

Quality of life in children with chronic kidney disease

Ari Fibrianto, Hertanti Indah Lestari, Yudianita Kesuma, Moretta Damayanti,
Eka Intan Fitriana, Rismarini Rismarini

Abstract

Background Chronic kidney disease (CKD) has become a global burden on the healthcare system and significantly impacts the quality of life of children with the condition.

Objective To assess quality of life in children with CKD as well as its relationship with sociodemographic, medical, and psychosocial factors.

Methods This cross-sectional analytic study was conducted from June to November 2021 at Dr. Moh Hoesin Hospital, Palembang. Children with CKD aged 2–18 years were included by consecutive sampling. Parents and patients were asked to complete the PedsQL™ generic score scale version 4.0 questionnaire.

Results We assessed quality of life in 112 children with CKD from parents' and children's reports in the PedsQL™ questionnaire. Physical and emotional parameters had the lowest scores. Based on parental reports, quality of life was significantly associated with disease severity ($P=0.002$), behavioral disorders ($P=0.007$), and sleep disturbances ($P=0.001$). Based on the children's reports, the factors significantly associated with quality of life were anemia ($P=0.044$), sleep disturbances ($P=0.024$), and behavioral disorders ($P=0.002$). Almost one-third of children with CKD had general impairment of quality of life, both from parental reports (32.1%) and children's reports (33.0%).

Conclusion Disease severity, anemia, sleep disturbance, and behavioral disorders were all associated with poorer quality of life in children with CKD. [Paediatr Indones. 2023;63:395-404; DOI: <https://doi.org/10.14238/pi63.4.2023.395-404>].

Keywords: QoL; CKD; children; risk factors

Chronic kidney disease (CKD) is a condition associated with permanent kidney damage, which can progress to end-stage renal disease (ESRD).¹ Approximately 11-13% of the world's population suffers from CKD.² Globally, the prevalence of stage II or lower CKD in children was reported to be 18.5-58.3 per million children in 2012.³ The ItalKid study reported an average incidence of 12.1 cases per year per million in children 8.8 to 13.9 years and a prevalence of 74.7 per million in this population.⁴ In Indonesia, national data on the incidence of CKD is not yet available, especially in children. However, the 2013 Basic Health Research (Riskesdas) report found that the prevalence of CKD in >15-year-olds was 0.2%.⁵ The mortality rate of children with CKD is estimated to be 30 times higher than that of healthy children.^{6,7}

CKD has become a global burden on healthcare systems and has been recognized as a major threat to humans, impacting the quality of life for both

Department of Child Health, Faculty of Medicine, Universitas Sriwijaya/ Dr. Mohammad Hoesin General Hospital Palembang, South Sumatera, Indonesia.

Corresponding author: Ari Fibrianto. Department of Child Health, Faculty of Medicine, Universitas Sriwijaya. Jenderal Sudirman KM 3,5 Street, Palembang, South Sumatera, Indonesia. Telp. +62 81278137016; Fax +62 711 351318; Email: rr_ey@yahoo.com.

Submitted July 7, 2022. Accepted November 8, 2023.

children and adults.^{8,9} The clinical manifestations, complications, and management of CKD affect children's quality of life due to disturbances in physical growth, barriers in development, such as in acquiring motor skills, cognitive disorders, poor school attendance due to frequent clinic visits or hospitalization, emotional disturbances, social relationship disorders, and lack of self-autonomy, which lead to disappointment and low quality of life.¹⁰⁻¹⁴

A previous study compared the psychosocial conditions of children with CKD to those of healthy children in Greece. Their results indicated that children with CKD experienced less social acceptance than healthy children. Children with CKD are physically weaker and less enthusiastic than healthy children.¹⁵ Another study examined the quality of life of 402 children with CKD using the *Pediatric Quality of Life Inventory* (PedsQLTM) tool. The mean total quality of life of CKD children was lower than that of healthy controls [74.78 (SD 14.26) vs. 82.87 (SD 13.16)]. Of children with CKD, 30% had a poor quality of life (score <70).¹⁶ In addition, Pardede *et al.*⁶ found that the prevalence of poor quality of life in children with CKD was 54.5% based on parental reports and 56.3% based on child reports.

Health-related quality of life is influenced by sociodemographic, medical, and psychosocial factors.¹⁴ Previous studies have not fully discussed factors that affect the quality of life of CKD children. Some involve only medical factors, while others only look at sociodemographic and/or psychosocial factors.^{1,6,16-17} Moreover, the results are sometimes contradictory. Pardede *et al.*⁶ concluded that the degree of CKD was not significantly related to the quality of life, while Francis *et al.*¹⁷ and Ademola *et al.*¹⁸ noted that children with a more severe degree of CKD had worse quality of life. In Indonesia, research on the quality of life of children with CKD has been limited.⁶ Therefore, a comprehensive assessment of quality of life in children with CKD is important in order to provide appropriate interventions to improve the quality of life of children with CKD. As such, we aimed to assess quality of life and determine the sociodemographic, medical, and psychosocial factors associated with quality of life in children with CKD at using the *PedsQLTM 4.0 Questionnaire*.

Methods

This cross-sectional analytic study was done to assess quality of life in children aged 2-18 years with CKD who were treated with conservative therapy and hemodialysis. We assessed the association of quality of life with sociodemographic factors, medical factors, and psychosocial factors. The study was conducted in the Outpatient Clinic of the Nephrology Division and Inpatient Unit of the Child Health Department/Dr. Mohammad Hoesin Hospital, Palembang, South Sumatera, from June to November 2021.

Study participants were pediatric patients with CKD treated at the Child Health Department of Dr. Mohammad Hoesin Hospital who fulfilled the inclusion criteria (children aged 2-18 years with a diagnosis of CKD). Participants were recruited by a consecutive sampling method. Exclusion criteria were children with communication problems due to conditions such as intellectual disability, autism, Down syndrome, or cerebral palsy, decreased consciousness, parents' refusal to participate, or incomplete data.

The dependent variable in this study was quality of life of the subjects, evaluated using *PedsQL™ 4.0* with the developers' agreement. *The PedsQL™ Questionnaire* consisted of a child self-report for ages 5-18 years and a parent proxy report for ages 2-18 years. Quality of life was considered to be poor if the total summary score was <70.¹⁷

The independent variables were grouped into sociodemographic, medical, and psychosocial factors. Sociodemographic factors included age, sex, children's and mother's educational level, area of residence, and socioeconomic status. Medical factors consisted of etiology of CKD, disease severity, onset, time since diagnosis, nutritional status, stature, anemia, hypertension, CKD-mineral bone disorder (CKD-MBD), and treatment modality. Psychosocial factors comprised behavioral disorder or sleep disturbance. Mother's educational level was classified as high if they had completed junior high school and low if they had not. Area of residence was classified as rural and urban. Socioeconomic status was assessed by family income based on the provincial monthly minimum wage (IDR 3,043,111 or approximately USD 217).

All data were recorded on study forms and analyzed using *SPSS version 26.0* (IBM, Armonk, New York). Bivariate analysis was done using the

Chi-square test. Variables with a P value <0.25 were further analyzed by multivariate analysis using logistic regression. This study was approved by the Ethics Commission, Faculty of Medicine, Universitas Sriwijaya.

Results

We initially included 129 participants in the study, but only 112 fulfilled the inclusion criteria and had complete data. Nine out of the 112 participants (8%) could not complete the children's report due to their young age (<5 years). We made an adjustment to the question about school due to the COVID-19 pandemic conditions at the time of the study. Low quality of life was reported by both parents (32.1%) and children (33.0%). The mean total quality of life score for CKD children based on parents' and children's reports were similar, namely 76.86 (SD 17.08) and 75.69 (SD 16.61), respectively. Most children reported physical and emotional function as the most commonly affected areas, whereas parents reported mostly physical and school function as the most commonly affected areas. Mean quality of life scores reported by parents and children in each domain are listed in **Table 1**.

The majority of participants were male (53.6%). Subjects had a median age of 11.5 (range 4-17) years, with 35.7% of subjects aged <10 years and 64.3% aged 10-17 years. Based on education level, 83.9% of children had not completed junior high school. Most subjects were in elementary school (40.2%) and junior high school (28.6%). Seven (6.3%) subjects had dropped out of school. There was a similar proportion of mothers with high (50.9%) and low (49.1%)

education levels. Most patients had a total family income below the minimum wage (67.9%) and lived in urban areas (59.8%) (**Table 2**).

The results of the analysis of sociodemographic factors and quality of life in children with CKD are shown in **Table 2**. None of the sociodemographic factors studied were significantly associated with quality of life. However, age was included in the multivariate analysis since it had a P value of 0.10 for parents' report and 0.23 for children's report.

In our study, the etiology of CKD was mostly caused by glomerular disorders, with most subjects at an early stage. The youngest age at diagnosis was 1 year and the oldest was 17 years (median 10 years). Fifty-eight (51.8%) subjects had their CKD onset during adolescence. The shortest duration of illness was 1 month and the longest was 121 months (median 18 months). The majority of subjects (87.5%) had a duration of illness of <60 months. Subjects' nutritional status distribution was 48.3% well-nourished, 38.4% obese and overweight, and 13.4% malnourished. Almost half of subjects had short stature (49.1%), while 50.9% had anemia, 62.5% had hypertension, and 39.3% had CKD-MBD. The proportion of subjects who underwent hemodialysis and continuous ambulatory peritoneal dialysis (CAPD) were 9.8% each, while the remaining 80.4% received conservative therapy. Two-thirds of children received steroids and one-third received immunosuppressants within the previous 3 months. A total of 39 (34.8%) subjects experienced sleep disorders, while 16 (14.3%) had behavioral disorders (**Table 3**).

According to parents' reports, negative associations with quality of life were noted for disease severity, short stature, anemia, CKD-MBD, treatment modality, steroid usage, behavioral disorder, and sleep

Table 1. QoL score in children with CKD

Domain	Parent's report* (n=112)	Children's report* (n=103)
Physical function	72.49 (25.96)	71.99 (25.36)
Emotional function	75.49 (18.69)	73.93 (20.01)
Social function	88.66 (14.27)	85.83 (16.09)
School function	72.23 (20.29)	71.20 (22.71)
Overall score	76.86 (17.08)	75.69 (16.61)

*mean(SD)

Table 2 . Analysis of sociodemographic factors and QoL in children with CKD (N=112)

Variables	n(%)	Parent's report (n=112)			Children's report (n=103)		
		Mean overall QoL score (SD)	OR (95%CI)	P value	Mean overall QoL score (SD)	OR (95%CI)	P value
Sex							
Female	52 (46.4)	76.94 (15.72)	0.89	0.77	76.51 (15.12)	0.72	0.44
Male	60 (53.6)	76.79 (18.31)	(0.4 to 1.97)		74.88 (18.07)	(0.32 to 1.65)	
Age group							
<10 years (child)	40 (35.7)	80.00 (15.93)	2.07	0.10**	76.66 (17.66)	1.63	0.23**
10-18 years (teen)	72 (64.3)	75.12 (17.55)	(0.86 to 4.99)		75.23 (16.02)	(0.64 to 4.15)	
Child's education level							
Below junior high school	94 (83.9)	76.56 (17.16)	1.81	0.33	75.35 (16.69)	1.91	0.28
Junior high school or above	18 (16.1)	78.43 (17.03)	(0.55 to 5.95)		77.25 (16.62)	(0.58 to 6.32)	
Maternal education level							
Low	55 (49.1)	77.69 (17.05)	0.90	0.78	76.36 (16.69)	1.30	0.53
High	57 (50.9)	76.07 (17.23)	(0.40 to 1.98)		74.97 (16.90)	(0.57 to 2.98)	
Socioeconomic status							
Low	76 (67.9)	76.54 (17.15)	1.11	0.80	76.05 (16.43)	0.98	0.96
High	36 (32.1)	77.54 (17.15)	(0.47 to 2.62)		74.92 (17.23)	(0.41 to 2.36)	
Residency							
Rural	45 (40.2)	75.34 (17.18)	1.53	0.30	74.74 (17.12)	1.32	0.52
Urban	67 (59.8)	79.13 (16.87)	(0.67 to 3.51)		76.97 (16.02)	(0.57 to 3.05)	

disturbances. According to the children's report, negative associations with quality of life were noted in disease severity, short stature, anemia, hypertension, modality of therapy, steroid usage, behavioral disorder, and sleep disturbance. The analysis of quality of life in children with CKD with medical and psychosocial factors is shown in **Table 3**.

Multivariate analysis revealed that disease severity [OR 9.084 (95%CI 2.918 to 28.281); $P < 0.001$], behavioral disorders [OR 6.912 (95%CI 1.681 to 28.416); $P = 0.007$], and sleep disturbances [OR 6.848 (95%CI 2.390 to 19.620); $P < 0.001$] were significantly associated with quality of life based on parental reports, whereas anemia [OR 3.926; (95%CI 1.035 to 1.3898); $P = 0.044$], sleep disturbances [OR 6.444 (95%CI 1.278 to 32.493); $P = 0.024$] and behavioral disorders [OR 5.723 (95%CI 95% 1.924 to 17.022); $P = 0.002$] were significantly associated with quality of life based on children's reports. Multivariate analysis are shown in **Tables 4** and **5**.

Discussion

In our study, the mean scores of global quality of life for children with CKD based on parental and child reports were 76.86 and 75.69, respectively. Similarly, a previous study stated that the average quality of life total score of children with CKD based on children's reports was 74.78. The proportions of poor quality of life based on parental and child reports were 32.1% and 33.0%, respectively. Thirty percent children with CKD experienced poor quality of life.¹⁶ However, another study reported that poor quality of life prevalences in children with CKD based on parent and child reports were 54.5% and 56.3%, respectively.⁶ Physical function was most frequently affected, according to parents' and children's reports. Gerson *et al.*¹⁶ stated that children with CKD had significantly lower physical, school, emotional, and social domain scores than healthy children.

We found no association between sociodemographic factors and the quality of life of children with CKD from either parents' or children's reports. Age and quality of life had no significant association with low quality of life ($P = 0.10$ in parents' reports; $P = 0.23$ in children's reports). In contrast,

Table 3. Analysis of medical and psychosocial factors and QoL in children with CKD

Characteristics	n(%)	Parent's report (n=112)			Children's report (n=103)		
		Mean overall QoL score (SD)	OR (95%CI)	P value	Mean overall QoL score (SD)	OR (95%CI)	P value
Etiology of CKD							
Glomerular	77 (68.8)	79.35 (16.67)	2.88 (1.24 to 6.69)	0.012	77.47 (16.26)	1.72 (0.73 to 4.05)	0.216
Non-glomerular	35 (31.3)	71.40 (16.94)			72.08 (16.98)		
Disease severity							
Later stage (4-5)	27 (24.1)	67.63 (16.20)	7.44 (2.87 to 19.34)	0.001	67.70 (17.91)	4.16 (1.64 to 10.6)	0.002
Early stage (1-3)	85 (75.9)	79.80 (16.37)			78.39 (15.35)		
Age at onset							
1-9 years (childhood)	54 (48.2)	77.37 (17.06)	0.80 (0.36 to 0.77)	0.583	75.51 (16.25)	0.76 (0.33 to 1.76)	0.519
10-17 years (adolescent)	58 (51.8)	76.40 (17.24)			75.83 (17.03)		
Duration of illness							
>60 months	14 (12.5)	71.82 (16.30)	1.09 (0.48 to 2.47)	0.834	71.82 (12.76)	1.09 (0.47 to 2.54)	0.843
<60 months	98 (87.5)	77.58 (17.15)			76.30 (17.12)		
Nutritional status							
Overweight to obese	43 (38.4)	78.88 (14.81)	0.73 (0.32 to 1.67)	0.449	77.98 (15.15)	0.96 (0.41 to 2.24)	0.930
Underweight to normal	69 (61.6)	75.61 (18.34)			74.24 (17.44)		
Stature							
Short	55 (49.1)	72.39 (17.30)	2.43 (1.07 to 5.52)	0.031	71.68 (16.22)	3.01 (1.29 to 7.27)	0.010
Normal	57 (50.9)	81.18 (15.85)			79.62 (16.20)		
Anemia							
Present	57 (50.9)	72.20 (16.83)	4.60 (1.90 to 11.13)	0.001	70.90 (17.44)	6.83 (2.50 to 18.65)	0.001
Absent							
Hypertension							
Present	70 (62.5)	74.69 (16.26)	1.90 (0.80 to 4.47)	0.144	73.10 (16.62)	3.59 (1.32 to 9.78)	0.010
Absent	42 (37.5)	80.48 (17.99)			80.52 (15.71)		
CK-MBD							
Present	44 (39.3)	73.43 (18.44)	2.28 (1.01 to 5.13)	0.044	73.35 (17.98)	1.98 (0.86 to 4.56)	0.106
Absent	68 (60.7)	79.08 (15.88)			77.36 (15.50)		
Treatment modality							
Dialysis	22 (19.6)	66.37 (15.65)	9.33 (3.23 to 26.99)	0.001	66.67 (17.27)	4.72 (1.72 to 12.97)	0.002
Conservative	90 (80.4)	79.43 (16.50)			78.00 (15.73)		
Steroid use							
Yes	71 (63.4)	80.81 (15.78)	0.21 (0.09 to 0.50)	0.001	78.81 (15.46)	0.42 (0.18 to 0.97)	0.039
No	41 (36.6)	70.02 (17.27)			70.77 (17.36)		
Immunosuppressant use							
Yes	40 (35.7)	79.51 (15.75)	0.48 (0.20 to 1.17)	0.103	77.86 (16.56)	0.74 (0.31 to 1.77)	0.503
No	72 (64.3)	75.39 (17.71)			74.42 (16.64)		
Behavioural disorders							
Present	16 (14.3)	60.73 (15.41)	9.00 (2.65 to 30.55)	0.001	59.92 (14.04)	6.77 (1.94 to 23.64)	0.001
Absent	96 (85.7)	79.55 (15.88)			78.17 (15.65)		
Sleep disturbances							
Present	39 (34.8)	64.03 (15.03)	8.13 (3.33 to 19.89)	0.001	63.45 (16.05)	7.90 (3.13 to 19.95)	0.001
Absent	73 (65.2)	83.72 (13.92)			81.99 (13.07)		

Chi-square; CI=confidence interval; OR=odds ratio; significant if P <0.05; **Included in multivariate analysis (P <0.25).

a previous study reported that children with CKD aged 13-18 years had the lowest quality of life.⁶ Several psychological theories suggest that health-related quality of life declines specifically with age.

Pubertal adolescents often face problems coping with their environment. Our differing results could have been due to differences in age grouping: we grouped subjects into adolescents and children based on cut-off

Table 4. Multivariate analysis of of quality of life's determinants based on parent's report

Variables	B	S.E.	Wald	OR (95%CI)	P value
Disease severity	2.207	0.579	14,503	9.084 (2.918 to 28.81)	0.000
Behavioral disorders	1.933	0.721	7.184	6.912 (1.681 to 28.416)	0,007
Sleep disturbances	1.924	0.537	12,835	6.848 (1.390 to 19.620)	0.000
Constant	-2.517	0.447	31682	0.081	0.000

Table 5. Multivariate analysis of of quality of life's determinants based on child's report

Variables	B	S.E.	Wald	OR (95% CI)	P value
Anemia	1.368	0.68	4.04	3.926 (1.035 to 14.898)	0.044
Hypertension	1.549	0.802	3.736	4.708 (0.979 to 22.653)	0.053
Steroid use	-1.138	0.634	3.224	0.32 (0.092 to 1.11)	0.073
Behavioral disorders	1.863	0.825	5.094	6.444 (1.278 to 32.493)	0.024
Sleep disturbances	1.744	0.556	9.837	5.723 (1.924 to 17.022)	0.002
Constant	-3.030	0.766	15.668	0.048	0

points set by the Ministry of Health of the Republic of Indonesia, while the aforementioned study grouped subjects based on the *PedsQLTM Questionnaire* age grouping (2-4, 5-7, 8-12, and 13-18 years).^{6,18}

Most subjects' educational status were elementary school (40.2%) and junior high school (28.6%). Seven (6.3%) subjects had dropped out of school. Morton et al. reported that 71% of adult patients with CKD since childhood dropped out of school due to illness.¹⁹ In addition, a study found a marked difference in school attendance between controls and CKD patients, with 57% of patients reporting delayed education due to health problems.²⁰ In our study, children's education status was not significantly associated with impaired quality of life (P=0.33 in parents' reports; P=0.28 in children's reports). A previous study also noted no significant relationship between children's education and quality of life based on parents' reports, but in children's reports, secondary education had a 3.962 times higher risk of poor quality of life (P<0.05; 95%CI 1.621 to 9.681).⁶ Our differing results may have been due to differences in the operational definition of the grouping of children's education levels. We classified children's education levels into below junior high and junior high or above, while Pardede et al.⁶ classified them into low, medium, and high levels.

Maternal education was not significantly

associated with quality of life (P=0.78 in parents' reports; P= 0.53 in children's reports), similar to the findings of Pardede et al.⁶ Didsbury et al.²¹ performed a systematic review of the quality of life studies of children with chronic illness and found that children with CKD whose mothers had completed more than 16 years of schooling had better overall mean scores across the four PedsQL questionnaire domains [school (P<0.05), emotional function (P < 0.05), physical function (P<0.05), and social function (P<0.05)] compared to children whose mothers had low education. Higher levels of parental education are believed to increase parents' awareness and knowledge about their children's health and generally support better jobs and incomes, leading to better HRQOL and life expectancy.²² However, maternal level of knowledge is not always in line with the level of formal education. Knowledge can be obtained from informal education, media, and maternal experience.²³

Family income was not significantly associated with quality of life, nor was place of residence. These findings are in agreement with those of two previous studies.^{6,24} One other study, however, noted that children living in rural areas had better health-related quality of life than those in urban areas.²² Perceptions and expectations about health-related quality of life and living facilities differ between rural and urban

children.²⁵ Our differing results may have been due to different research locations as local conditions, community perceptions, and living facilities may differ.

Bivariate analysis revealed that the CKD etiology had a significant relationship with poor quality of life based on parental reports. To the best of our knowledge, there has been no past research linking CKD etiology with the quality of life.

Most subjects (75.9%) were in the early stages of CKD (stage 1-3). Children with more severe CKD (stages 4-5) had a 7.44 times higher risk for poor quality of life based on both parents' and children's reports compared to those in stages 1-3. This significance was maintained in multivariate analysis of factors affecting quality of life according to parents' reports. Advanced CKD entails more severe symptoms and complications and increasingly complex treatment, both of which affect all aspects of quality of life. Most studies reported that patients with lower kidney function had worse health-related quality of life. In a study that used the health utility index (HUI) to assess quality of life, children with CKD stages 1-2 had higher quality of life than those with CKD stages 3-5. The decrease in quality of life measures was more pronounced in the domains of cognition, pain, and emotion.²⁶ Another study noted that disease-specific health-related quality of life significantly declined with advancing stage of CKD.²⁷ Patients with stage 4 CKD showed greater impairment in physical, social, and school function than their healthy counterparts. In a study using the *20-Item Medical Outcomes Study* (MOS-SF-20™) to evaluate health-related quality of life, patients with stage 4-5 CKD had lower scores in self-esteem, physical performance, and general physical activity, but not in socialization.¹³ However, some other studies found no significant association between the severity of CKD and quality of life.^{6,15}

There was no significant difference in quality of life, be it according to parents' or children's reports, between childhood- and adolescent-onset CKD. Similar findings have been reported by Clave et al.²⁴ We found that duration of illness of >60 months vs. <60 months did not affect quality of life, contrary to a previous study that reported children who had CKD for >60 months to have a 1.571 times higher risk of poor quality of life than those with <60 months of illness.⁶ Another study reported that the proportion of life lived with CKD was positively associated with

PedsQL physical domain scores, with an increase of 0.8 points in physical functioning score for every 10% increase in the proportion of life lived with CKD. Time spent with CKD was associated with higher overall quality of life scores, indicating adaptation.¹⁶

We did not find a significant association between nutritional status and quality of life, in agreement a study that reported no significant difference in quality of life scores between obese and non-obese patients with CKD.¹³ Nearly half of our subjects had short of stature (49.1%), which was negatively associated with quality of life both according to parents' and children's reports. Short stature is common in children with CKD; in a study, an estimated 36% of children with CKD had a z-height score < -1.88.28 Short stature was significantly associated with poorer quality of life.²⁶ In a prior study, 17% of children with CKD had short stature, but while their physical domain quality of life scores were lower than those of those the normal height group, the difference was not statistically significant.²⁵ Short stature has been associated with lack of self-worth and self-confidence in navigating environments. Short stature in children with CKD may also be related to the chronicity and complications of CKD that inhibit growth.²⁹

Anemia, found in 50.9% of our subjects, had a significant negative association with quality of life. In agreement with our results, two previous studies found that children with more severe anemia had a significantly lower quality of life.^{30,31} Anemia can cause fatigue, reduced exercise capacity due to lack of oxygen carried to body tissues, impaired immunity, and reduced cognitive abilities.³²

We found a significant association between hypertension and lower quality of life based on children's reports. A previous study showed a small but significant difference in quality of life in CKD patients with vs. without hypertension.³³

In this study, subject who underwent dialysis had a lower quality of life. The choice of therapeutic modality has been reported to negatively affect children's quality of life according to children's reports, especially in the physical domain. Patients undergoing dialysis commonly have end-stage renal disease necessitating renal replacement therapy. Dialysis frequency, repeated hospital admissions, and dialysis risks such as anemia and infection affect the quality of life of children with CKD.¹³

Forty (35.7%) subjects in our study received immunosuppressive agents within the previous three months. The use of immunosuppressants did not significantly affect quality of life. Steroid treatment, received by 63.4% of our subjects, significantly affected quality of life based on both parents' and children's reports on bivariate analysis, possibly through their side effects of weight gain, gingival hypertrophy, acne, and Cushingoid appearance. However, the association did not persist when other factors were taken into account in multivariate analysis. To our knowledge, no study has linked the quality of life of children CKD with steroid or immunosuppressant use.³⁴

The presence of behavioral disorders was significantly associated with lower quality of life based on parents' and children's reports. Symptoms of depression and anxiety negatively affect the perception of health-related quality of life. In addition, lower resilience scores were associated with clinically significant depressive symptoms. One study found that 47% of CKD patients reported psychological problems during childhood, 27% of whom were referred for treatment. The frequency of referrals to a psychologist and/or psychiatrist was 35.7% among CKD patients, compared to only 3.5% among controls. Such symptoms were also associated with poorer overall health-related quality of life scores, as well as lower scores in school, social and psychosocial subdomains.¹⁹

Sleep disturbances, found in 39 (34.8%) subjects, were significantly associated with lower quality of life in bivariate analysis, based on reports from both parents and children. Sleep disturbances (including restless leg syndrome/paroxysmal leg movements, sleep-disordered breathing, and insomnia) in CKD stages 1 to 4 may affect the patient's quality of life.²⁰ In a study which assessed sleep quality using the *Pittsburgh Sleep Quality Index* (PSQI), PSQI scores were low in healthy volunteers, but highest in pre-dialysis patients.³⁵

There were several limitations in our study, such as a relatively small sample size, lack of a comparison with healthy controls, difficulties in obtaining questionnaire responses from subjects aged 5-7 years. In addition, our study design was only able to describe conditions at the moment of observation, as we did not observe quality of life for a certain period of time.

Finally, we conclude that in children with CKD, anemia, behavioral disorders, and sleep disturbances

affect quality of life from the children's perspectives, whereas disease severity, behavioral disorders, and sleep disturbances affect quality of life from the parents' perspective. The quality of life of children with CKD should be assessed from the time the child is diagnosed and repeated periodically, especially in children with risk factors for advanced CKD.

Conflict of interest

None declared.

Acknowledgments

We would like to thank the Department of Child Health at Medical Faculty of Universitas Sriwijaya and Dr. Mohammad Hoesin Hospital.

Funding acknowledgement

The authors received no specific grants from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. El Shafei AM, Hegazy IS, Fadel FI, Nagy EM. Assessment of quality of life among children with end-stage renal disease: a cross-sectional study. *J Environ Public Health*. 2018;2018:8565498. DOI: <https://doi.org/10.1155/2018/8565498>.
2. Hill NR, Fatoba ST, Oke JL, Hirst JA, O'Callagan AO, Lasserson DS, et al. Global prevalence of chronic kidney disease - a systematic review and meta-analysis. *PLoS One*. 2016;11:e0158765. DOI: <https://doi.org/10.1371/journal.pone.0158765>.
3. Assadi F. The epidemic of pediatric chronic kidney disease: the danger of skepticism. *J Nephropathology*. 2012; 1: 61-4. DOI: <https://doi.org/10.5812/nephropathol.7445>.
4. Ardissino G, Dacco V, Testa S, Bonaudo R, Claris-Appriani A, Taioli E, et al. Epidemiology of chronic renal failure in children: data from the ItalKid project. *Pediatrics*. 2003;111:e382-7. DOI: <https://doi.org/10.1542/peds.111.4.e382>.
5. Badan Penelitian dan Pengembangan Kesehatan, Kementerian Kesehatan RI. Hasil Riset Kesehatan Dasar Tahun 2013.

- Jakarta: Kemenkes RI; 2013.
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;30:812-18. DOI: <https://doi.org/1319-2442.265456>.
 7. Kaspar CDW, Bholah R, Bunchman TE. A review of pediatric chronic kidney disease. *Blood Purif.* 2016;41:211-7. DOI: <https://doi.org/10.1159/000441737>.
 8. Trifiro G, Sultana J, Giogianni F, Ingrassiotta Y, Buenmi M, Muscianisi M, et al. Chronic kidney disease requiring healthcare service: a new approach to evaluate epidemiology of renal disease. *Biomed Res Int.* 2014;2014:268362. DOI: <https://doi.org/10.1155/2014/268362>.
 9. Boudreau JE, Dube A. Quality of life in end stage renal disease: a concept analysis. *CANNT J.* 2014;24:12-20. PMID: 24783768.
 10. Spieth LE, Harris CV. Assessment of health-related quality of life in children and adolescents: an integrative review. *J Pediatr Psychol.* 1996;21:175-93. DOI: <https://doi.org/10.1093/jpepsy/21.2.175>.
 11. Copelvitich L, Warady BA, Furth SL. Insight from the chronic kidney disease in children (CKiD) study. *Clin J Am Soc Nephrol.* 2011; 6:2047-53. DOI: <https://doi.org/10.2215/CJN.10751210>.
 12. Tong A, Lowe A, Sainbury P, Craig JC. Experiences of parents who have children with chronic kidney disease: a systemic review of qualitative studies. *Pediatrics.* 2008;121:349-60. DOI: <https://doi.org/10.1542/peds.2006-3470>.
 13. López CA, Escribano AF, Cantanero GG, Luque A, García EI. Calidad de vida percibida por niños con enfermedad renal crónica y por sus padres [Perceived quality of life in children with chronic renal disease and in their parents]. *Nefrologia.* 2010;30:103-9. Spanish. DOI: <https://doi.org/10.3265/Nefrologia.pre2009.Dic.5683>.
 14. Karimi M, Brazier J. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics.* 2016;34:645-9. DOI: <https://doi.org/10.1007/s40273-016-0389-9>.
 15. Dotis J, Pavlaki A, Printza A, Stabouli S, Antoniou S, Gkogka C, et al. Quality of life in children with chronic kidney disease. *Pediatr Nephrol.* 2016;31:2309-16. DOI: <https://doi.org/10.1007/s00467-016-3457-7>.
 16. 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:e349-57. DOI: <https://doi.org/10.1542/peds.2009-0085>.
 17. Varni JW, Burwinkle TM, Seid M. The PedsQL as a pediatric patient-reported outcome: reliability and validity of the PedsQL measurement model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res.* 2005;5:705-19. DOI: <https://doi.org/10.1586/14737167.5.6.705>.
 18. Kementerian Kesehatan Republik Indonesia. Peraturan Menteri Kesehatan Republik Indonesia Nomor 25 Tahun 2014 Tentang Upaya Kesehatan Anak. Jakarta: Kemenkes RI; 2014.
 19. Morton MJS, Reynolds JM, Garralda ME, Postlethwaite RJ, Goh D. Psychiatric adjustment in end-stage renal disease: a follow up study of former pediatric patients. *J Psychosom Res.* 1994;38:293-303. DOI: [https://doi.org/10.1016/0022-3999\(94\)90034-5](https://doi.org/10.1016/0022-3999(94)90034-5).
 20. Moreira JM, Soares CMBM, Teixeira AL, e Silva ACS, Kummer AM. Anxiety, depression, resilience and quality of life in children and adolescents with pre-dialysis chronic kidney disease. *Pediatr Nephrol.* 2015;30:2153-62. DOI: <https://doi.org/10.1007/s00467-015-3159-6>.
 21. Didsbury MS, Kim S, Medway MM, Tong A, McTaggart SJ, Walker AM, et al. Socio-economic status and quality of life in children with chronic disease: a systematic review. *J Paediatr Child Health.* 2016;52:1062-9. DOI: <https://doi.org/10.1111/jpc.13407>.
 22. Sitaresmi MN, Indraswari BW, Rozanti NM, Sabilatuttaghiyya Z, Wahab A. Health-related quality of life profile of Indonesian children and its determinants: a community-based study. *BMC Pediatr.* 2022;22:103. DOI: <https://doi.org/10.1186/s12887-022-03161-0>.
 23. Ary D, Jacobs LC, Sorensen C, Razavieh A. Introduction to research in education. Belmont: Wadsworth Cengage Learning; 2010. ISBN-13: 978-0-495-60122-7
 24. Clavé S, Tsimaratos M, Boucekine M, Ranchin B, Salomon R, Dunand O, et al. Quality of life in adolescents with chronic kidney disease who initiate haemodialysis treatment. *BMC Nephrol.* 2019;20:163. DOI: <https://doi.org/10.1186/s12882-019-1365-3>.
 25. Al-Uzri A, Matheson M, Gipson DS, Mendley SR, Hooper SR, Yadin O, et al. The impact of short stature on health-related quality of life in children with chronic kidney disease. *J Pediatr.* 2013;163:736-41.e1. DOI: <https://doi.org/10.1016/j.jpeds.2013.03.016>.
 26. Francis A, Didsbury MS, van Zwieten A, Chen K, James LJ, Kim S, et al. Quality of life of children and adolescents with chronic kidney disease: a cross-sectional study. *Arch Dis Child.* 2019;104:134-40. DOI: <https://doi.org/10.1136/archdischild-2018-314934>.
 27. Ademola BL, Obiagwu PN, Aliyu A. Assessment of health-related quality of life of chronic kidney disease patients in

- aminu kano teaching hospital, Kano. Niger J Clin Pract. 2020;23:906-11. DOI: https://doi.org/10.4103/njcp.njcp_589_19.
28. Seikaly MG, Salhab N, Warady BA, Stablein D. Use of rhGH in children with chronic kidney disease: lessons from NAPRTCS. *Pediatr Nephrol* 2007;22:1195-204. DOI: <https://doi.org/10.1007/s00467-007-0497-z>.
 29. Mendley SR, Spyropoulos F, Counts DR. Short stature e in chronic kidney disease treated with growth hormone and an aromatase inhibitor. Hindawi Publishing Corporation. *Case Reports in Pediatrics*. 2015;2015. Article ID 738571. DOI: <https://doi.org/10.1155/2015/738571>
 30. Wua TCM., Langi FLFG, Kaunang WPJ. Kualitas hidup pasien hemodialisis di Unit Hemodialisis Rumah Sakit Umum Pusat Prof. Dr. R.D. Kandou Manado. *Jurnal KESMAS*. 2019;8:127-36.
 31. Senduk CR, Palar S, Rotty LWA. Hubungan anemia dengan kualitas hidup pasien penyakit ginjal kronik yang sedang menjalani hemodialisis regular. *e-CliniC*. 2016;4:105-10. DOI: <https://doi.org/10.35790/ecl.v4i1.10941>.
 32. Luo L, Chen Q. Effect of CKD-MBD phenotype on health-related quality of life in patients receiving maintenance hemodialysis: a cross sectional study. *J Int Med Res*. 2020; 48: 0300060519895844. DOI: <https://doi.org/10.1177/0300060519895844>.
 33. Ayoub A, Nelson K, Wood P, Hijazi KH. The relationship between laboratory values and quality of life of dialysis patients in the United Arab Emirates. *Renal Soc Australasia J*. 2014;10:12-20.
 34. 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;31:1579-91. DOI: <https://doi.org/10.1007/s00467-015-3186-3>.
 35. Karatas A, Canakci E, Turkmen E. Comparison of sleep quality and quality of life indexes with sociodemographic characteristics in patients with chronic kidney disease. *Niger J Clin Pract*. 2018;21:1461-7. DOI: https://doi.org/10.4103/njcp.njcp_146_18.