Health-related quality of life in children with chronic kidney disease in Assiut, Egypt

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Abstract

Background: Chronic kidney disease (CKD) is known to be one of the major health issues in children under the age of 18 years. CKD affects every organ in the body therefore, has a major consequence on both mortality and quality of life (QoL) of children. **Objective:** To compare QoL in diseased and healthy children and find out factors associated with QoL score in children with CKD. **Method:** a cross sectional comparative study was conducted on 250 children with CKD and 250 healthy peers using the Pediatric qualify of life inventory (PedsQL) 4.0. **Results:** Healthy children achieved statistically significant higher mean PedsQL™ in all domains of quality of life in all domains of PedsQL™. Children on conservative treatment achieved statistically significant higher scores in all domains of PedsQL™ than those on dialysis. There was no statistically significant difference in all domains of PedsQL™ regarding the severity of CKD. Children receiving hemodialysis reported lower scores in all dimensions of QoL than children on conservative treatment. **Conclusion:** HRQoL of children with CKD assessed by PedsQL™ was lower compared to healthy controls and school functioning was the most affected dimension. ***Study limitations:*** Children were recruited during routine follow up or after hemodialysis session so, reported scores were not in direct response to an acute event in disease process requiring hospitalization. ***Implications*:** Application of psychosocial counseling program for children and their families together with social and educational support groups to enable children with CKD to live and function independently in adulthood.

Key words: *chronic renal disease, CKD, pediatric, quality of life*

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Introduction:

Chronic kidney disease (CKD) is known to be a major public health concern worldwide with increasing prevalence and incidence that threatens to reach a true epidemic. Its actual prevalence and incidence may be underestimated by epidemiologic data as it is usually asymptomatic, especially in early stages.[1] Because of genetic and environmental factors, the magnitude of CKD differs from one geographical region to another.[2]

Previous studies reported a prevalence of CKD between 15–74.7 per million children.[3] Other reports showed a high prevalence of CKD in other countries. The prevalence range from 6% in Europe and North American countries to 18.7% in Japan.[4]

Recently, the World Health Organization (WHO) has added kidney and urologic disease to the globally tracked mortality information, and this should be a reliable source of such information over time.[5]

In a developing country like *Egypt*, with insufficient resources and low-quality primary health care, end-stage renal disease (ESRD) is possibly the "tip of the iceberg," where patients are diagnosed with the renal disease after they have reached renal failure. The exact incidence and prevalence of CKD in children in Egypt is unknown due to absence of a national registry.[2]

Health-related quality of life (HRQoL) has been described as the subjective perception of an individual's illness, and the effect that illness and its treatment have on the individual's functioning in different domains.[6]

As CKD affects every organ in the body, it has a major impact on both mortality and quality of life (QoL) of children.[7] Children with CKD are at greater risk for delays in neurocognitive growth and reduced quality of life.[8]

Recently, HRQoL was increasingly recognized as a predictor for treatment success in children with chronic diseases and is recommended to include HRQoL measurement in clinical trials.[9]

The present study aimed to compare QoL in both healthy and diseased children and to find out factors associated with QoL score in children with CKD.

*Study hypotheses:*Children with CKD have poorer HRQoL than healthy children. HRQoL in children with CKD is affected by several factors

Method

A cross sectional comparative study was conducted in two sites: health insurance clinic and Assiut University Children Hospital (nephrology outpatient clinic, nephrology department and dialysis unit) in Assiut city- Upper Egypt.

Study participants: 2 groups: **1- Diseased children:** all eligible school aged children with CKD attended Children University Hospital and the health insurance clinic in Assiut could participate in the study.

Any child (8- ≤18 years) diagnosed as having CKD and receiving any type of renal replacement therapy, conservative treatment, dialysis or kidney transplantation.

Children with acute kidney disease and Children with chronic disease other than CKD were excluded from the study.

2- Healthy children: Apparently healthy children (8- ≤18 years) recruited from the same or a similar locality of diseased children. Age and sex matched to the patients with no history of any chronic diseases including CKD.

Sample size was calculated using the G*Power version 3.1.9.4. The minimum size of each group (stage of GFR) was estimated based on a statistical significance level of 0.05 and a power of 0.80 and mean difference in QoL between cases and controls (74.78 ± 14.26 vs 82.87 ± 13.16 respectively) [9]. The calculated sample size was 47 child/ group which was increased by researchers to 50. Using a design effect of 5 (as there are 5 stages of CKD), thus the total sample was 250 children with CKD and 250 healthy children.

All legible ESRD children registered in the dialysis unit in Children University Hospital were included in the study (Total coverage of all ESRD cases). For children on conservative treatment, health insurance clinic works only on Sunday and Tuesday every week whereas the nephrology outpatient clinic in Children University Hospital works five days per week.

A systematic random sample from eligible attendants was used and yielded two days/week/clinic.

Ethical Consideration

Approval from the Ethics Review Committee of Assiut Faculty of Medicine to conduct this study.

An official permission was obtained from director of health insurance sector for the Middle Upper Egypt for data

collection from health insurance clinic in Assiut.

An official permission was obtained from the director of Children University Hospital for data collection from the nephrology outpatient clinic, nephrology unit and dialysis unit in Children University Hospital in Assiut.

Preparation of the sociodemographic questionnaire.

Request of the Arabic version of the Pediatric quality of life inventory (PedsQL) 4.0 generic core scales (GCS) from Mapi Research Trust, ePROVIDE™ online distribution [10].

Data collection tools:

Four tools were used in the study. *Tool I:* demographic and clinical data questionnaire. Demographic data such as age, sex, residence and education. Clinical data such as duration of the disease, cause of CKD, treatment modality and family history of CKD. (for patients only).

Tool II: Family Socio-economic Scale, revised version 2010.[11] It assesses family socioeconomic status and consists of 4 elements, Parent's education level (8 items), Parent's occupation (2 items), Total family monthly income (6 items), Lifestyle of the family (12 items). The income element had been adjusted according to the inflation rate.[12]

Tool III: Assessment of health-related quality of life (HRQoL) using the Arabic version of the PedsQL™ Pediatric qualify of life inventory (PedsQL) 4.0 Generic Core Scales (GCS). It is a 23-item questionnaire which includes: Physical subscale (8 items), Emotional subscale (5 items), Social subscale (5 items), School subscale (5 items).

The answer of the PedsQL ask the children to rate each item using a 5-point rating scale ranging from 'never' to 'almost always' as follow: 0 → never a problem, 1 → almost never a problem, 2 → sometimes a problem, 3 → often a problem, 4 → almost always a problem.

The instructions ask how much of a problem each item has been during the past month.[13]

After that, reverse scoring for each subscale from 0–100 scale was done as follows: 0=100, 1=75, 2=50, 3=25, 4=0, so that higher scores indicate a better HRQoL.

The PedsQL™ yields 3 summary scores:

Psychosocial score = sum of the items over the number of items answered in the emotional, social, and school subscales.

Physical score = physical subscale score.

Total score: sum of all the items over the number of items answered on all the scales.[14]

The PedsQL child self-report for ages 8–12, and 13–18 years was used.

The Arabic version of the PedsQL™ has proved to be understandable and feasible to use. It has demonstrated good reliability for both healthy and children with chronic illnesses. It also showed good construct and validity, making it suitable for research and clinical use in Egypt. Cronbach's α internal consistency values for the total and subscale scores exceeded 0.70. Test–retest reliability was high (reliability coefficient exceeded 0.9).[15]

Internal consistency and clinical validity have been demonstrated. Internal consistencies for the total scale score were as follows: child self-report total score Cronbach's 0.91; physical score: Cronbach's 0.87; and psychosocial score: Cronbach's 0.86 [16].

A pilot study was carried out on 10% of the sample to determine the administrative procedures needed, test the feasibility, assess clarity of the questions, the need for any rewording and/or rephrasing and to assess time required for its filling. No modification was required in the questionnaire and the average time required for its filling was about 20-25 minutes depending on the response of the participants.

Operational definitions: Children with CKD: any child presented with kidney damage (any structural or functional abnormality involving pathological, laboratory or imaging findings) for ≥3 months and/or a glomerular filtration rate (GFR) < 60 ml/min/1.73 m^2 for ≥3 months**.**[17]

Markers of kidney damage (one or more).[18]: Albuminuria, urine sediment abnormalities, electrolyte, or other abnormalities due to tubular acidosis, abnormalities detected by histology, structural abnormalities detected by imaging, history of kidney transplantation.

End-stage renal disease (ESRD): is defined as irreversible decrease in kidney function, which is severe enough to be fatal in the absence of dialysis or transplantation. ESRD is included under stage 5 of the National Kidney Foundation Kidney Disease Outcomes Quality Initiative classification of chronic kidney disease, where it refers to individuals with an eGFR < 15 mL/min per 1.73 m^2 body surface area, or those requiring dialysis irrespective of glomerular filtration rate.[19] (Table 1)

Severity (Staging) of CKD: children with CKD were classified according to the eGFR using Updated Bedside Schwartz formula as follows: eGFR (ml/min per 1.73 m^2) = 41.3 × (Height / Scr), where height is in meters and Scr (serum creatinine) is in mg/dl **[20].**

According to the eGFR, children with CKD were classified as follows **[21]**:

Stage	GFR (ml/min/1.73m^2)	Terms
Stage 1	> 90	Normal or high
Stage 2	60-89	Mildly decreased
Stage 3a	45-59	Mildly to moderately decreased
Stage 3b	30-44	Moderately to severed decreased
Stage 4	15-29	Severely decreased
Stage 5	< 15	Kidney failure

Height: children with CKD were classified according to the Egyptian growth charts stature for age.[22]

Growth parameters and their interpretation by the WHO.[23]

Percentile	Height for age
> 99	May be abnormal
> 97	Normal
> 85	Normal
50	Normal
< 15	Normal
< 3	Stunted
< 1	Severely stunted

Ethical consideration

The aim of the study was explained to caregivers before starting data collection. Voluntary participation of the child whose caregiver agreed to participate in this study was assured. Verbal informed consent was obtained from both caregivers and children before participating in the study (verbal consent was accepted by Ethical Review Board of Faculty of Medicine, Assiut University (IRB no 17200418) due to the high prevalence of low education levels especially in rural areas, prevailing culture of fear of signing any document and the nature of research which is not interventional, only questionnaire-based). Privacy and confidentiality of all data was assured.

Statistical analysis

Data entry, cleaning, analysis and recoding (if needed) was done using the Statistical Package for Social Science (SPSS) version 20. Descriptive statistics were calculated as the mean and standard deviation (SD) for continuous variables and as frequency and percentages for categorical variables. Chi-squared ($\chi 2$) and Fisher's exact tests were used as the test of significance for categorical variables. One-way ANOVA test was utilized for the three or more-group comparison of continuous variables and

Student-t test for the two-groups. Multivariate linear regression analysis was applied to identify the different predictors of QoL. Odds ratio was calculated as a measure of association at

Table (1): Characteristics of the studied children with CKD and matched controls by their socio-demographic characteristics.

Characteristics	Cases (N= 250)	Controls (N= 250)	Statistical test	p-value
Age			**t.test**	
- Mean ± SD (Range)	11.9 ± 3.1 (8-18)	12.1 ± 2.9 (8-18)	0.64	> 0.05
Sex			**X^2**	
- Male	168 (67.2 %)	157 (62.8 %)	1.06	> 0.05
- Female	82 (32.8 %)	93 (37.2 %)		
Residence				
- Urban	38 (15.2)	42 (16.8 %)	0.23	> 0.05
- Rural	212 (84.8)	208 (83.2 %)		
Education stage				
- Primary	144 (57.6)	141 (56.4)	13.4	< **0.05**
- Preparatory	65 (26)	62 (24.8)		
- Secondary	31 (12.4)	47 (18.8)		
- No schooling	10 (4)	0 (0)		
Mother's working status				
- Housewife	236 (94.4)	164 (65.6)	64.8	< **0.05**
- Working mother	14 (5.6)	86 (34.4)		
Socioeconomic class				
- Low	73 (29.2 %)	15 (6 %)	86.5	< **0.05**
- Middle	169 (67.6 %)	166 (66.4 %)		
- High	8 (3.2 %)	69 (27.6 %)		
Family history of CKD				
- Yes	43 (17.2 %)	3 (1.2 %)	8.4	< **0.05**
- No	207 (82.8 %)	247 (98.8 %)		

95% confidence limit and statistical significance level was considered when P-value ≤ 0.05 for all statistical tests.

Results

A total of 500 children were included in the study (250 cases & 250 controls). The mean age of the children with CKD was 11.9 ± 3.1 years and for controls was 12.1 ± 2.9. Males represented 67.2% in cases and 62.8% in controls. Most of cases and controls were residing in rural areas (84.8% & 83.2% respectively). There was no statistically significant difference in children's age, sex, and residence (p-value > 0.05) between cases and controls.

Only 10 children with CKD (4%) had never been to school, the rest of children were in the different stages of education. Most cases and controls were in the primary stage (57.6% & 56.4% respectively). Most of mothers of cases were housewives (94.4%) compared to 65.6% of controls. As regards socioeconomic status (SES), two thirds of both cases and controls were in the middle SES (67.6% & 66.4%) respectively. Family history of CKD was found in 17.2% of cases and only 1.2% of controls.

There was a statistically significant difference between cases and controls as regards educational stage, mother's job, socioeconomic status and family history of CKD (P-value< 0.05). (Table 1)

As regard HRQoL, healthy children achieved significantly higher mean PedsQL™ in all domains of QoL than children with CKD. There was statistically significant difference between cases and controls in HRQoL measured by PedsQL™ (p-value < 0.001). (Table 2)

Table (2): PedsQL™ Generic Core Scales score in the studied children with CKD and their matched control.

PedsQL	Cases (N= 250)	Controls (N= 250)	t. test	p-value
	Mean ± SD			
- Physical	61.5 ± 30.2	83.9 ± 14.5	10.5	< **0.05**
- Emotional	66.6 ± 32.1	78.9 ± 18.4	5.3	< **0.05**
- Social	73.8 ± 31.6	89.2 ± 13.3	7.1	< **0.05**
- Schooling	48.9 ± 24.9	76.4 ± 18.6	13.8	< **0.05**
- Psychosocial	63.3 ± 22.7	81.5 ± 12.7	11.1	< **0.05**
Total score	62.8 ± 23.4	82.4 ± 11.3	11.9	< **0.05**

Table (3): Clinical characteristics of the studied children with CKD.

Characteristics	Number (250)	(%)
Age at onset of CKD		
Mean ± SD (Range)	7.2 ± 3.9 (1-17)	
Disease duration		
≤ 5 years	158	63.2
> 5 years	92	36.8
Height		
- Normal height	132	52.8
- Short stature	118	47.2
Cause of CKD		
Nephrotic syndrome	171	68.4
Congenital anomalies	22	8.8
Glomerulonephritis	20	8
Unknown	12	4.8
Renal stones	9	3.6
Lupus nephritis	9	3.6
Others	7	2.8
Treatment modality		
- Conservative	214	85.6
- Hemodialysis	36	14.4
Stage of CKD*		
Stage 1	59	26.6
Stage 2	20	9
Stage 3	15	6.8
Stage 4	16	7.2
Stage 5	112	50.4

**Stage of CKD: total = 222 (28 children with CKD had no renal function test used in staging of CKD).*

The mean age at onset of CKD was 7.2 ± 3.9 years and the duration of CKD exceeded 5 years in 36% of cases. Regarding height, 47.2% of cases had short stature. The most common cause of CKD was nephrotic syndrome (68.4%) followed by congenital anomalies (8.8%) and glomerulonephritis (8%).

Most cases (85.6%) received conservative treatment and 14.4% were on regular hemodialysis. Regarding CKD severity, about half of the studied children (50.2%) were in stage 5 and 26.6% were in stage 1 CKD. (Table 3)

Children on conservative treatment achieved statistically significant higher scores in all domains of QoL, except in school function, there was no statistically significant difference. Children with duration of CKD > 5 years achieved higher scores than children with duration ≤ 5 years, with statistically significant difference only in physical domain and total PedsQL score. There was no statistically significant difference in all domains of PedsQL™ between different stages of CKD with school function having the lowest score and social domain the highest score in all disease stages.

Children from the middle SES achieved higher scores for QoL than those in the low and middle classes with statistical significance difference in the social, school, psychosocial and total PedsQL™.

Children with normal height achieved higher scores in all domains of QoL than children with short stature. There was statistical significance difference in all the domains of PedsQL™ by height except with the emotional domain. (Table 4)

Using Spearman Rank correlation, there was statistically significant negative correlation between high total PedsQL™ and dialysis as a treatment modality, low socioeconomic class, short stature, and shorter CKD duration (r = -0.38, -0.13, -0.19, -0.12 respectively, P <0.05, n =250) (Table 5). Linear regression analysis for predictors of the total PedsQL™ showed that about 17.2% of the variations in the total impact score were explained by treatment modality, SES, height and duration of CKD (R2 =0.172), but only treatment modality (p-value < 0.001, CI= 15.3 – 31) was significant predictors for the total PedsQL™. (Table 5)

Table (4): PedsQL™ Generic Core Scales analysis according to independent categorical variables in children with CKD in Children.

	Physical	Emotional	Social	School	Total PedsQL
Treatment modality					
Conservative	67.1 ± 26.6	69.4 ± 30.5	77.3 ± 30.1	50 ± 23.6	66.4 ± 21.1
Dialysis	28.7 ± 30.3	49.9 ± 36.2	53.1 ± 32.9	42.1 ± 31.8	41.3 ± 25
P.value	**< 0.05**	**< 0.05**	**< 0.05**	> 0.05	**< 0.05**
Duration of CKD					
≤ 5years	58.1 ± 31.5	64 ± 31.9	72.2 ± 33.1	48.3 ± 24.5	60.6 ± 24.2
> 5years	67.4 ± 27.2	70.9 ± 31.9	76.5 ± 28.8	50.2 ± 25.9	66.5 ± 21.6
P.value	**< 0.05**	> 0.05	> 0.05	> 0.05	< **0.05**
Stage of CKD					
I	61.9 ± 26.6	64.4 ± 32.6	73.4 ± 33.2	48.7 ± 25.5	61.5 ±23
II	70.3 ± 26.3	66.5 ± 28.5	75 ± 34.3	52.5 ± 26.5	66.6 ± 21.7
III	63.9 ± 27.3	70.7 ± 30.8	72 ± 38.2	48 ± 20.4	63.7 ± 22.1
IV	52.9 ± 26.5	65.3 ± 37.6	79.4 ± 31.9	41.5 ± 16.8	58.9 ± 19.2
V	58.7 ± 33.6	64.5 ± 31.9	70.5 ± 31.1	49.1 ± 27.1	61.2 ± 24.6
P.value	> 0.05	> 0.05	> 0.05	> 0.05	> 0.05
Socioeconomic class*					
Low	52.1 ±33.5	59.2 ± 31.5	62.7 ± 37.3 **a**	36.8 ± 28.1 **a**	53.2 ± 25.9 **a**
Middle	63.5 ± 29.5	68.3 ± 31.5	76.8 ± 28.6 **b**	51.5 ± 24 **b**	65 ± 21.9 **b**
High	63.3 ± 28.5	67 ± 34.3	73.1 ± 34.4 **a,b**	50.8 ± 22.1 **b**	63.5 ± 24.2 **b**
P.value	> 0.05	> 0.05	**< 0.05**	**< 0.05**	**< 0.05**
Height					
Normal	66.9 ± 26.8	69.3 ± 30.2	78.8 ± 27	52.5 ± 24.3	66.9 ± 20.2
Short stature	55.6 ± 32.8	63.5 ± 33.9	68.2 ± 35.3	44.8 ± 25.2	58.2 ± 25.8
P.value	**< 0.05**	> 0.05	**< 0.05**	**< 0.05**	**< 0.05**

**ANOVA Post hoc: P.value is significant among subgroups with no similar superscript letter.*

Discussion:

In this study, the HRQoL assessed by PedsQL™ was statistically significant lower in children with CKD than in healthy children. In general, healthy children achieved significantly higher mean scores in all domains of QoL than children with CKD.

This result seems to be largely supported by reports of previous studies. Statistically significant differences was also identified between children with CKD and healthy controls on all domains of HRQoL with the kidney disease group having lower scores.[9,15, 24, 25, 26, 27, 28, 29]

Our findings were also supported by previous studies using different QoL scales. In a previous study carried out at the pediatric renal clinic, at Mansoura University Children's Hospital, Egypt,

using the Personal Wellbeing Index-School Children, the mean score was significantly lower in kidney disease groups than in the healthy group.[30]

Unlike our findings, using the Generic Children's Quality of Life Measure, children with CKD had significantly higher QoL than the general population. The authors suggest that CKD children "live with the illness" and have a lower expectations of their lives since they accept their life as it is.[31, 32]

Table (5): Correlation and Multiple linear regression of predictors of total PedsQL™ Generic Core Scales score in the studied children with CKD.

Variable	Correlation*		Regression			
	r	sig	Beta	t	Sig.	95% CI
- Treatment modality	-0.38	< **0.05**	0.35	5.8	< **0.05**	15.3 – 31
- Socioeconomic class	-0.13	< **0.05**	0.11	1.9	> 0.05	0.4 – 9.1
- Height	-0.19	< **0.05**	0.09	1.3	> 0.05	1.4 – 9.3
- CKD duration	-0.12	< **0.05**	0.08	1.3	> 0.05	1.2 – 9.9
Constant				13.2	**<0.05**	59.8 – 80.8
R square			0.172			

* *Spearman correlation was used*

The most marked difference from healthy controls was in school functioning. This may be due to the complex medical treatment and the frequent follow up visits that interfere with school attendance. Family overprotection, fatigue, sleep disturbance and cognitive function impairments associated with deterioration of kidney function also interfere with school attendance. In children undergoing hemodialysis, time of dialysis sessions also interfere with school attendance and study performance in ESRD children. This finding also has been published in other studies.[9, 24, 27]

On the other hand, while the scoring was lower than in healthy children, our children provided the highest scores on the social dimension. This finding may be linked to the use of defense mechanisms or due to narrowing of the intimate community of friends only to the closest community. This finding is consistent with the result of Medyńska et al.[33] In addition, supportive social reinforcement for adolescents with CKD has been reported to significantly boost QoL and may serve as a protective factor against depression and anxiety.[34]

In our study, children with CKD reported lower score on physical functioning compared to healthy controls. This adverse effect of CKD in the physical functioning may be attributed to growth impairment and pubertal delay correlated with childhood onset CKD. The physical features such as short stature and bone deformities, which appear during the puberty period, are essential aspects of self-acceptance and self-esteem.[33]

Comparing PedsQL™ in children with CKD by treatment modality revealed that conservative group achieved statistically significant higher scores in all domains of QoL except in school function as there was no statistical significance difference.

Children on dialysis have additional difficulties such as dietary and fluid restriction, use of multiple medications, school absenteeism or drop out of school, social isolation, physical changes, increased behavioral and emotional distress, frequent hospital admission, daily routine changes with dependence on dialysis machine [35]. Dialysis put children on the 'sick role', preventing them from participating normally in daily life as their healthy peers. It is not surprising, considering the restrictions put on them, that children and adolescents with the most aggressive treatment perceived their QoL in the less optimistic side.[36]

As the evaluation of school function was generally low in conservative and dialysis groups, no statistically significant difference was identified in school function between both groups, as children on dialysis may also had the benefit of private teaching than children on conservative treatment. Our result is consistent with a recent study that was conducted at Abo El-Reesh Hospital, Cairo University, using the PedsQL™ and revealed impaired performance in physical, social, emotional and school functions among children with CKD and the worst performance was reported in those on dialysis.[37]

Our results were also supported by previous studies in which dialysis group also rated significantly lower than conservative group in all domains of QoL.[25,27,38] In the dialysis group, Marciano et al. also found lower scores but with no significant difference.[28] Using the 50-item Child Health Questionnaire-Parent form, adolescents on dialysis also had lower physical and psychosocial scores than those on conservative therapy.[39]

Regarding the duration of CKD, children with duration of CKD > 5 years achieved higher scores than children with duration ≤ 5 years, with statistical significance difference only in physical domain. The 'response shift' hypothesis may be an explanation for this surprising result. The response shift indicates that the internal expectations of the patients change as they respond to the diagnosis of their medical conditions, resulting in higher HRQoL as coping with illness becomes a norm.[40]

Contrary to our assumption, HRQoL results do not vary by extent of CKD as there was no statistical significance difference in all domains of PedsQL™ between different stages of CKD. This could be explained by the fact that the instruments lack sensitivity to differentiate between stages of CKD.[36] In addition, this lack of association may be explained by the fact that eGFR as a chemical parameter per se cannot consider co-morbidities, social factors or context, psychological makeup and other contributors to HRQoL.[41] Therefore, longitudinal analysis of HRQoL with decrease in eGFR will be very helpful in detecting the relationship between CKD severity and HRQoL. This finding is consistent with previous studies.[36,42,43,27,9]

Further analysis revealed that there was statistical significance difference in the social, school, psychosocial and total PedsQL™ by SES. Children from the middle SES reported higher scores in all domains than those in the higher and lower SES. Low SES affects all aspects of QoL while high SES raises life expectations which cannot be met when CKD is present, resulting in lower QoL scores.

In those with low SES, the effect of CKD increases stress, anxiety and emotional pressure. Several studies link low SES to reduced adherence to treatment and find SES to have a significant effect on children's access to kidney disease prevention and treatment.[44]

Previous study shows that children with low SES (as measured by family income) may experience lower QoL in general.[45] The Kids with CKD study revealed that children from lower SES are about 1.5 times more likely to experience fair or poor HRQoL compared to those of higher SES.[46] In comparison, the majority of children in Shtiza et al. study was from low SES, but this was not linked with lower HRQoL scores.[18]

Our study also highlighted the effect of short stature in HRQoL of children with CKD. Statistical significance difference was reported in all the domains of QoL except with the emotional domain as children with short stature achieved lower scores in all domains of QoL. Growth failure in children with CKD

results from several causes, primarily abnormalities in mineral and bone metabolism. Short stature is considered a major contributor to poor QoL among adolescents with CKD and more than one-third of them were below the 3rd percentile for height and about 45–60% of adults with childhood-onset CKD have short stature.[47]

Short stature usually has negative physical and psychological impact on the child, affecting the child's self-perceived health and distinguishing him from his peers. Our findings were similar to those published in previous studies.[41, 45, 48, 9]

Conclusion

HRQoL of children with CKD assessed by PedsQL™ was lowered compared to healthy controls and school functioning was the most affected dimension. Children receiving hemodialysis reported lower scores in all dimensions of QoL than children receiving conservative treatment. HRQoL was significantly associated with treatment modality, short stature and socioeconomic status, but on multivariate analysis, only treatment modality was significant predictor of HRQoL of the children with CKD.

Strengths and limitations: This study is one of the first studies using PedsQL™ measures to evaluate the QoL of children with CKD from all aspects. However, Children with CKD were recruited in the study during a routine follow up visit or after hemodialysis session and so the reported scores are not in direct response to a disease exacerbation requiring hospitalization. Also, none of the enrolled children was receiving renal transplantation or peritoneal dialysis, making no chance to compare between these different treatment modalities.

Recommendations

HRQoL assessment tools should be introduced in the routine clinical care of children with CKD. Further studies on national or multicentric level should be conducted to develop a special program for QoL improvement in children with CKD. Further researches are required to assess the short-term impact of acute events in disease process on children.

Implications:

Training and encouraging health care provider to offer more psychosocial counselling for children with CKD and their families.

Establishing psychosocial and educational support groups together with group therapy for children with CKD to improve wellbeing, psychosocial adaptation to CKD and share experiences.

Paying more attention to development of social and independent functioning of children with CKD to prepare them for active participation in society in adult life.

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