.03	7.9 (0.8; 15.0)	0.03	7.6, 0.04 (−0.4; 15.6)	0.06	5.7 (−2.9; 14.2)	0.19
The stage of the disease	−3.5, 0.2 (−5.5; −2.3)	<0.0001	−2.3 (−5.4; 0.9)	0.16	−4.6, 0.3 (−6.2; −3.0)	<0.0001	−2.3 (−6.0; 1.4)	0.21
Serum creatinine	−1.3, 0.1 (−1.9; −0.6)	<0.0001	0.4 (−0.9; 1.7)	0.54	−1.8, 0.2 (−2.4; −1.1)	<0.0001	−0.6 (−2.1; 0.94)	0.46
Hemoglobin concentration	4.2, 0.3 (2.6; 5.7)	<0.0001	3.4 (1.7; 5.1)	<0.0001	2.4, 0.1 (0.5; 4.2)	0.01	0.6 (−1.4; 2.6)	0.56
r^2=0.40, constant=38.3					r^2=0.29, constant=62.7			
$Y_i=B_0+B_1X_1+B_2X_2+B_3X_3+B_4X_4$..... $+B_8X_8$					$Y_i=B_0+B_1X_1+B_2X_2+B_3X_3+B_4X_4$..... $+B_8X_8$			

CI, confidence interval.

of kidney diseases. However, Pardede *et al.*[6] reported that children diagnosed with CKD for more than 60 months had a higher risk of having low parent-reported HRQOL scores. On the contrary, Gerson *et al.*[9] reported that increased disease duration among children with CKD was associated with an increase in the child's self-reported physical heath mean score as well as an increase in the parent-reported mean scores for physical and emotional domains of HRQOL.

Conclusion

Children with CKD and their parents reported highly significant mean scores for different domains of HRQOL compared with their sex-matched and age-matched controls. Children with CKD: boys had significantly higher mean scores for physical and psychological domains compared with females. Older children, especially at adolescence, had a significantly lower mean scores for school functioning compared with children in younger-age groups. Female sex, the stage of the disease, presence of other chronic diseases, serum creatinine, and serum hemoglobin were found to affect the children self-reported total health mean scores. Detection of CKD at early stages of the illness, improving hemoglobin concentration in the affected children, and prevention of comorbid illnesses might help to improve the HRQOL for those children and their parents.

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Conflicts of interest

There are no conflicts of interest.

References

1. Sosnowski R, Kulpa M, Ziętalewicz U, Wolski JK, Nowakowski R, Bakuła R, *et al*. Basic issues concerning health-related quality of life. Cent European J Urol 2017; 70:206.
2. Cho MH. Clinical approach to quality of life in children with end-stage renal disease. Korean J Pediatr 2013; 56:323.
3. Tjaden LA, Grootenhuis MA, Noordzij M, Groothoff JW. Health-related quality of life in patients with pediatric onset of end-stage renal disease: state of the art and recommendations for clinical practice. Pediatr Nephrol 2016; 31:1579–1591.
4. Levin A, Bilous R, Coresh J. Chapter 1: definition and classification of CKD. Kidney Int Suppl 2013; 3:19–62.
5. Levey AS, Coresh J, Balk E, Kausz AT, Levin A, Steffes MW, *et al*. National Kidney Foundation practice guidelines for chronic kidney disease: evaluation, classification, and stratification. Ann Intern Med 2003; 139:137–147.
6. Pardede SO, Rafli A, Gunardi H. Quality of life in chronic kidney disease children using assessment Pediatric Quality Of Life Inventory™. Saudi J Kidney Dis Transpl 2019; 30:812.
7. Goldstein SL, Gerson AC, Goldman CW, Furth S. Quality of life

for children with chronic kidney disease. Semin Nephrol 2006; 26:114–117.
8. Kiliś-Pstrusińska K, Medyńska A, Chmielewska IB, Grenda R, Kluska-Jóźwiak A, Leszczyńska B, *et al*. Perception of health-related quality of life in children with chronic kidney disease by the patients and their caregivers: multicentre national study results. Qual Life Res 2013; 22:2889–2897.
9. Gerson AC, Wentz A, Abraham AG, Mendley SR, Hooper SR, Butler RW, *et al*. Health-related quality of life of children with mild to moderate chronic kidney disease. Pediatrics 2010; 125:e349–e357.
10. McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF. Quality of life in children with chronic kidney disease – patient and caregiver assessments. Nephrol Dial Transplant 2006; 21:1899–1905.
11. Armstrong FD. Neurodevelopment and chronic illness: mechanisms of disease and treatment. Ment Retard Dev Disabil Res Rev 2006; 12:168–173.
12. Lopes M, Ferraro A, Koch VH. Health-related quality of life of children and adolescents with CKD stages 4–5 and their caregivers. Pediatr Nephrol 2014; 29:1239–1247.
13. Goldstein SL, Graham N, Burwinkle T, Warady B, Farrah R, Varni JW. Health-related quality of life in pediatric patients with ESRD. Pediatr Nephrol 2006; 21:846–850.
14. Tong A, Wong G, McTaggart S, Henning P, Mackie F, Carroll RP, *et al*. Quality of life of young adults and adolescents with chronic kidney disease. J Pediatr 2013; 163:1179–1185.
15. Imani PD, Aujo J, Kiguli S, Srivaths P, Brewer ED. Chronic kidney disease impacts health-related quality of life of children in Uganda, East Africa. Pediatr Nephrol 2021; 36:323–331.
16. Baek HS, Kang HG, Choi HJ, Cheong HI, Ha IS, Han KH, *et al*. Health-related quality of life of children with pre-dialysis chronic kidney disease. Pediatr Nephrol 2017; 32:2097–2105.
17. Massengill SF, Ferris M. Chronic kidney disease in children and adolescents. Pediatr Rev 2014; 35:16–29.
18. Kul M, Çengel-Kültür SE, Şenses-Dinç G, Bilginer Y, Uluç S, Baykan H. Quality of life in children and adolescents with chronic kidney disease: a comparative study between different disease stages and treatment modalities. Turk J Pediatr 2013; 55:5.
19. Heath J, MacKinlay D, Watson AR, Hames A, Wirz L, Scott S, *et al*. Self-reported quality of life in children and young people with chronic kidney disease. Pediatr Nephrol 2011; 26:767–773.